- \par\par
n68. Politically Incorrect with Bill Maher (ABC television broadcast, Mar. 1
9, 1998). \par
\par
----------End Footnotes----------
- \par\par
Now, at this point in the show, Sally Jesse Raphael, one of the guests, jump
s in and says - and you know it is not good when Sally Jesse is your champion -
\'22You are unfair to these transgendered.\'22 Bill Maher interrupts, saying,
\'22What do you mean 'these?' There is one. This is it.\'22 n69\par
\par
----------Footnotes----------
- \par\par
n69. Id. \par
\par
----------End Footnotes----------
- \par\par
Obviously this is an example of rabid nasty transphobia, but let's try to be
a little more specific about what is going on here. Does it represent some kin
d of fear on Bill Maher's part about gender fluidity where the relation between
sex and gender is very much unmoored, that one can simply change their gender
by starting to look like Yentl? Well, yes, obviously it is about this fear. Is
it about the fear that non-genetic men will usurp genetic male privilege? (I ha
ve a friend who calls genetic men \'22accidental men,\'22 but I will use the po
litically correct though still not completely scientifically sound term \'22gen
etic men.\'22) \par\par
According to Maher, Alex has a girlfriend and Maher seems both concerned and
jealous about this whole girlfriend idea. So it \'5B*377\'5D is clearly a
little bit about that. But the kicker to his extended riff on Alex Myers, one t
hat he saves until the end of the segment, is that this guy would change back t
o being a woman, a high-fem woman no less, in a second, to get a space on a lif
eboat on the Titanic. \par\par
This brings me to my last \'22grandiloquent point.\'22 This transphobic stor
y transitions into a slightly different kind of story. It is questioning the pe
rmeability of the boundaries of the sex/gender classification system. And those
boundaries are so contested because this gender system that we have now is one
of the key mechanisms through which scarce resources - boats, in the case of t
he Titanic, Social Security and other state benefits in the case of legal marri
age - are distributed or not distributed. A regime that does not adhere to the
doctrine of the separation of gender and state is going to produce a lot of anx
ieties and clashes about its rules of gender classification. Conversely, if one
's beliefs and practices about gender played as little a role in determining on
e's position vis-a-vis the legal opportunity structures as the way one's religi
ous beliefs and practices now do, the myriad of conflicts about gender - from g
ays in the military to transsexuality - would continue no doubt, but would be e
mptied of the considerable force of state sanction. \par\par
Thank you. \par\par
MS. KERN: Thank you very much. \par\par
Professor Franke? \par\par
PROFESSOR FRANKE: I hope you do not mind if I come over here. I teach torts
in this room. So on behalf of both my torts class and Fordham Law School, I wan
t to welcome you all here. \par\par
It is exciting to me to have so many lesbian and gay people and friends here
at Fordham, which is not to say that we do not have friends here the rest of t

he week. \par\par
There has been sort of a nice thread where we have each picked up where the other one left off. I want to try to do that, as well, and ask a question that I think is lurking where Paisley ended, which is: What is transgender-based dis crimination a question of? Why should we, as lesbian and gay, bisexual or heter osexual people, care about transgender-based discrimination? We tend to bundle groups of identity-based concepts into civil rights categories. Why do we add t ransgendered people and issues affecting transgendered into the lesbian, gay an d bisexual movement as opposed to say, the women's movement? I do not profess t o have a complete answer to this question, but I am going to begin by making t he question more complex and then suggest some answers. \par\par
\'5B*378\'5D Just as any adequate account of the nature of discrimination against black people, for instance, must go beyond the mere status of a person' s race to questions of white supremacy in order to provide an adequate account of race discrimination, or any adequate account of discrimination against women must go beyond biological facts of people to an adequate account of patriarchy , I think that in order to provide an adequate description of discrimination ag ainst transgendered people, we have to include the cultural norms that compel i n subtle and, as we have heard from these stories, not so subtle ways a set of compulsory gender identities and norms. \par\par
In the short time that I have today, I am going to cut through the niceties and suggest what I think are two fundamental strategic errors that have been ma de - not by everyone but by some - in advocating on behalf of the rights of tra nsgendered people, and then elaborate a little bit on why I think those are mis takes. Then if you are interested, we can talk about them a little more during the questions. \par\par
First, is that I think it is a significant mistake for us to advocate to add transgendered people to the laundry list of protected statuses that appear in most antidiscrimination laws: sex; race; national origin; religion; and, if you are lucky, sexual orientation. I do not think we should add another semicolon and add transgendered people. \par\par
Second, explaining in part, why I hold the just expressed view, I think it i s an even graver mistake to see the discrimination faced by transgendered peopl e as to be problems in which only transgendered people have a stake. All of us have a stake, whether we are transgendered or not, in the kinds of discriminati on that people who are believed to be transgendered experience. \par\par
Now let me, as my two prior panelists have done, begin by giving you some ex amples, and I think there is a particular importance to our telling stories and giving examples in this area, because these are parts of life that so often ar e ignored and silenced. It is extremely important for us to work from real-life experiences and the types of problems and violence that people experience day- to-day who are transgendered. \par\par
First, Big Boy restaurant refused to hire a preoperative transgendered woman as a hostess because she was transgender. When she brought an action for sex d iscrimination, the court dismissed the complaint and held that the law does not protect males dressed or acting as females, or vice versa. According to the co urt, that is \'5B*379\'5D not what sex discrimination laws were intended to or should be interpreted to apply to - not surprising, for any of you who have looked at this area at all. \par\par
Secondly, a preoperative transgendered woman who worked at Boeing, the big a irplane manufacturer out in Washington, was told by her employer that they had a policy regarding the employment of transgendered persons; apparently, in Wash ington there are a number of transgendered employees that had worked there - an d that as long as she was pre-op, she could not use the women's bathroom and co

uld only wear either male or unisex clothing. Curiously, though, unisex clothin g was defined by Boeing to include blouses, sweaters, slacks, flat shoes, and - then this is the great part - nylon stockings, earrings, lipstick, foundation , and clear nail polish, no colors. \par\par

She was, however, instructed in addition not to wear clothing that was exces sively feminine, such as dresses, skirts and frilly blouses. Blouses are okay; frilly blouses are not. \par\par

Now, remember, as a preoperative transsexual she has to live in the gender r ole that she is choosing to officially occupy. So she has to thread a needle be tween unisex on the one hand and overly feminine on the other, and in order to do so, this poor woman's supervisor was instructed to tell her each day whether or not her attire was acceptable. The test that the supervisor was instructed to apply was whether her dress would be likely to cause a complaint were she to use a men's room at the Boeing facility. This is the \'22transgendered woman i n the men's room at Boeing\'22 test. \par\par

One day she comes to work wearing an outfit that had been previously approve d by her supervisor but decided that day to accessorize it with pink pearls and was fired immediately for wearing clothing that was excessively feminine. She brings an action in state court in Washington and ultimately loses in the Washi ngton Supreme Court. n70\par

\par

----------Footnotes----------

\par\par

n70. \i Doe v. Boeing Co., 846 P.2d 531 (Wash. 1993).\i0 \par

\par

----------End Footnotes----------

\par\par

Finally, a masculine woman worked as a teacher in a juvenile detention cente r where her supervisor, a female judge, described the unwritten dress code as t hat which was \'22appropriately feminine\'22 - because, after all, they were ro le models for the young girls in their charge - and this woman was ultimately f ired for wearing the \'22Brooks Brothers look,\'22 the look that all of you who are either lawyers working in firms or will be some day know well. \'5B*380\ '5D She would not wear skirts; she wore pants and was fired for that reason, that she was a bad female role model. \par\par

Now only the first two examples here involve transgendered people, but the p rinciple at stake in all three, I believe, is the same. This is about coerced e nforcement of gender orthodoxies through workplace rules, and we could come up with other examples in other parts of life. This orthodoxy reflects a collapsin g of gender, which is a set of cultural norms and biological sex in such a way that femininity is understood as the natural and authentic expression of female agency, and masculinity is understood as the natural and authentic expression of male agency. So just as you cannot mix and match sex and gender, masculinity and maleness, femininity and femaleness, so too you cannot switch sides. Men d o not become women. Males do not become females. \par\par

These qualities, sex and gender, are regarded as being normatively immutable . In that sense, it is naturally impossible to change, and we should not want t o in the first place. So it is wrong of us to want to pull something off that i s not possible to do anyway. \par\par

There is a Supreme Court case from 1989 which I am sure many of you are fami liar with Price Waterhouse v. Hopkins, n71 that should have resolved all of th ese cases. There, Ann Hopkins, who had been a very well-performing woman at one of the top accounting firms, applied for partnership. She was denied partnersh ip because - and if you are a litigator, this is just the greatest thing that t

hey actually put this in writing - she was \'22too macho.\'22 She should enroll in a course at charm school to learn how to walk more femininely, talk more femininely, dress more femininely, wear makeup, have her hair styled, wear jewelry and learn how to accessorize like the poor woman at Boeing did.\par
\par
----------Footnotes----------
\par\par
n71. \i 490 U.S. 228 (1989).\i0 \par
\par
----------End Footnotes----------
\par\par
So Ann Hopkins did not wear the pearls and lost the job. Now she won her sex discrimination suit in the U.S. Supreme Court, because the Court interpreted the sex discrimination provisions in Title VII to include the imposition of gender-based norms on men and women. n72 To punish a woman because she acts aggressively or to hold a view that women should not act aggressively or cannot is gender-based discrimination, according to the Supreme Court in 1989. n73 An incredibly important decision, an incredibly important victory. We were all excited. I was very excited when this case was \'5B*381\'5D decided, and we thought, \'22Well, this is really going to change the landscape of Title VII sex-based discrimination to include gender norms.\'22\par
\par
----------Footnotes----------
\par\par
n72. See \i id. at 229.\i0 \par\par
n73. See id. \par
\par
----------End Footnotes----------
\par\par
Well, sad to say, it has not. You would have thought that this ruling would have invalidated the three examples of the types of workplace rules that I gave you before, but it just has not been the case. You continue to see courts uphold the idea of clothing rules that enforce the idea that certain clothes belong to men and other clothes belong to women and that you cannot switch sides. So people who are born male wear women's clothes as part of a transsexual process continue to be discriminated against in the workplace, on the theory that Title VII or workplace antidiscrimination laws do not reach transgendered people, without understanding that this is not about some hybrid special situation; this is about gender norms. \par\par
To my mind, both our legislative and litigation strategies on behalf of transgendered people should not be to add transgendered people or transgenderism - or whatever the word is in your jurisdiction - into the laundry list of identity groups or statuses that are protected by human rights laws, but instead to robustly interpret what our sex-and gender-based discrimination laws prohibit, which includes the idea that real men do not sleep with men, real women are not masculine, real men do not want to be women. They all stem from a central similar notion about who men and women are and how we should behave in the world to perform our gender identities. \par\par
MS. KERN: Thank you, Katherine. \par\par
\'5B*382\'5D \par\par
Sticks and Stones: The Nexus Between Hate Speech andViolence\par
\par
MR. CHEN: Welcome. My name is Jack Chen. I am a member of Fordham Law School's class of 1996. I first approached James about organizing this panel, partially

because of the media's response to the Matthew Shepard incident, n74 and also because of Reverend Phelps's \'22www.godhatesfags.com\'22 Web site that serves as a very clear example of hate speech.\par
\par
----------Footnotes----------
\par\par
n74. See supra note 4 (describing the Shepard hate crime). \par
\par
----------End Footnotes----------
\par\par
What I was hoping to do today was try to put our arms around the bigger issues, some of the grayer aspects of what really constitutes hate speech and how it may be related to bias crimes and what we can do to begin thinking about trying to address this in society. \par\par
To my immediate left is Laura Edidin, managing attorney of the New York City Gay and Lesbian Antiviolence Project; then we have Professor Brian Levin, director of the Center on Hate and Extremism and a Criminal Justice Professor at California State University, San Bernardino; and lastly, Professor Jack Battaglia from Touro Law School. \par\par
First, we will start with Laura, who will give us some examples of hate speech that are experienced by people of lesbian, gay, bisexual, transgendered and HIV status (\'22L/G/B/T/H\'22). \par\par
MS. EDIDIN: The Anti-Violence Project serves L/G/B/T/H crime victims. The areas of crime in which we do counseling, advocacy and legal services include domestic violence, bias crime, rape and sexual assault, pickup crimes and police misconduct, and I will also add HIV-related violence, because that is also a program that I coordinate. We define HIV-related violence as anytime someone is victimized because of their actual or perceived HIV status. \par\par
Part of the work that we do is bearing witness to the pain and trauma that are suffered by L/G/B/T/H crime victims, and it is in that role that I am here today. I want to talk about violence in the nexus with hate speech. I am studiously avoiding defining hate speech at this point because I want to just have all of us hear what it sounds like, give you a sense of what it feels like, and what it looks like. When I initially sat down to think about it, my first instinct was to intellectualize what hate speech is. I wanted to back off a step and talk about what we probably all agree is hate speech just by listening to it, and then draw some examples in the end of \'5B*383\'5D speech that I would like to see what people's opinion is on whether it is what your visceral reaction would categorize as hate speech. \par\par
I am just going to start by giving some examples of narratives about victims of crime, and then wrap up with some thoughts and some ideas. \par\par
I am going to start in the area of domestic violence and tell you some stories. The first one is about a woman. She and her partner lived together with their two children, and this woman's mother had mental illness and substance abuse issues. She wanted to come live with this couple, and they said, \'22We do not really think this is a good idea for our kids to have you in the home.\'22 \par\par
She was not happy with that, so one of the ways in which she dealt with that was by standing on the corner near their apartment, yelling all day long, \'22See that woman over there? She is a pussy-eating dyke. She is a fucking lesbian.\'22 \par\par
It escalated from there to her moving across the street to the stoop and telling the kids, \'22You want to know what your mom is doing? I will tell you what she is doing. She is eating that woman's pussy.\'22 \par\par

Then it escalated from there into her approaching their front door and pound ing on it until she broke in, insisting on sleeping there for the night. \par\ par

Another example is of a woman who resides in this country illegally. She was dating a man for a long time, and he said, \'22Why don't we just get married? It would make things easier with immigration, and we have been together a long time and have generally been thinking about it.\'22 She says, \'22Okay, let's d o it.\'22 \par\par

About a month after they were married, she tested positive for HIV, and when she sat down to tell her husband, he was initially very supportive and said, \ '22Well, let's go get another test and double-check, and I will get one, too.\' 22 When the test confirmed that she was positive and that he was negative, he t urned very abusive, told her that she was dirty, that she was a carrier, that n o one else would have her now that she was soiled by having HIV, threatened to reveal her HIV status in order to jeopardize her immigration proceedings and us ed it as an excuse to have sex outside their marriage. \par\par

The impact of this kind of language is really complicated, but what these ex amples bring out is the shame that is involved on the part of the victim when t hey are on the receiving end of abuse like that. For example, in the instance o f the woman whose mother was harassing her, she started to pull away from her p artner. There \'5B*384\'5D started to be tension in their relationship. A l ot of it came out of internalized homophobia and the shame around the fact that she was in love with a woman. \par\par

As for the woman who has HIV, she started to see an effect in her health. I think that is true generally of people who are victims of crime, but when someo ne already has a compromised immune system, they feel that physical impact of t he abuse even stronger. \par\par

To give you another example of domestic violence, a transgender woman entere d into a traditional marriage. At the time, he lived his life as a man and his wife knew that his gender identity was as a woman, but at the time he did not p resent as a woman to the world. They married, had two children, and at a certai n point he decided that he wanted to live his life as a woman and started dress ing as a woman. \par\par

His wife became very abusive. She would sit at the breakfast table and tell this transgender woman that she was ugly, that she was disgusting, that she rep ulsed her, and it escalated to the point where she threw a skillet full of egg s in the woman's face. \par\par

Moving into the area of bias crime, a very recent example that we encountere d was a case where two African American women were driving a car in Manhattan a nd the light turned yellow, and they decided to stop for the light. The taxicab driver who was behind them was not happy about that and started honking his ho rn, stuck his head out the window to see what they looked like, and noticed a r ainbow bumper sticker on their car. He started calling them \'22black bitches,\ '22 \'22nigger dikes\'22 and other sundry names. When that did not get the resp onse he was looking for or did not satisfy him, he started ramming his taxi int o their car in the hopes of pushing it into the oncoming traffic in the interse ction. I will tell you that, thanks to the work of one of our victim advocates, Momie Moran, the taxi driver's license was revoked and there was a fine. \par \par

Another example of HIV-related bias crime is a composite of a couple of diff erent stories that we have heard - there was a gay man who lived with his adopt ed son in an apartment building where one of the neighbors started to harass hi m on the basis of his sexual orientation and HIV status, and that ranged everyt hing from yelling \'22Die, AIDS faggot,\'22 to putting burning garbage on his d

oorstep, to scrawling on food delivery menus that were stuck on the door, \'22t
hese men are gay, they are spreading AIDS, they are child molesters.\'22 It esc
alated to the point where an order of protection was issued on behalf of the fa
ther and his adopted son, thanks to the good work of another legal intern. \pa
r\par
\'5B*385\'5D I want to talk about the impact of those crimes. Victims of c
rimes where hate language is used, where it is motivated by bias, may try to ch
ange their behavior as a way of avoiding being victims of another crime. For ex
ample, the women may have wanted to take the rainbow sticker off their car. Vic
tims may avoid gay-identified establishments; for example, victims of crimes ou
tside of a gay bar or a gay bookstore or an AIDS service organization may avoid
those places. \par\par
There was an instance in Brooklyn recently where a woman with short hair was
walking down the street and a man approached her and said, \'22You want to kno
w what it is like to be a man? I will show you what it is like to be a man.\'22
He took her, pulled her by the hair and pulled her head down and beat her head
until she was incapacitated. The impulse may be for her to grow her hair out,
since that is what seemed to be what made her a target. \par\par
Another impact on victims of crime, particularly crime where hate speech is
used, is the tendency to blame themselves for what happened - \'22I should not
have been out so late; I should not have gone home with someone I did not know.
\'22 That has a lot of consequences, not the least of which is failure to seek
medical attention, for example. \par\par
I spoke with one man who was the victim of a bias attack, and I said, \'22Ar
e you injured?\'22 He said, \'22No, no, just a couple of little things.\'22 I s
aid, \'22Okay, well, what is bothering you?\'22 He said, \'22Well, you know, my
ear.\'22 I said, \'22Why don't you tell me more about that?\'22 He said, \'22I
don't have any hearing in one of my ears.\'22 \par\par
To him, that was not a serious injury, and I think part of that dynamic is n
ot only a bit of self-denial; it is easier to believe that you are not injured,
because it is easier to believe that what happened to you was not so serious.
But part of that dynamic is also self-blame - \'22Well, it is my own fault. Wh
at was I doing on the subway that late at night where no one else was?\'22 \pa
r\par
Giving some examples from rape and sexual assault, a transgender woman was v
olunteering for a while at a nursing home. She knew a lot of people there very
well. When a rumor got started that she was not really a woman, she ignored it.
She thought, \'22These are people I know, they are my friends, and if they hav
e a question, they are going to come and ask me.\'22 \par\par
What ended up happening was she was lured into a storage room. Her superviso
r said, \'22There is something here I want to show you; come on in.\'22 When sh
e got there, there was a gang of \'5B*386\'5D employees who sexually assaul
ted her, pulling at her clothes, grabbing at her crotch, grabbing her breasts,
and yelling things like, \'22What do you have down there? What are you? Are you
a man? Are you a woman?\'22 - calling her \'22an anti-man, a faggot, a cocksuc
ker, a she-man.\'22 \par\par
There was another recent example of a man who went to a bar, met someone he
found attractive and invited him back to his apartment, hoping to have a drink.
The two of them had a conversation. The other man apparently had slipped some
knockout drugs in his drink, and he awoke to find that he had been raped, and t
he perpetrator was taking his wallet off the table as he was awaking, calling h
im a \'22stupid faggot.\'22 \par\par
For victims of crimes like these, in addition to other crimes, there are oft
en flashbacks to the incident. It may also trigger flashbacks to other incident

s of violence that they have experienced. It makes very spotty memories. They m
ay actually physically recall the violence that was perpetrated against them. T
hey can feel the hands of their coworker grabbing at their crotch or clawing at
their breasts. \par\par

Moving to an example of police misconduct, another area that we do work in,
a transgender woman lives at home with the family, and her mother was concerned
that she was not well and called EMS. They showed up and determined that the w
oman was fine. She had apparently taken some cold medicine. She left the apartm
ent, and after EMS left, some housing police showed up. The police said, \'22We
are looking for John Doe.\'22 In this transgender woman's family, they still r
eferred to her by her male name, which is John Doe. Her family replied, \'22Oh,
John Doe went out, everything is fine, we are sorry, it was a mistake.\'22 \p
ar\par

As the police were leaving, they walked by a very attractive woman, and they
acknowledged her - perhaps held the door for her -- and she went over and knoc
ked on the door of the apartment from where they just left. When the door opene
d, the person who answered the door said, \'22Oh,\'22 and called to the police
and said, \'22This is the person you were looking for.\'22 They came back and s
aid, \'22We were looking for John Doe. This is clearly not a John Doe. Look at
her, she is gorgeous.\'22 \par\par

Allegedly - and I say allegedly as a good lawyer would, because there is a c
ivil suit in the works - the police forced their way into the apartment, starte
d calling her names like \'22trans-testicle, he-she, what-is-it.\'22 One office
r allegedly followed her into a bathroom in the apartment and started assaultin
g her. She said, \'22Please do not \'5B*387\'5D hit me in my chest and face
; I had silicone implants and I have had plastic surgery.\'22 Of course, that i
s exactly what they went for. \par\par

People who have been victims of crimes like that may see changes in their sl
eeping and eating patterns. They may have nightmares. I know of people who are
on dream suppressants to help them sleep through the night. Some are unable to
function at work or focus on anything in particular. \par\par

I hope that gives you some sense of what these crimes look, sound and feel l
ike. What I want to do now is throw out some ideas about the relationship betwe
en speech and violence, how they are linked, how they work together to oppress
people, and then at the very end return to hate speech. \par\par

What do we mean in terms of hate speech? First, hate speech and violence are
alike in the sense that they both hurt, and there is evidence that the afteref
fects of hate speech are, in fact, more dramatic and traumatic than the physica
l violence of a victim of a non-bias crime. For example, people who are victims
of a bias crime may take more than twice as long to recover psychologically th
an victims of similar crimes not motivated by bias. It is such a cliche, but we
hear clients say all the time that the bruises heal, but the psychological sca
r from the words remains. Every time they hear the same hateful words, it reope
ns that scar. \par\par

The other way in which I think they are similar is that what we see in a lot
of crimes motivated by bias is the idea of overkill. They are not stabbed once
, twice or three times, but rather stabbed ten, fifteen or twenty times. It is
this idea of overkill, doing more than is necessary to mortally wound a person.
\par\par

There is some sense that the phenomenon of overkill comes from this idea tha
t the perpetrator is literally trying to rub out the very existence of that per
son, and in some way, hate speech has that same dynamic. It is not enough to sa
y \'22Is that a he-she, what is that?\'22 The perpetrator will say, \'22You are
a fucking trans-testicle. What is that?\'22 They may repeat over and over the

same language: \'22faggot, fucking faggot.\'22 Most of this stuff is not very o
riginal. You hear it over and over again. \'22Die, AIDS faggot.\'22 That kind o
f repetitive and overkill quality serves the same kind of purpose. It refuses t
o allow that person autonomy in how they identify. \par\par

Now I want to talk about how speech and violence work together. The way in w
hich language and violence work together is if someone kicks you in the head an
d calls you a faggot, the next time someone calls you a faggot, you know what t
hat means. You do not need someone to tell you that you are going to get kicked
in \'5B*388\'5D the head or if that person wanted to they could kick you i
n the head. The word alone carries the threat. \par\par

They work together in the sense that when speech is used and the perpetrator
is very clear that they have targeted this person because of their identity, w
hether sexual orientation, gender identity or their HIV status. \par\par

When a perpetrator uses speech and makes it very clear why he or she is comm
itting the crime, he or she are making it clear not only to that individual, bu
t to the community. To give you an example, if I am mugged at the J Street subw
ay station in Brooklyn, I am going to take a different train and get off at Cla
rk Street instead. I am attacked and told that it is because I am an AIDS-infec
ted loser, what am I going to do to avoid that happening again? What is any pe
rson who has HIV or AIDS going to do? That sense of security and control over y
our life, that you are able to change your behavior or something about yourself
to make sure you are not victimized again, is a loss because, in a sense, it i
s a whole community that is being targeted. \par\par

Finally, I want to talk a little bit about another way in which violence and
speech work together. The use of hate speech during a crime, particularly L/G/
B/T/H hate speech, may alienate people from access service. For example, if I a
m mugged, I will go to the police station and say, \'22I was mugged. Here is wh
at happened: I was walking down the street, the guy pulled a handbag off my sho
ulder, and I want to report it. In the process, I broke a finger, and I am goin
g to see a doctor.\'22 \par\par

If I go to a gay bar and I meet someone and I bring them home and the minute
they get in the door, they turn on me and they pull out a knife and they say,
\'22you stupid bitch, or you dumb faggot, I am not here because I am interested
in you; I am here because I want your wallet,\'22 and then they cut me on the
way out the door, I am going to have to go to the police station and explain wh
at this person was doing in my apartment. What am I going to say? \'22Well, off
icer, I am a gay man and I went to a gay bar, I picked someone up and brought h
im home.\'22 The officer will say, \'22Why did you bring them home?\'22 I will
have to reply, \'22I was interested in having sex with him.\'22 \par\par

If you are not out, that is not something that you are going to do. You woul
d probably think that the police are not interested in serving you as a member
of that community. \par\par

For a clearer example, let's say you are coming out of a gay bar by yourself
. Suppose someone follows you and attacks you. The \'5B*389\'5D fact that t
he speech was used may prevent you from reporting what happened. \par\par

For people of transgender experience, who are already alienated from service
s, particularly medical services, it is not very likely that they are going to
seek medical attention. If they do not have access to regular health care and a
doctor who knows them and their story, they are going to have to walk into an
emergency room and explain to someone they have never met before why they appea
r to be a woman but anatomically are a male. Similarly, if the police generally
target people of transgender experience and harass them, they are not likely t
o report such incidents. \par\par

Finally, I want to talk about the definition of hate speech, and I will give

you a couple of examples, rather than cite a definition myself. Focusing on th
e transgender woman again whose wife became abusive when she decided to start a
cting on feelings of being a woman by dressing and living as a woman. When she
decided to start living her life as a woman, she went to her employer and asked
a couple of things. She said, \'22I would like to wear the woman's uniform rat
her than the man's uniform, and rather than you calling me John Doe, I would li
ke you to call me Jane Doe.\'22 \par\par

Her employer started the conversation by saying, \'22I do not understand wha
t you mean. Do you have a penis?\'22 \par\par

The client said, \'22Yes, I do.\'22 \par\par

\'22Well, do you want the penis?\'22 \par\par

The client said, \'22Well, I am considering sex reassignment surgery.\'22 \
par\par

\'22Well, when you have the operation, how does it work? What do they do to
your penis? Are you going to have breasts? How does that work?\'22 \par\par

Then the client said, \'22Now that you asked me all those questions, how do
you feel about my requests?\'22 \par\par

The employer, much to my amazement, said, \'22Well, you can wear the woman's
uniform. We cannot call you Jane Doe because your union card says John Doe, an
d in order to get your union card changed, you have to change a whole bunch of
other identification - which, by the by, is not very easy to do. So we are not
going to call you Jane Doe. We are going to call you John Doe.\'22 And they con
tinued to do that. \par\par

This same woman shopped regularly at a grocery store in her neighborhood, an
d after she started dressing as a woman and living as a woman, the bag boy at t
he grocery store continued to call her \'22sir.\'22 As many times as she correc
ted him and said, \'22I am a woman, \'5B*390\'5D please call me ma'am,\'22
he continued to call her \'22sir.\'22 Those examples of calling someone \'22Joh
n Doe\'22 instead of \'22Jane Doe,\'22 asking questions or making statements li
ke \'22I have never heard of someone who has a penis who is a woman,\'22 or \'2
2do you have a penis,\'22 or \'22are you going to get rid of your penis,\'22 ca
lling her \'22sir\'22 instead of \'22ma'am\'22 - I think those things push the
edge of the envelope and may have sharpened our focus of what hate speech is, e
ven though we know it when we feel it, to try to put it into words, in the same
way that the experience of transgender people in general inform the work that
we do every day, making connections between discrimination based upon sex, on s
exual orientation, on gender and parsing those things out and thinking carefull
y, thoughtfully and thoroughly about all those different areas. \par\par

Finally, the other thing I want to throw out there is the fact that a lot of
times speech involves multiple forms of behavior. One of the things I would en
courage us to talk about today is making connections. When someone calls you a
\'22homo-ass nigger,\'22 what did that get them? How is that different than if
they just called you \'22a homo\'22 or \'22a nigger,\'22 and why layer those th
ings? Why pile them up? What implications does that have for us as service prov
iders, for us as theorists, for us as litigators, in terms of thinking about th
e ways in which different forms of oppression work together, the way in which l
anguage can tell us something about those connections? \par\par

MR. CHEN: Thank you, Laura. Brian Levin has worked on a number of cases that
have touched on hate speech and bias crimes and has also testified in front of
Congress once or twice. \par\par

I have asked him here to give us a broader view of the legislative scenery a
nd discuss what is happening for different states, how hate crime legislation w
orks, and also talk a little bit about the current bill that is in front of Con
gress that would include sexual orientation. \par\par

MR. LEVIN: Thank you. What I am going to try to do is actually frame that di
scussion in the last part of my talk. What I want to do first, though, is get t
o the nexus issue, the title of this conversation. I think that hate crime is
a vitally important issue for our society and one that really warrants a nation
al conversation. \par\par

As someone who has been very involved in public policy, and particularly wit
h hate crimes, since 1986, I can really sense how our discussion of this issue
has significantly degenerated. I have a palpable sense that we are no longer ta
lking to each other; but rather at each other, and in some ways I think the med
ia and the general level of discourse has oftentimes succumbed to incivility an
d sensationalism. \'5B*391\'5D That is something I am not going to dwell on
here, but I do think it is important to discuss because homophobia is somethin
g that takes place not only in discreet singular events, but also in a larger c
ontext where many take advantage of using hurtful and negative stereotypes to a
chieve a particular political agenda. \par\par

Table 1. Hate Crime Incidents in the United States by Year n75\par
\par
\par
\par
\'5Btdm'Year',qc \'5Btcgp1,m'Incidents',qc \'5Btcgp1,m'% of Total Police Depts
.',qc\'5D \'5Btu3;3\'5D YearIncidents % of Total Police Depts. Submitting Repor
ts \'5Btu3;3\'5D 1991 4558 17% 1992 6623 39% 1993 7587 41% 1994 5932 46% 1995 7
947 60% 1996 8759 71% 1997 8049 70% \'5Btu3;3\'5D Total Incidents AntiGay,Lesbi
anor Bisexual(Number/%) \'5Btu3;3\'5D 1995 7947 1002/12.6% 1996 8759 1001/11.4%
1997 8049 1090/13.5% \'5Btu3;3\'5D \par
\par

I will talk specifically, though, about the intersection of hate speech and ha
te crime. One of the things I have always felt is that you can evaluate a socie
ty in part by how it treats two different things. The first is the level of tol
erance that society has for discourse, including the kind of uncivil discourse
that I just railed against. Secondly - and in no particular order of importance
- is how a society reacts to diversity and to those who, by virtue of those di
fferences, are sometimes cast in a position of being the most vulnerable in tha
t society. At times, those interests conflict. What we have in our discussion t
oday, I think, is the intersection of these important values.\par
\par

----------Footnotes----------

\par\par

n75. See FBI Uniform Crime Reports, Hate Crime Statistics Annual Report. The
majority of agencies submit reports counting zero hate crime in their jurisdic
tion. \par
\par

----------End Footnotes----------

\par\par

Let me try to wear two hats here. On the one hand, I am an attorney. On the
other hand, I am a professor and criminologist. I recognize that many of you wi
ll leave here saying, \'22Jack, why did you invite that guy,\'22 because the wo
rld is not divided up into these artificial boundaries that lawyers make, nor i
s it divided up into the artificial boundaries that criminologists make. With t
hat small disclaimer, \'5B*392\'5D let me go into what I think are two of t
he many issues that exist with regard to this nexus. \par\par

The first thing is how far should criminal laws go to punish bigoted or disc
riminatory behaviors, if they should at all? Let me say in the beginning that I
think there can be a non-bigoted and non-prejudiced argument that laws should

not cover so-called hate crimes, and I will try to define them in a bit. I hap
pen to be on the opposite end of that debate, but I do think one can make a pri
ncipled argument on the opposite side. \par\par
Unfortunately, the last several times I have taken part in any public discou
rse on the topic, I did not have the benefit of principled discussion. A lot of
it just devolved into a presentation of stereotypes, homophobia and a substant
ive misstatement as to the purposes of the criminal law. \par\par
We do punish discrimination in our society, both on the civil and criminal s
ide of the law. n76 Now, the definition of discrimination sometimes does not ge
t you very far. Discrimination is treating similarly situated people differentl
y without a legal or sufficient basis. Now, if you do not think there are looph
oles in that definition, there certainly are.\par
\par
----------Footnotes----------
\par\par
n76. See, e.g., \i Roberts v. United States Jaycees, 468 U.S. 609 (1984).\i0
\par
\par
----------End Footnotes----------
\par\par
In addition, there are many immoral things in this society, many hurtful thi
ngs, many horrible things, that we simply do not punish by the force of law. Th
at does not mean that we as a society necessarily condone those things. The law
is a very strong instrument, and I think we must be selective as to what it ad
dresses. \par\par
The second issue, which has caused me considerable distress for a very long
time is if you embrace civil and criminal anti-discrimination laws, what kind o
f classifications do you protect? On what basis in law? Is there any kind of fi
xed or definitional reason that we include race, religion or national origin in
some states, but not sexual orientation, disability or gender in others? Forty
-one states have hate crime laws, but only twenty-two cover sexual orientation.
Those are important issues, as well, that we are going to try to get to. \par
\par
\'5B*393\'5D \par\par
Table 2. 1999: Jurisdictions With Criminal Hate Crime Statutes Covering Sexu
al Orientation - 22States n77\par
\par
\par
\par
\fl \par----------\par\par
AZ LA OR\par
CA ME RI\par
CT MA TX\par
DC MN VT\par
DE MO WA\par
FL NE WI\par
IA NH\par
IL NJ\par----------\par\par
\f0 \par
\par
The next issue regards speech: what constitutes speech, and how far should we
allow speech to go? As a general rule, speech or communicative expression that

does not fall into certain unprotected categories is, in fact, insulated from punishment based on its content. In fact, since R.A.V. v. St. Paul, n78 even un protected areas of speech have a minimal level of protection based on content.\ par
\par
----------Footnotes----------
\par\par
n77. See National Gay & Lesbian Task Force: Hate Crime Laws in the United St ates, Center on Hate & Extremism <http: www.ngltf.org>. Texas hate crime law co vers bias or prejudice against groups without identifying the actual groups pro tected. \par\par
n78. \i 505 U.S. 377 (1992).\i0 \par
\par
----------End Footnotes----------
\par\par
The crux of this issue is that mere offensiveness of speech alone is not a b asis for a proscription. n79 Interestingly, in many other parts of the world - Canada, the U.K. and Germany for instance - incitement to racial hatred or so-c alled group defamation laws are on the books. They are very rarely used in part because it is so hard to prosecute them. In England, for example, very few cas es come up under that law.\par
\par
----------Footnotes----------
\par\par
n79. See, e.g., \i Texas v. Johnson, 491 U.S. 397 (1989).\i0 \par
\par
----------End Footnotes----------
\par\par
In fact, we had laws like this in the United States during the first half of the 20th Century. At that time, laws punishing group defamation were on the bo oks. In fact, a challenge went up to the Supreme Court in Beauharnais v. Illino is. n80 The Supreme Court validated the law. Since then, however, the primary l egal foundations upon which the Beauharnais decision was based upon have been c ut down, although technically Beauharnais has never been overruled. Since then, though, it is important to recognize that offensiveness is not a basis for pun ishing or preventing speech by force of law.\par
\par
----------Footnotes----------
\par\par
n80. \i 343 U.S. 250 (1952).\i0 \par
\par
----------End Footnotes----------
\par\par
\'5B*394\'5D Nevertheless, there are certain communications that are crime s in and of themselves. Conspiracy - an agreement with another person to commit a crime, is not insulated by the First Amendment from criminal prosecution. n8 1 Threats are certainly punishable - nasty letters to the President about his p olicies are protected, but do not threaten him. n82 That is, I think, an import ant area of delineation. Criminal solicitation where someone requests or encour ages another person to commit a crime is another example of a form of communica tion. n83\par
\par
----------Footnotes----------
\par\par

n81. See Model Penal Code 5.03. \par\par
n82. \i Watts v. United States, 394 U.S. 705 (1969);\i0 see also \i 18 U.S.C. 871\i0 (a) (1994). \par\par
n83. Model Penal Code 5.02. \par
\par
----------End Footnotes----------
\par\par
In addition, speech can be used as evidence to prove intent or motive in a crime. Now, intent is the \'22what\'22 of the crime, the desired purpose or the knowledge in committing the crime. Motive generally is not an element of a crime, although it certainly can be. For instance, why you break into a house can determine whether or not you get convicted of criminal trespass or burglary. If you enter the home to commit a crime inside and that is your motive, if you will, that is the heightened offense of burglary, and motive actually becomes an element to the offense. n84 So in order to make it more confusing, sometimes motive becomes a material element of an offense, depending upon how the elements of the crime are written. In any event, even if it is not an element of the crime, motive can certainly be used to determine upon conviction the severity of one's sentence.\par
\par
----------Footnotes----------
\par\par
n84. See Model Penal Code 221.1-2. \par
\par
----------End Footnotes----------
\par\par
Well, that being said, what do you do about hurtful offenses being targeted at group members, the kind that Laura spoke so eloquently about, that do not fit into these existing niches? The first thing I will admit to you is that hate speech has consequences. Hate speech, particularly about historically oppressed minorities, has an effect. It changes people's behavior. It harms them in ways that they relate to others, something particularly harmful to a democratic and pluralistic society. n85 However, the majority view on the First Amendment says we must tolerate a certain amount of bad discourse in a free society and the way to beat bigoted speech is with enlightened discourse, which leads us next to hate crime laws.\par
\par
----------Footnotes----------
\par\par
n85. See, e.g., Charles Lawrence, Is There Ever a Good Reason to Restrict Free Speech on a College Campus? Yes., The Stan. Law. (Fall 1990). \par
\par
----------End Footnotes----------
\par\par
The Supreme Court decided two cases involving hate crime laws, including one that involved a cross burning by a teenaged \'5B*395\'5D skinhead, the R.A.V. v. St. Paul. n86 In that case, the cross burning law at issue punished only certain types of cross burning that were used to express certain views. It did not punish all cross burnings that were used to terrorize people, but only those cross burnings that communicated certain types of bigotry deemed unacceptable by the city. The Supreme Court in essence said, \'22You cannot do that. If you burn a cross on a black family's lawn to express racial hatred, that would be a crime, but if you are burning a cross at a home for mentally ill people, a category of the law left out, that would not be punished. No, we are not going

to allow that, because the criminality hinges on the bigotry, hinges on the pre judice, rather than the underlying terrorist act and we do not want to punish p eople for their prejudice.\'22\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n86. \i 505 U.S. 377 (1992).\i0 \par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - -
- \par\par
The next year, the Supreme Court was asked to rule on a different type of la w that was better drafted. The law at issue in Wisconsin v. Mitchell n87 punish ed the intentional selection of a crime victim based on a particular group cate gory, such as race or sexual orientation. This kind of discriminatory selection resulted in an enhanced penalty to be added on to the punishment for an underl ying crime.\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n87. \i 508 U.S. 476 (1993).\i0 \par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - -
- \par\par
Well, the first difference between R.A.V. and Mitchell is that you had to co mmit a crime first with Wisconsin's law in order to be punished. So that was on e thing. The second thing is the prejudice was not the primary target of the Wi sconsin law; but rather the discriminatory selection of a crime victim. Interes tingly, if there was a gay offender that went around beating up gay people, wor e a mask, and said homophobic things to promote gay solidarity in the city, he would be a hate offender, and his actions would be punishable, irrespective of the fact that he did not have the kind of animus that we usually think of with violent homophobes. \par\par
Therefore, discrimination is an act that can be punished. n88 It is treating someone differently. While the prejudice that leads to it cannot be punished, the act of discrimination itself can be.\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n88. See, e.g., \i Roberts v. United States Jaycees, 468 U.S. 609 (1984).\i0
\par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - -
- \par\par
Well, let's look at the kind of laws we have on the books, so I can close wi th that. There is no one type of hate crime law. However, the most broadly appl icable laws fall into two categories. \par\par
The first type is the intentional selection style statute I just spoke of, w here intentionally selecting a crime victim based on their group status is puni shed. That is one type. \par\par
\'5B*396\'5D Another type is the stand alone civil rights type statute, wh ich punish the interference with someone's civil rights through force or threat . Some also add protected group categories such as race, religion, sexual orien tation - that is another of the most broadly applicable kind. n89 This type of law does not require the charging of an additional offense.\par

\par
----------Footnotes----------
- \par\par
n89. See, e.g., Cal. Penal Code 422.6 (West 1999). \par
\par
----------End Footnotes----------
- \par\par
But there are many other types of state laws, which unfortunately time does not give me the ability to go over right now. \par\par
Unfortunately, there is no broadly applicable federal hate crime law. There is the Sentencing Enhancement Act of 1994 of the Violent Crime Control and Law Enforcement Act of 1994, n90 which does cover sexual orientation, but you have to commit an underlying federal offense first, of which there are a limited num ber. So if you \'22gaybash\'22 in a post office or a maritime vessel, the crime is covered. But not on a military base, apparently, since the Uniform Code of Military Justice does not have a hate crime provision.\par
\par
----------Footnotes----------
- \par\par
n90. Pub. L. No. 103-322 280003 (1994). \par
\par
----------End Footnotes----------
- \par\par
There are also separate federal criminal civil rights laws that cover variou s things, such as conspiracies n91 and housing. n92 There is a thirty-one year- old law that covers race in certain civil rights deprivations. n93 It covers re ligion and national origin with a smaller number of violent deprivations. These protected rights are crisscrossed to certain protected groups. So if you attac k someone because of their race because they want to vote, or because they were going to serve on a jury or something like that it would be covered, but not i f you were gay. It is very convoluted and quite stark as to what gets covered a nd what does not.\par
\par
----------Footnotes----------
- \par\par
n91. See \i 18 U.S.C. 241\i0 (1994). \par\par
n92. See \i 42 U.S.C. 3631\i0 (1994). \par\par
n93. See \i 18 U.S.C. 245\i0 (1994). \par
\par
----------End Footnotes----------
- \par\par
The latest bill, the Hate Crime Prevention Act of 1999, n94 changes existing deficiencies by amending section 245 of title 18 of the United States Code 245 to protect on the basis of gender, sexual orientation and disability. It also includes a requirement involving a nexus to interstate commerce in order to ful ly establish federal jurisdiction over criminal civil rights offenses involvin g those added categories. n95 The Supreme Court consistently relied upon a show ing of Congress' constitutional authority in upholding antidiscrimination laws and it is usually hooked into the Thirteenth \'5B*397\'5D Amendment and the Commerce Clause. So presumably the Commerce Clause can be construed to empower Congressional action because if you beat up a gay person, that would stop that gay person from coming to that state or that city to engage in commerce. This proposal was a just defeated on Capitol Hill.\par
\par

----------Footnotes----------
- \par\par
n94. S. 622, 106th Cong. (1999); H.R. 1082, 106th Cong. (1999). \par\par
n95. See \i United States v. Lopez, 514 U.S. 549 (1995);\i0 \i Bronkala v. Virginia Polytechnic & State Univ., 935 F. Supp. 772 (W.D. Va. 1996).\i0 \par

\par
----------End Footnotes----------
- \par\par
New York State does not have an adequate hate crime law. n96 It has a provis ion called aggravated harassment, which is, again, probably the most ineffectiv e hate crime law in the United States, if you call it a hate crime law at all.\ par
\par
----------Footnotes----------
- \par\par
n96. N.Y. Penal Law 240.30-31. \par
\par
----------End Footnotes----------
- \par\par
New York State does not have a hate crime law that covers sexual orientation . About twenty states do. Interestingly enough, this year Colorado, n97 Wyoming , n98 Idaho n99 and Utah, n100 have all failed to enact new hate crime laws or amend existing laws to cover gays. The debate has been degraded by, I think, tw o things: homophobia on the one hand and, on the other hand, a misrepresentatio n of the actual severity of hate crime.\par
\par
----------Footnotes----------
- \par\par
n97. See H.R. 1074, 62nd Leg., 1st Reg. Sess. (Colo. 1999). \par\par
n98. See S. 84, 55th Leg.; H.R. 117, 55th Leg. (Wyo. 1999). \par\par
n99. See H.R. 36, 55th Leg; 1st Reg. Sess. (Idaho 1999). \par\par
n100. See S. 34, 54th Leg., Gen. Sess. (Utah 1999). \par
\par
----------End Footnotes----------
- \par\par
Hate crimes are more likely to involve assault; these assaults are more like ly to involve injury; they are more likely to involve copycat offenses, retalia tory crimes; they are more likely to involve strangers, imprecise weapons of op portunity, multiple assailants - all objective measures of severity. n101 When you inject the homophobia into things, however, it becomes a debate or a refere ndum on the theology of how it relates to gay rights.\par
\par
----------Footnotes----------
- \par\par
n101. See J. Levin, J. McDevitt, The Rising Tide of Bigotry and Bloodshed: H ate Crimes (1993); B. Levin, Hate Crimes: Worse by Definition, 15 J. Contemp. C rim. Just., Feb. 6, 1999. \par
\par
----------End Footnotes----------
- \par\par
In closing, I think it is important to recognize that this is not simply a g ay, lesbian or transgendered issue. It is a human rights and civil rights issue . This is an issue that I have been working on for more than fourteen years to

try to get these important laws passed, and to show how these crimes are more s evere. But, again, I think we are losing something if we say we merely want the se laws because they involve more assailants and because they involve imprecise dangerous weapons of opportunity. I think it is also an attack of moral violen ce on a pluralistic democracy, because if there is one thing that the United St ates, and hopefully the Fourteenth Amendment, should stand for is the notion th at no matter \'5B*398\'5D what group you are in, you are entitled to the ba sic dignity and civility of life in a free society. \par\par

That is why a hate crime is different. In the same way, as when a witness is attacked in a mob criminal trial, it is not just an attack on that particular individual, or when a police officer is attacked or when the President is assas sinated. There is a symbolic significance to these crimes which makes these cri mes acts of terrorism, and in that way, even if they were no more serious from a criminological standpoint, I think that heightened punishment would be warran ted, because I believe that it shakes the very basis and foundations of a plura listic society. \par\par

I want to give you a Web site, www.hatemonitor.org, and thank you so much fo r giving me the privilege to come here and hopefully rekindle the kind of natio nal conversation that we need so that people of goodwill can make sure that the se kinds of statutes are passed and enforced to protect all those who reside wi thin our society. Thank you. \par\par

MR. CHEN: Thank you, Brian. Lastly, I have asked Jack Battaglia to come and speak, because one of the things I noticed after the Matthew Shepard incident n 102 was the discussion in the media about the types of hate speech that happens on college campuses, as well as in high schools. We have the infamous \'22scar ecrow incident\'22 on the float of the college fraternity, just to name one of the more highly publicized incidents. n103 I have asked Jack to come talk about what is going on right now in the legal field with respect to students who fac e hate speech, who suffer such incidents in schools, and who is responsible and what are the remedies.\par

\par

----------Footnotes----------

\par\par

n102. See supra note 4 (discussing the incident). \par\par

n103. See CSU Students Protest Anti-Gay Incident on Campus, Associated Press Newswire, Oct. 19, 1999. \par

\par

----------End Footnotes----------

\par\par

MR. BATTAGLIA: When I realized I was going to be the last speaker on the las t panel for the day, two things occurred to me: the first, that I had better no t speak too long and, secondly, that maybe this was a special responsibility. T hen I realized that my topic, which is antigay harassment in schools, provides a very convenient opportunity to close the circle on some of the things that we re talked about during the plenary session this morning. \par\par

The answer that Matt Coles, for example, gave to the question that was put t o him about his priorities for our movement - of the three he mentioned, one wa s schools. As the discussion progressed, there was a focus on the relation betw een law and culture and, in particular, the limitations of law to make changes in \'5B*399\'5D culture; how, instead, sometimes the changes in culture have to come first; If there is any institution in our country in which cultural bat tles take place, it is the schools. \par\par

In fact, certainly at the lower educational levels (elementary school throug h high school) the educational mission includes transmitting values to students

- cultural values - that represent civic virtue. There is always significant v
ying among people in the community about just what those values will be and how
they will be transmitted. \par\par

Another theme of the plenary session was how, as lawyers, we have to follow
our community in terms of the needs and interests that we pursue in what we do,
whether it is in litigation or legislation, or other arenas of advocacy. It is
quite clear that in the area of antigay harassment, there is a reluctance to l
itigate on the part of parents of students who have been harassed. There are a
number of reasons for this reluctance, most of which I bet you can suspect and
would understand. \par\par

So a possibility for reaching the result a different way, perhaps, is someth
ing that should be at least part of the goal, and part of that is a recognition
that what we are trying to do, what advocates are trying to do, is not only to
provide compensation or other remedies for the particular individual in the pa
rticular circumstance, but to make the offensive behavior stop, and to make it
stop not only at the institution at which this particular individual has been h
arassed, but to make it stop throughout the system. \par\par

With that, my focus is going to be on a couple of avenues of available redre
ss that are directed to school districts and schools as opposed to the individu
als who are the actors in antigay harassment. For example, I am not going to ta
lk about generally applicable criminal laws or hate crime laws that might be av
ailable to punish the particular offender; nor will I talk about state tort rem
edies that may be available to provide some redress. \par\par

Instead, I am going to talk briefly about two federal remedies: the possibil
ity of action under Section 1983 of the federal civil rights laws n104, and und
er Title IX of the Education Amendments of 1972. n105 Then, I am going to talk
a little bit about how the First Amendment might limit the ability of schools a
nd school districts to restrict the harassment that we would like to see elimin
ated from the school system.\par

\par

- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par

n104. \i 42 U.S.C. 1983\i0 (1994). \par\par

n105. \i 20 U.S.C. 1681\i0 (1994). \par

\par

- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - -
- \par\par

\'5B*400\'5D There was extensive discussion during that session about the
Nabozny n106 case, which was a Seventh Circuit decision rendered under Section
1983, in which a young man who had been subject to years of harassment through
both middle school and high school was able, after a jury verdict of liability,
to negotiate a settlement of slightly under $1 million, for the harm that was
done to him when the school authorities literally ignored his and his parents'
complaints about the harassment.\par

\par

- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par

n106. \i Nabozny v. Poalesny, 92 F.3d 446 (7th Cir. 1996).\i0 \par

\par

- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - -
- \par\par

Very briefly, that case was based on Section 1983 for the deprivation of con
stitutional rights under the color of state law. Only public schools are subjec
t to suit under Section 1983 to the extent that the basis for the violation is

a federal constitutional right, because, as you know, only governmental actors can violate the Constitution. \par\par

The claims that were asserted in Nabozny were of two types, based on two sep arate provisions of the Fourteenth Amendment: the Due Process Clause and the Eq ual Protection Clause. I will deal with the due process claims quickly because they have not been successful, not only in this context but generally. The due process argument is essentially that there is a liberty interest in being free from harm, which is deprived without due process of law when an educational ins titution does not act to protect students from harm, particularly after being p ut on notice that harm is occurring. \par\par

The Supreme Court's jurisprudence generally under the Due Process Clause mak es it very difficult to establish a duty on the part of an educational institut ion to protect a student from third-party harm, and in fact, those claims were unsuccessful in Nabozny. I mention the clause, however, because there is always the possibility, given other factual circumstances, that a due process violati on could be established. So it is something you should look at. \par\par

The Nabozny case was ultimately decided in Nabozny's favor under the Equal P rotection Clause, and the nature of the denial of equal protection was twofold. The court found that Jamie Nabozny was deprived of equal protection because of his sex in that the school district treated claims of harassment from male stu dents differently than they treated claims of harassment from female students. n107 So there was intentional discrimination, based on sex, that was redressabl e under the Equal Protection Clause through Section 1983.\par

\par

----------Footnotes----------

- \par\par

n107. See \i id. at 454-55.\i0 \par

\par

----------End Footnotes----------

- \par\par

\'5B*401\'5D Perhaps more significant in the long term, Nabozny was also a ble to establish a deprivation of equal protection based upon his sexual orient ation. The court relied on Romer v. Evans n108 as establishing a new paradigm i n federal constitutional law in the area of sexual orientation, soon to oversha dow Bowers v. Hardwick. n109 The basis for the claim that the school district a cted intentionally to discriminate against Jamie Nabozny based on his sexual or ientation was statements that were made by the school authorities when he compl ained - statements like, \'22well, what do you expect? If you are out, if you a ct gay, you can expect that you will be harmed.\'22 The court found that the st atements established that the school authorities acted with a discriminatory mo tive with respect to Nabozny's sexual orientation. n110\par

\par

----------Footnotes----------

- \par\par

n108. \i 517 U.S. 620 (1996).\i0 \par\par

n109. \i 478 U.S. 186 (1986).\i0 \par\par

n110. See \i Nabozny, 92 F.3d at 460.\i0 \par

\par

----------End Footnotes----------

- \par\par

Before I go any further, one of the important reasons why I highlight these federal causes of action is that, unlike most remedies under state law, you can obtain attorneys fees if you are successful with a 1983 claim or a Title IX cl aim, and that is quite significant. \par\par

Moving onto Title IX, the statute prohibits discrimination because of sex in educational programs that receive federal funding. n111 Since virtually all sc hools and school districts, public and private, receive federal funds, there is a possibility of an action under Title IX; but here the argument gets a little bit more attenuated. The argument is that antigay harassment, at least of cert ain kinds, is in the nature of sexual harassment, and that sexual harassment co nstituting discrimination because of sex, is redressable and subject to remedy under Title IX.\par

\par

----------Footnotes----------

\par\par

n111. See \i 20 U.S.C. 1681\i0 (a) (1999). \par

\par

----------End Footnotes----------

\par\par

The Supreme Court of the United States is currently considering whether, in fact, Title IX provides a remedy for what is called student-on-student or peer harassment, as opposed to teacher-on-student harassment, and that ruling may pr eclude the possibility of an action for damages. n112 However - and this may be even more important than the attorneys' fees point - Title IX is enforced by t he Office of Civil Rights of the Department of Education, and there is an admin istrative proceeding, an administrative remedy, that can result in the loss of funding to a school district if the school district does not take action to rem edy a situation that involves sexual harassment. \'5B*402\'5D Moreover, the Department of Education has been willing to recognize that antigay harassment can be sexual harassment that is covered by Title IX.\par

\par

----------Footnotes----------

\par\par

n112. See \i Davis v. Monroe County Bd. of Educ., 119 S. Ct. 1661 (1999)\i0 (holding that a private cause of action for damages is available). \par

\par

----------End Footnotes----------

\par\par

However, the guidelines make a very strange distinction between general anti gay harassment and harassment of a sexual nature. If the harassment is of a sex ual nature, even though it is antigay harassment, it is sexual harassment cover ed by the statute. But, if the antigay harassment does not have a sexual compon ent - that is, if it is harassment just with a sexual orientation cast - then i t is not covered. The reason it is not covered is because the statute does not prohibit or provide a basis for redress of sexual orientation discrimination. O nly sex discrimination is covered by the law, so there is a little bit of sleig ht of hand going on there. \par\par

Moving onto the First Amendment question, the R.A.V. case n113 that Brian ta lked about is often used by those who would resist attempts to take action agai nst harassment based on group membership as standing for the proposition that t his kind of harmful speech/behavior is protected First Amendment activity. The context of R.A.V., as Brian told you, was a cross burning, and the case is some times characterized as holding that cross burning is protected by the First Ame ndment.\par

\par

----------Footnotes----------

\par\par

n113. See \i R.A.V. v. St. Paul, 505 U.S. 377 (1992).\i0 \par

\par
----------End Footnotes----------
- \par\par
But R.A.V. did not hold that cross burning is protected by the First Amendme nt; R.A.V. only held that a particular statute, drafted so as to cover cross bu rning only, when it is used to effect a certain response because of race, was u nconstitutional on its face. Justice Scalia went out of his way in the very fir st paragraph of the majority opinion to point out that there were all sorts of other statutes that legitimately could prohibit and penalize and criminalize th e cross burning that took place in that case; in fact, he pointed out that ther e was another charge, which was not being challenged, on which these individual s were convicted because of the cross burning. n114\par
\par
----------Footnotes----------
- \par\par
n114. See id. at 370-80. \par
\par
----------End Footnotes----------
- \par\par
Another point about the R.A.V. case is that Justice Scalia distinguished the criminal statute in that case from action taken to remedy Title VII, i.e., emp loyment discrimination actions, including those based on sexual harassment. Jus tice Scalia carved out from the thrust or the effect of the opinion conduct, i. e., discriminatory harassment, even when comprised of speech, that would be re dressable under antidiscrimination laws - which would also \'5B*403\'5D cov er Title IX or any other law that prohibits discrimination, including discrimin ation based on sexual orientation. n115\par
\par
----------Footnotes----------
- \par\par
n115. See id. at 389. \par
\par
----------End Footnotes----------
- \par\par
Another important point on the First Amendment is that the Supreme Court has developed a somewhat separate jurisprudence for the application of the First A mendment in schools. Beginning with a case most of you are probably familiar wi th that goes back to the Vietnam protest era, the Tinker case, n116 the Court h as held that high school authorities may censor or sanction student speech when it substantially interferes with order or discipline or with the rights of oth er students.\par
\par
----------Footnotes----------
- \par\par
n116. \i Tinker v. Des Moines Indep. Community Sch. Dist., 393 U.S. 503 (196 9).\i0 \par
\par
----------End Footnotes----------
- \par\par
Subsequently, in Hazelwood, n117 the Court relaxed even that standard for sc hool-sponsored speech, or speech which takes place in a context that somebody c ould think constituted endorsement by the school, such as in the classroom or i n programs that are part of the curriculum. In those cases, the Court said that the school can take action that is reasonably related to legitimate pedagogica

l concerns.\par
\par
----------Footnotes----------
\par\par
n117. \i Hazelwood Sch. Dist. v. Kuhlmeier, 484 U.S. 260 (1988).\i0 \par
\par
----------End Footnotes----------
\par\par
Well, it seems to me that there is an extraordinary amount of room there, both under the Tinker formulation, which is a little bit more stringent, and the Hazelwood formulation, for penalizing antigay harassment in schools. \par\par

A qualification on that conclusion is that, above the high school level, with respect to colleges and universities, the Supreme Court - and courts generally - have shown a greater reluctance to authorize restrictions on speech. The notion of the university as a place where people come in order to exchange ideas, in order to find truth and develop truth, is the countervailing consideration. Another aspect, of course, is the age of the students. It is considered more likely, as we would expect, that the role of the school would be more protective, and legitimately more protective, at the lower levels than on the university level. \par\par

Again, what is important about the Tinker/Hazelwood formulation in the lower grades is that it explicitly recognizes that schools have a role in teaching civic virtue and teaching the values of our dominant society, which includes teaching tolerance and the right of students to be free from harassment. \par\par

\'5B*404\'5D \par\par

Name Reporting And Partner NotificationLegislation\par
\par
MS. COOPER: I am Liz Cooper. I teach here at Fordham. The panelists we have this afternoon are absolutely wonderful people. I will introduce them in the order that they are going to be speaking in. Catherine Hanssens is the director of the AIDS Project at Lambda Legal Defense and Education Fund. Matthew Carmody is an attorney with Brooklyn Legal Services. Haley Gorenberg is with The Legal Support Unit of Legal Services for New York City. Mildred Pinot is an attorney with the Legal Aid Society, herself with the Volunteer Law Office. \par\par

MS. HANSSENS: Thank you, Liz. \par\par

The issues of names-based HIV reporting and partner notification have been debated for some time, but the debate picked up heat over the last year. A focal point of that debate has occurred in New York, which adopted in 1998 a law mandating names reporting and partner notification. n118\par
\par
----------Footnotes----------
\par\par
n118. See N.Y. Pub. Health Law 2130 (McKinney 1999). \par
\par
----------End Footnotes----------
\par\par
Although the law was scheduled to go into effect in January, 1999, final regulations implementing the law have not been issued. The law is vague or ambiguous in a number of important respects, and until we see the interpretation from the health department, we do not know exactly what the law will mean for people in New York with HIV who are contemplating getting testing. \par\par

The panelists here today thought it might be helpful to say something about

why names reporting has become the debate that it has; why the Centers for Dise
ase Control and Prevention (\'22CDC\'22) has been pushing so hard for this, and
how we think you should assess whether this kind of a program makes sense, foc
using also on what the pros and the cons are. We also will address specifically
how name reporting and partner notification are treated under New York law. Fi
nally, we will discuss how those of you who might either be contemplating getti
ng tested or who work with clients that might deal with the new law. \par\par

For the last several years, the CDC has been waging an aggressive campaign i
n states around the country to institute a national system of HIV test reportin
g. The CDC takes the position that names-based reporting is essential to get a
more accurate picture of the epidemic. The CDC also contends that names reporti
ng will be used to facilitate individual follow-up, so that health departments
can track people supportively and get them into services. \par\par
\'5B*405\'5D The CDC suggests that this names reporting initiative reflect
s broad community input and consensus. Contrary to what the CDC says there has
not been substantial, meaningful community input into the CDC's recommendations
for HIV surveillance, and in fact, it was very difficult for advocates - and
impossible for people on the streets - to get copies of the CDC's proposed guid
elines until they published it in December, 1998. \par\par
Basically, the CDC is proposing that states adopt a system that reports posi
tive test results; they suggest this system should mirror the way AIDS reportin
g is done, which in all fifty states at this point is by name, as it has been f
or some time. While they do allow states the option of adopting what is called
a \'22unique identifier system,\'22 which means that instead of using names, yo
u can use some kind of a code, the proposed guidelines question the effectivene
ss of a unique identifier system and indicate that funding will hinge on a high
rate of accuracy for reported data. In several states, unique identifiers for
HIV reporting are a combination of initials, birth date and a portion of the in
dividual's Social Security number. But there certainly is no universal, single
definition of unique identifiers. Consider, for example, that anybody here who
uses the internet also has a unique identifier for that purpose. Obviously, it
is relatively easy to create a unique identifier system and that allows assignm
ent of accurate, individualized codes while millions of people use a system at
one time. \par\par
The CDC, nonetheless, is really actively discouraging any alternative to nam
es-based HIV reporting. The CDC is making it clear that they may hinge the avai
lability of federal money for HIV surveillance on a state's adoption of the CDC
's preferred system. At the same time, however, while they explicitly recognize
that the option of anonymous testing is essential to ensure that the maximum n
umber of people are willing to get tested, the CDC refuses to withhold federal
dollars from states that adopt laws to make anonymous testing unavailable. So f
ar, eleven states that have names reporting also have banned the option of anon
ymous testing. \par\par
I, along with most advocates of people with HIV, believe that the CDC's prop
osal for names reporting is ill-advised and that it does not advance the public
health goals that it is intended to serve. A primary objection to names report
ing is that it threatens people's confidentiality, or more importantly, that th
ere is a strong perception among people at risk of HIV that it will discourage
many people from getting tested altogether. \par\par
\'5B*406\'5D While a number of the studies of the impact of names reportin
g on willingness to test are somewhat flawed, the clear majority of studies tha
t have attempted to assess this indicate that a significant number of people wi
ll be deterred from getting tested if they have to give their name or if they f

eel the result could be tracked back to them. Most importantly, those who objec t to or who worry about names reporting are disproportionately people in alread y marginalized communities: people who are gay, people of color, IV drug users and at-risk youth. The primary goal of any health official in this epidemic has to be to increase testing, treatment and prevention. A reporting system that u ndermines this essential goal is simply bad public health policy. \par\par

The current estimates are that up to 900,000 people in this country are livi ng with HIV, with at least 40,000 new infections every year; CDC reports make i t pretty clear that these new infections occur disproportionately among younger people, particularly among young gay men, women with substance-abusing partner s, people of color and those who use drugs intravenously. \par\par

When we are trying to assess the efficiency of a public health program, we n eed to get a sense of where the new infections are occurring and whether the pu blic health measure that is supposed to deal with this is going to be more prod uctive than destructive in accomplishing the goal. \par\par

HIV testing and counseling is described as central to the CDC prevention eff orts, and yet the current estimates are that roughly forty to fifty percent of 900,000 people with HIV in this country have not been tested. \par\par

HIV, like many other frightening and expensive diseases, has always involved significant social risk as well as medical and public health risk, and histori cally people with stigmatized diseases - in the past, it was TB, STDs, syphilis - have been marginalized and demonized. What is happening with people with HIV is nothing new. \par\par

That type of social risk can and does deter people from getting diagnosed an d treated. There is social science data that supports this premise, so there is a historical and current reason to be concerned. \par\par

In order to understand the impact of reportable HIV testing and whether the good outweighs the bad, we have to have the sense of the actual prevalence of h armful attitudes towards people with HIV, actual harmful policies aimed at peop le with HIV and some understanding of the subjective perception of individuals who are \'5B*407\'5D at risk of the harm to them if they are identified as having HIV. We can look at the laws that are in existence, we can look at the a vailable evidence of stigma and attitudes, and we can try to get a sense from t hat. \par\par

A recent study published in 1998 by research psychologist Gregory Herek show ed that by comparing a 1998 survey of peoples' attitudes about HIV with an iden tical survey conducted eight years earlier, the level of stigma and misundersta nding that people have has remained relatively constant, and actually in some a reas has increased. A substantial number of people across all sorts of economic and educational backgrounds and experiences are uncomfortable working with peo ple with HIV, using a glass that somebody with HIV has used, even if it has bee n sterilized, wearing a sweater of somebody with HIV even if it has been dry-cl eaned and believe that they are at risk by driving in the same car with people with HIV. The risk is real. \par\par

One of the primary problems in looking at what this will accomplish will act ually give a better picture: if about fifty percent of those people who are inf ected are not voluntarily testing, and we have reason to believe that stigma an d suspicion, political and medical system are still high, will we get accurate data? \par\par

I think we have very good reason to believe that names reporting will yield faulty data and, if anything, give us a very skewed and dangerously skewed, pic ture of who is infected, because if we rely on voluntary testing - people volun tarily going forward - and we have a fear of stigma and a fear of punishment, t hen we are going to disproportionately leave out those populations I mentioned

before that have been traditionally marginalized. In fact, the CDC has produced no data to suggest that names reporting will accomplish the goal of getting a better picture of the epidemic. \par\par

In addition, names reporting is not necessary to allow follow-up with individual patients. Even with a unique identifier system, it is possible to do a backward track through reporting physicians to reach individual people. The truth is that the CDC has rarely used names-reporting data to accomplish such tracking, and in a well-constructed system where you get the needed epidemiological information up-front, you rarely need to backtrack. The likelihood that there are going to be extraordinary and new means of transmission that we need to track is only going to become increasingly unlikely. \par\par

I have tried to identify some of the issues raised by names reporting. I laid out for you some of the issues you should be thinking \'5B*408\'5D about as the next panelists talk about what is planned here in New York. \par\par

MR. CARMODY: I am going to talk to you about partner notification. First I will give you some historical and theoretical background to partner notification, and then discuss how partner notification has been applied to HIV and what some of the problems that result are. \par\par

Partner notification is a public health measure, which are actions the state imposes upon society to protect it from public health risks like communicable diseases. There are many public health measures in existence today, such as receiving a simple flu vaccine to being quarantined for tuberculosis. However, most public health measures impose to some degree a restriction in a persons constitutional right to liberty under the Fourteenth amendment. \par\par

The legal authority for states to exercise their public health measures was set forth in the 1905 Supreme Court case Jacobson v. Commonwealth of Massachusetts. n119 This case was about a challenge to Massachusetts's mandatory small pox vaccine, citing that it was a violation of the plaintiff's personal liberty. The court describes in dicta how states have reserved for themselves a \'22police power\'22 through which state public health measure are implemented. This \'22 police power\'22 was indirectly reserved by the states during the Constitutional Convention, as they did not delegate this power directly to the federal government. This \'22police power\'22 allows the states to protect and preserve their populations apart from the protection provided by the federal government. Partner notification is just another example of the State exercising its police power to protect its populations from communicable diseases.\par

\par

----------Footnotes----------

\par\par

n119. \i 197 U.S. 11 (1905)\i0 \par

\par

----------End Footnotes----------

\par\par

Partner notification originally started back in the 1930s by the then-Surgeon General Thomas Parran. Originally called \'22contact tracing,\'22 partner notification was envisioned after antibiotics were discovered as a cure for syphilis so that the state could more directly bring the cure to infected people, rather than waiting for the infected people to discover their infection and seek treatment. Surgeon General Parran wanted every case of venereal disease to be located, reported, its source ascertained and all contacts then informed about the possibility of infection, provided a Wasserman test (a test for venereal disease), and, if infected, treated. In seeking out infected people this way, the state could prevent transmission of Syphilis before people developed symptoms and thus \'5B*409\'5D realized their infection. There is a very good book by

Gabriel Rotello called Sexual Ecology, n120 which examines more closely how di
seases such as HIV spread through communities, and how communities can either f
oster or deter disease transmission.\par
\par
----------Footnotes----------
\par\par
n120. Gabriel Rotello, Sexual Ecology: AIDS and the Destiny of Gay Men (1997
). \par
\par
----------End Footnotes----------
\par\par
Although partner notification's primary purpose is to stop the spread of com
municable diseases, primarily venereal disease, it also has the secondary purpo
se of treating infected people. Although this was not really stressed with othe
r sexually transmitted diseases in which partner notification was used, such as
syphilis, gonorrhea, chlamydia, etc., because you could always cure a person w
ith antibiotics when he or she discovered his or her infection. You will see wi
th HIV how this secondary purpose becomes more and more important, especially a
s scientific theories are increasingly suggesting that early treatment of HIV i
s essential to a longer life after infection. \par\par
Applying partner notification programs to HIV infection and transmission is
different from other diseases in several respects. One, there is no cure for HI
V. Therefore, even if they notify someone of their infection, the state cannot
prevent further transmission by this individual with a shot of penicillin. The
only way the State can prevent is by encouraging a behavioral change in the ind
ividual: meaning counseling and educating the person how to prevent him or her
from transmitting the virus to other people, and hoping that this person they h
ave spent so much time and money on will listen and obey. Unfortunately, since
HIV is primarily transmitted by sex and intravenous drug use, it is hard for pe
ople to simply listen and obey, because sex and drug uses involves a whole host
of physiological and psychological pressures and variables that the state is n
ot really able to or prepared to deal with for effective behavior modification.
Therefore, after a person is contacted through a partner notification program,
whether that person further transmits HIV to others really depends on the pers
on and their situation. This is a lot less effective than a shot of penicillin
for a syphilis infection. \par\par
The second variable is that HIV has a really long incubation period. It take
s three to six months after infection before a person even starts producing ant
ibodies, and it takes up to 10 years and more before someone might develop symp
toms. It is very difficult for people to remember who they have exposed to HIV
for such a long duration of time. Most partner notification programs limit the
\'5B*410\'5D partners they are willing to contact to people who have been e
xposed only a year or two ago. But even here, it may be very difficult for peop
le to remember all their sex and needle sharing partners in the previous two ye
ars, much less to provide a state with identifying information about these peop
le. This is very different than diseases like syphilis and gonorrhea where symp
toms usually manifest within a week to ten days, as it is much easier for peopl
e to remember who they had sex with last Wednesday, for instance, and the proba
ble whereabouts of that person now. \par\par
Economically, this long incubation period has real ramifications. It has bee
n estimated that it takes upward of $5000 to perform one partner notification o
n average. n121 This is primarily due to the amount of work it takes to track a
person down whose identifying information is either very sketchy or is outdate
d. People who perform HIV partner notification must do things like comb shootin

g galleries and homeless shelters looking for the named contacts. This takes a lot of time and money. As endorsers of HIV partner notification have pointed out, this is still a lot less money than it takes to treat a person with HIV over the duration of their lifetime, so there is still a cost benefit to running partner notification programs. However, I think it is important to question how existing prevention efforts would be affected if all that money was poured into education, counseling and testing programs, rather than into partner notification.\par
\par
----------Footnotes----------
\par\par
n121. See Cheryl Ellenberg, HIV Partner Notification Activities in New York State: A Comparative Analysis - Executive Summary, AIDS Institute 4 (1996). \par
\par
----------End Footnotes----------
\par\par
HIV is also different in the social treatment of those infected. Possible discrimination, violence and de-racization await those who are infected. There is also an inherent distrust of the state to protect infected individuals from these harms. Partner notification programs generally rely on the cooperation of the participants to provide information in which the program can function. It may be very hard for people to give up this information, thinking that the contact may figure out the informant's identity and seek some sort of revenge. \par\par
This leads to the question of whether mandatory HIV partner notification could be considered an invasion of privacy. The type of privacy which frames this issue is really that of informational privacy, because we are talking about controlling the use of a person's HIV related information - whether this HIV related information can and should be disclosed in a limited form to a person's contact via the State. It is different than the privacy issue at issue \'5B*411\'5D in Jacobson because the State action involved in that case involved the person's bodily integrity, not what happens to the information of the person's status as being or not being vaccinated. \par\par
One of the primary cases involving informational privacy is Whalen v. Roe. n122 This U.S. Supreme Court case challenged a New York statute mandating the reporting of all prescriptions for controlled substances, along with the name of the prescribing doctor, dispensing pharmacy and patient receiving the drug to the N.Y. Department of Health. The challenge was based on the assumption that people would not go to their doctors to get necessary health care if they thought their name was going to be on some list in the Department of Health as someone who receives a prescription for controlled substances. The Supreme Court said that there were two interests involved: an interest of avoiding disclosure of personal matters, and an interest in independence of making certain kinds of important decisions. The Court held that these two interests were adequately safeguarded by the Department of Health, and therefore there was not privacy infringement. However, you might imagine some argument in which these interests are not adequately protected by the Department of Health when applying this standard to mandatory HIV partner notification.\par
\par
----------Footnotes----------
\par\par
n122. \i 429 U.S. 589 (1977).\i0 \par
\par

----------End Footnotes----------
- \par\par
Another important case dealing with informational privacy is Nixon v. Administrator of General Services. n123 This case was brought by Nixon to prevent the government from going through his private tapes, stating that there were personal conversations recorded on them and therefore mandatory disclosure should be considered an invasion of privacy. The Court applied a balancing test, weighing the expected privacy against the public interest in such an intrusion. Since the overwhelming majority of the content of the tapes was not personal, and the personal information would not be widely disclosed, the Court held that his privacy interests were not Constitutionally violated. This standard would be less useful in a facial challenge to a mandatory HIV partner notification law because even though the expected privacy of a person's HIV status is high, the public interest in this information would probably be considered even higher, particularly when the name of the HIV infected person would presumably be kept confidential.\par
\par
----------Footnotes----------
- \par\par
n123. \i 433 U.S. 425 (1977).\i0 \par
\par
----------End Footnotes----------
- \par\par
I see I am out of time. I just want to emphasize the dis-empowering nature of mandatory HIV partner notification law. HIV affects mainly people who are in traditionally marginalized \'5B*412\'5D populations, namely people of color, gay men and substance abusers. Mandatory HIV partner notification further disadvantages these populations by subjecting them to liberty infringements and consequently possible discrimination, harassment and violence. It is hard to believe that states are subjecting their citizens to such effects when partner notification is marginally effective when applied to HIV and other HIV prevention programs that are not dis-empowering in nature could be just as or more effective as partner notification with a comparable increase in funding. \par\par
MS. GORENBERG: I would like to spend some time talking about the actual law that is to be implemented in New York. \par\par
As has already been said, we are waiting for the regulations that will give us some detail about how this law is actually going to go into effect. They are overdue. We have been told that we will have an opportunity for comments, that they will not be instituted as emergency regulations. In fact, we had thought as panelists that we might have them some time this week and be able to discuss what we saw in the regulations that were proposed. \par\par
Since there will be a comment period and we have an opportunity to participate in that, what I would like to do is go over some sections of the law and identify what I consider to be some hot spots to watch for implementation and regulatory effect. \par\par
The law that we are talking about here that combines these two elements, names reporting and contact tracing, is a new Title 3 of Article 21 of the Public Health Law, Sections 2130 and about ten sections following. It was enacted on July 7, 1998, to take effect in 180 days, which have now elapsed. \par\par
The law has two parts. One of them is the so-called \'22names reporting\'22 - and I will tell you why I am saying \'22so-called\'22 in a moment - and the other piece is the contact tracing or partner notification piece. n124\par
\par
----------Footnotes----------

- \par\par
n124. See N.Y. Pub. Health Law 1230-1239 (McKinney 1998). \par
\par
----------End Footnotes----------
- \par\par
Starting with names reporting, the first thing that is interesting to note a bout this statute is that the law itself does not say that names must be report ed. When it talks about the index patient, the HIV-positive person, it says tha t information identifying the index patient is to be reported, as well as the n ames of the contacts. n125 Well, clearly the legislature knows how to use the w ord \'22names.\'22 They used it to talk about the contacts. But in the phrase p receding, they talked about \'22information identifying the case.\'22 n126 This \'5B*413\'5D brings to mind - it certainly brought to mind for a lot of us w ho wanted to comment on this law - the possibility that a unique identifier sys tem would be possible and that there was nothing in the law that prohibited its use. We said that in our comments, and we hear that it probably is not going t o be well-received and that actually some of the people who were pushing the la w up in the state government were not too pleased to see that possible interpre tation.\par
\par
----------Footnotes----------
- \par\par
n125. See id. 2130.3. \par\par
n126. See id. \par
\par
----------End Footnotes----------
- \par\par
So, in a political world I would say that we do not have high hopes of seein g a unique identifier system coming out of this particular law, but we certainl y made the argument, the argument is there to be made, and maybe we will be ple asantly surprised. \par\par
The other thing I would like to say about the names reporting issue is to hi ghlight the fact that this law preserves anonymous testing. It very clearly pre serves anonymous testing, n127 which makes a lot of sense in a public health co ntext, if this is really going to be at all taken seriously as a public health law, since we know that some people will not get tested unless they have an ano nymous option. We consider that to be a very important thing for people to know , for advocates to know, and anybody working with a population that is taking t he possibility of testing seriously to know: anonymous testing does still exist in the State of New York and is specifically preserved.\par
\par
----------Footnotes----------
- \par\par
n127. See id. 2138. \par
\par
----------End Footnotes----------
- \par\par
The duty to report under this law is a duty on behalf of physicians, anybody else who is authorized to diagnose HIV or related illnesses and laboratories. n128 What those entities have the duty to report, according to this law, is an initial determination or diagnosis of HIV, HIV-related illness or AIDS. n129 No w the duty to report AIDS already existed in other law, but I want to call atte ntion to this issue of the initial determination, or diagnosis, and also talk a bout the fact that we have read that together with the preservation of anonymou

s testing.\par
\par
----------Footnotes----------
\par\par
n128. See id. 2130.1. \par\par
n129. See id. 2130.1(a)-(c). \par
\par
----------End Footnotes----------
\par\par
One of the arguments that advocates have made - and it remains to be seen wh
ether the regulations will reflect - is that if we know that the preservation o
f anonymous testing is very important to the public health, because some people
will be deterred from testing and getting diagnosed early if they are not give
n the opportunity for anonymous testing, and we have a law that says very clear
ly in three places that the duty to report applies to initial testing \'5B*41
4\'5D and initial determinations and initial diagnoses, n130 then I would cer
tainly argue that somebody who enters the health system through anonymous testi
ng for an initial diagnosis or determination and at that point goes for follow-
up treatment or confirmatory testing could logically be excluded from the repor
ting requirements. That would be an extremely valid public health decision to m
ake, especially when you see that the law recognizes the preservation of anonym
ous testing as an important public health measure. Again, a hot spot to watch f
or in the regulations.\par
\par
----------Footnotes----------
\par\par
n130. See id. \par
\par
----------End Footnotes----------
\par\par
I want to put all of these points that we are making about reporting and nam
es and lists in a little bit of context here. \par\par
People have already mentioned stigmatizing diseases and stigmatizing infecti
ons and the effects on populations that are already undeserved in many ways. We
have already noted that it seems that people who are deterred from testing are
also disproportionately the people who are very often at greatest risk for HIV
infection, and that that is a very dangerous intersection. \par\par
There are two more points that I want to mention as far as context when we t
alk about names reporting, lists and what it means to our clients or to patient
s or to any of us to be on these lists and reported and in databases. \par\par

My first call that I got for advice as the HIV Advocacy Coordinator at Legal
Services was from somebody who said that he had just found out that his confid
entiality had been breached, because he had met a guy at a bar the week before,
and it turned out that this person worked at the Division of AIDS Services and
Income Support, the public assistance source for people with HIV in New York C
ity. They went out on a date, and a couple of days later he got a letter from t
his government employee revealing that this person had used his position to loo
k him up in the database, saw he was receiving services associated with his HIV
, and wrote on the outside of the envelope that the caller was HIV-positive, an
d how terrible it was that he had not disclosed this on the date. \par\par
Lists and databases can be used in scary ways. There are real-life examples.
It is not just that we are saying that there is a theoretical potential. I mea
n, the questions of who has access, whether they are qualified people, people w

ho understand confidentiality or might be inclined to use information for their own reasons, are very serious. I have seen it put into play in the real world. \par\par

\'5B*415\'5D The other thing that I wanted to mention as far as context is that last legislative session we had names reporting and partner notification passed. This session we have seen proposed, and sometimes re-proposed, laws tha t would criminalize all kinds of behavior, including having sex with somebody i f you are HIV-positive or having sex with somebody if you are HIV-positive and do not disclose to them. Following right on the heels of the law creating a dat abase is the suggestion of creating laws that will make it a crime for people w ho know their HIV status to be doing various things. This is pretty scary. \pa r\par

I want to move from the names reporting hot spots into contact tracing and p artner notification. One of the things that this law does is modify who is cons idered to be a contact. There was already a legal provision talking about what is considered to be a contact for an HIV-positive person and that provision was limited to a sexual contact or needle-sharing partner. \par\par

The new law amends this section of the public health law, adding a phrase sa ying that a contact will also now be a person who is at risk of transmission as determined by the Health Commissioner, and we do not know what that is going t o be. We do not know how it is going to be interpreted or broadened, whether th at is going to mean somebody who received a needle stick. It is a big question, and it is a big question especially when people start talking about whether it is going to be limited to reasonable risk of transmission, or whether it is go ing to be anybody who is worried, with no medical support, that perhaps somehow their contact with someone could have led to transmission. \par\par

When we see recent studies that show that knowledge of actual risk of HIV tr ansmission is, if not plateauing, maybe even decreasing, then we have to be con cerned about what it means to say that some unelaborated \'22risk of transmissi on\'22 could justify application of this law. \par\par

Another issue for us to watch out for in the regulations is how a contact wi ll be identified. On one end of the spectrum is a suggestion that identifying the contact of an HIV-positive person should mean using information that comes out of a conversation that that person has with his or her physician, which is protected by a version of informed consent, where the physician would say, \'22 This is the result of your test, and now we are going to have a conversation ab out contact tracing or partner notification, and what contacts you have, and wh at we will be reporting,\'22 and that physician would explain what the partner notification law requires. \par\par

\'5B*416\'5D Actually, we could say that we might hope that this informati on would be given ahead of time, when the person is tested, but the bottom line is that in the context of creating this list of contacts to be reported to the State, there should be a conversation with the physician where the physician e xplains what information is to be taken and what will be done with it. Then peo ple could disclose as they see fit. That is one much more protected option that many advocates have supported. \par\par

At the other end of the spectrum is the possibility of some kind of sleuthin g through the person's file - I mean, perhaps when they entered care with this physician they had a relationship with somebody whom they mentioned, somewhere deep in the file, maybe a couple years back or whatever - that they might go lo oking in the background and using various old parts of the medical file in repo rts to the State, perhaps without any particular discussion about that with the patient. \par\par

Obviously, one of the big concerns is what that means for physician/patient

relationships in the future and whether people will be greatly deterred from sh
aring important aspects of their life and their sexual health and maybe drug us
e with their physician if we have a law in effect that means that anything is f
air game for reporting should you develop an illness in the future. \par\par

A couple of other points. The law as it is written right now says that when
the health departments come to do this actual contact tracing, it will strive f
or in-person notification unless circumstances reasonably prevent doing so. \p
ar\par
Well, what does that mean? I am excused because my car broke down when I was
supposed to go notify you? Does it mean I tried twice and you were not home an
d now I am going to stick notification on the door in a sealed envelope? I mean
, that is allowed in certain other cases for service of a notice. I think we wo
uld argue that it is not reasonable in this context, but there is no real expla
nation of what it means to say personal notification unless reasonably prevente
d from doing so. \par\par
There is a major question about the potential retroactive application of thi
s law, and that could be a real hot spot for litigation. If you have gone for a
n HIV test that was anonymous, then you know that you are given information - o
r you should be given information - on the current state of confidentiality law
and how your testing information and results will be kept private. If we do no
t see regulations that make it clear that application of this law is prospectiv
e only, then we see a real conflict with what people have \'5B*417\'5D sign
ed in the past that they thought protected them, that they thought gave them ce
rtain rights to confidentiality, and what this law now requires. \par\par
I think it is important to note that there are provisions in the laws regard
ing criminal and civil liability that not only protect somebody who is acting
in good faith trying to comply with this law but also protect someone who might
fail to cooperate with the law from criminal or civil liability. \par\par
There is a real question about what the section of the law that deals with d
omestic violence screening will look like when regulations are finally handed d
own. There is a section of the law that talks about recognition of domestic vio
lence risk and says that there will be identification and screening of both ind
ex patients and contacts for domestic violence risk. n131 But there is nothing
that says what will be done once these people are supposedly screened, and all
kinds of questions about how you would do that screening. For instance, if I ha
ve a brief relationship with somebody or went on a date and had sex with somebo
dy two days ago and do not know them very well, how would I contribute to an as
sessment of their risk for domestic violence?\par
\par
----------Footnotes----------
- \par\par
n131. See id. 2137. \par
\par
----------End Footnotes----------
- \par\par
I have asked some advocates for victims of domestic violence about this, say
ing, \'22Well, I understand the sensitivity of doing a domestic violence assess
ment of a person sitting with you - that is difficult enough. Now, what if I co
me in and say, 'Well, you know, I just met this person.' Do you think that you
can assess through me whether they are at risk for domestic violence?\'22 Nobod
y has really given me an answer for how on earth that could be effectively done
. \par\par
In any case, one would assume that coming out of this idea of recognizing do

mestic violence risk should be some sort of exclusion, at least a limited exclu
sion - that partner notification would not happen if it were likely to exacerba
te domestic violence. But right now what we have is a law that says \'22there s
hall be screening\'22 and provides no real direction about what might then be d
one with it. \par\par

So that is going to be a very interesting section to see come down in regula
tions, and I believe, from some of what I have heard, that it may be a section
that has been delaying the regulations. \par\par

All right, the last thing that I will say is that a demand that has been mad
e by advocates across the board has been that there \'5B*418\'5D should be
some kind of study of the effect of these measures some reasonable time after t
hey have been put into place, especially since we are talking about the possibi
lity of driving people from testing and treatment. \par\par

When we see that possibility in something called a public health law, the ef
fect must be examined, especially when we have studies and indications from cli
ents and patients that we may see severe adverse effects, and especially when w
e see in the Governor's new budget that millions of dollars are now proposed to
be diverted from proven methods of HIV prevention to this extremely expensive
system of names reporting and partner notification. \par\par

We really have to demand not only a study on rates of infection and deterren
ce linked to names reporting and partner notification, but also a look at what
programs are suffering to fund these measures. \par\par

MS PINOT: I was asked to talk about some potential scenarios as a result of
the new partner notification, contact tracing law. \par\par

I guess I should identify who I am. I am Mildred Pinot from the Community La
w Offices of the Legal Aid Society. I am a supervising attorney of the HIV/AIDS
Representation Project. I know some of the folks in the audience who I have ha
d the pleasure of working with during the course of my ten years at Legal Aid.
\par\par

So I am, in fact, going to talk about a couple of scenarios that have come u
p during the course of some community outreach and education that I have done,
in Upper Manhattan primarily, and in the Bronx, because I think it is really im
portant, exceedingly important, not just for us to educate ourselves but to edu
cate the community at large. And, as a service provider, I think it is really i
mportant to educate my clients and to have them, in turn, educate their familie
s, their friends and their acquaintances. And that goes for all of you as well.
\par\par

There are many issues that attach to this legislation. I know, as an advocat
e that was opposed to it, that traveled to Albany on more than one occasion and
spoke to many legislators, it was a difficult and disappointing process, becau
se never in my wildest dreams did I really think this was going to pass. This i
s retrogressive. \par\par

The complexion of the epidemic has changed. Have people noticed that? Intere
sting how now we have legislative efforts not only to mandate names reporting a
nd contact tracing, but also criminalization of behavior by individuals who hap
pen to be HIV positive. \'5B*419\'5D I am disgusted. I think it is horrific
, and there should be a public outcry about this. \par\par

Who is affected primarily? Women and men of color and poor people. It was ju
st announced recently - surprise surprise - that HIV/AIDS is an emergency in th
e African American community. Really? No! $156 million has been earmarked for p
revention. Now there is tons of controversy about how that money is going to be
used. Lovely. Let's just go out and educate the folks that are getting infecte
d the most. Who are they? Primarily adolescents. I heard a statistic the other
day that totally blew me away. It was like two people under the age of twenty-f

ive are infected per hour, on a daily basis. That is amazing. We are doing some thing wrong. We better start doing it right because if we do not, you think thi s is an epidemic now? This is going to start killing us off like we cannot imag ine. \par\par

What is involved? Access to early testing. I talk to teenagers during the co urse of my work. I am not supposed to, because I am supposed to represent the a dults, but I talk to their children, and I have kids who are thirteen, fourteen , fifteen, sixteen, some of whom are parents, telling me \'22I am not getting a test, I am not having my name going on some list, and then, you know, what if rumor has it that I am HIV-positive and somebody tries to come and kick my butt or kill me?\'22 That is the reality of potential domestic violence. That is th e reality of the situation that people do not talk about. I am not talking abou t, \'22Oh, I am going to curse you out because I am really enraged that you cou ld have possibility infected me.\'22 I am talking real fear of imminent danger. \par\par

So this is the stuff that comes up at community forums. \par\par

Back to my initial statement, the reason I think it is so important to engag e the communities that we serve is because most people do not ever see a copy o f legislation. People have never seen this. People do not have an opportunity t o read through the law. I take two-and-a-half hours with a community group or o ther audiences, and I spend an hour and fifteen minutes, and I read the law at community forums, and I have the audience tell me what they find problematic wi th it. So issues such as the one that Hayley brought up, which I guess are part of my scenarios, are some of the things that come up. \par\par

For example, I go to a doctor's office, my first time there. What do you all get when you go to a doctor's office? You get forms, right? You get that littl e clipboard and a pen. They tell you \'22could \'5B*420\'5D you please fill this out, could I see your insurance card\'22 - you know, the whole works. \p ar\par

On that form there is all kinds of information that you are listing. When I went for my first ob-gyn examination, I was a nervous wreck. I filled out all t he stuff. I got inside, and my doctor said, \'22Oh, your husband's name is Eric .\'22 \par\par

I said, \'22How did you know he was my husband?\'22 \par\par

She said, \'22Oh, I just assumed.\'22 You should never assume, because I do not share his last name. He is my husband, but she made an assumption, okay? \ par\par

Assumptions are made. She asked me about my sexual history, and I shared tha t information, because, of course, I wanted to do everything I could possibly d o to ensure that I had a healthy and good pregnancy. Okay, I am thinking now al l that information I gave this provider, who I had never met before - this was a cold call that Eric, my husband, made to a hospital in Westchester County; he figured we will go to Westchester - \'22small hospitals, we can get a private room when you finally give birth, not a big deal\'22 - I do not know who this w oman is, never met her before. \par\par

I am developing a relationship with her. She now has all kinds of informatio n about me. She knows how many times I have had miscarriages. She knows all abo ut my gynecological history. She has asked me questions about sexual partners. During the course of your conversation with a medical provider, you share infor mation. \par\par

She did not tell me anything about informed consent. She asked me if I wante d to be tested for HIV, if there was any reason why I thought I might be at ris k. No, I did not. She asked me if I had ever done IV drugs. No. Anybody I had e ver dated? I do not know. But these are just general questions that come up dur

ing the course of a regular visit with a physician. \par\par
I did not think anything of it then, just like I did not think anything of i
t when they asked me, \'22Is it okay to test your baby for HIV?\'22 My initial
response was I broke out into a sweat. I swear to God, I broke out into a sweat
. I was like, \'22they are going to test the baby for HIV.\'22 Well, that means
they are going to test me for HIV. I do not know if I can agree to this. The l
aw had not even passed at the time. \par\par
They said, \'22Well, we really encourage it.\'22 \par\par
I said, \'22Okay, test the baby.\'22 \par\par
When did I get my results? My child is two years old. Had I not called a yea
r later - a year later! - I would not have received the results of my child's H
IV test, because no one volunteered that, \'5B*421\'5D and my provider did
not volunteer it. I did not say anything because I wanted to see how long it wo
uld take. Now mind you, I think, had she been HIV-positive they would have told
me, especially because they know I am a lawyer. \par\par
It is telling, however, that these are problems. These are glitches within t
he law. I am at least savvy about this stuff. Most people are not. \par\par
So back to accessing care. Here I am at the doctor's office. I fill out a fo
rm, talk to my doctor, the doctor writes notes. Mind you, most doctors are not
going to want to be in the practice of engaging in partner notification. I do n
ot know that people talk about that, either. I talk to medical providers, and t
hey are asking me, \'22How the hell can I get around this? I mean, I do not wan
t to do this. Can't I just refer it to the Department of Health?\'22 \par\par

I answer, \'22No, it is your patient's option whether they want to ask you t
o do it or someone from the Department of Health.\'22 \par\par
They reply, \'22So then what do I do if my patient says that I should do it?
\'22 \par\par
Well, what do you think doctors are going to do? Do you think a doctor is go
ing to go out and try to personally contact someone that is a known contact? No
, they are going to delegate that responsibility to someone on their staff. Do
you think their nurses, physician assistants, anybody else that they work with
is really going to want to engage in partner notification? No. This is a real p
roblem. I do not know how they are going to do all of this. \par\par
It is a very expensive law. It is problematic. How is it going to go into ef
fect? \par\par
Yesterday was Friday. I spoke to someone from the Department of Health at a
legislative session we had up in Harlem: \par\par
\'22So, know anything about the amendments?\'22 \par\par
\'22Amendment? No, do not know a thing. We are having a little trouble getti
ng them together.\'22 \par\par
We have heard this for months. What is happening here? \par\par
First of all, I can tell you what is happening. No money was allocated to th
is legislation, and it is bad law. It was not properly thought out. It is going
to be very, very hard to implement. \par\par
Let us talk about the database. My ten-year-old stepson can get into almost
any database that exists. How are they going to ensure confidentiality? There i
s a lot of transmission of information here. You are going from a doctor or a l
ab or someone else who is authorized to give an initial diagnosis of a positive
HIV result, an initial HIV-related illness diagnosis, or a diagnosis of AIDS.
That \'5B*422\'5D goes from that whatever you want to call them - entity,
individual - to the State Department of Health. Then from the State Department
of Health it goes back to the local Department of Health. Gee, that is a lot of
transmission of information going around. Problems with potential breaches of

confidentiality obviously exist. Who will have access to this information if it is not encoded, it is not encrypted, if they are actually transmitting informa tion in terms of names? \par\par

I heard the story of all stories yesterday from a client. The client could n ot get some benefit, so he hooked up with somebody at the agency, and benefits got in place the next day. I say, \'22No, you need to stop.\'22 The client said , \'22Oh yeah? It is the truth, and I have no reason to lie to you.\'22 The cli ent goes on to say \'22Now I am having another problem with the same agency, bu t I do not feel like hooking up with anyone, and I need you to help me. I mean, the first time around, it was fine. But not again.\'22 Look, call me na<um i>v e. I did not think this stuff went down, all right? It goes down. I did not kno w about it. Now I know. \par\par

What if that agency person gets upset and divulges information? Obviously th ere was a breach in the instance that Hayley mentioned. Obviously these things happen more than I realized. This is the first I ever heard of the stuff. It is outrageous, and it is problematic, and we need to address it. That is why the commentary period is so important. \par\par

The other thing that I was told yesterday is there will be no public hearing s but only written comments. Do you know what that means? Written comments mean no one is going to read them. Okay? We better make some major hoopla about thi s, either for public hearings or to ensure that our comments are, in fact, read , and that it is documented who read them and what recommendation was made upon reading the comments, because otherwise it is an exercise in futility. \par\p ar

MS. GORENBERG: When my o.b. asked me if I wanted to be tested, I had the sam e sweat reaction. I said \'22Okay, let's do it, I gotta see,\'22 and the lab lo st the test. Leads to fantastic confidence in the system, I must say. \par\par

MS. PINOT: Unbelievable. People seem to think that we make this stuff up. It is not made up. Now, we are pretty mellow about it. Most people are not that m ellow about it. It freaks them out. It is a major decision to be tested. It is not something to be taken lightly. Your entire life changes, or could potential ly change, but it \'5B*423\'5D is being treated as a one-shot deal, especia lly in light of partner notification/contact tracing, and that is problematic. \par\par

Do people think that folks in the neighborhood do not know who works for the Department of Health? They know. Just like when you have an STD, people know. Word gets out. If they think you are HIV positive, word is going to get out. Pe ople start seeing the same kind of envelopes, same people knocking on doors, wo rd is going to get out. We talk about stigma. \par\par

MS. PINOT: If your baby gets tested, derivatively you get tested. Your partn er is going to be informed if the child is positive. Your partner is going to b e informed, if they know who he or she is. \par\par

MS. GORENBERG: I filled out the form when I walked into the doctor's office. \par\par

MS. PINOT: They know who it is. It is a problem. It is a real problem. And t his is stuff that my clients were telling me: \'22If I have a baby, you know th ey test the baby.\'22 \par\par

\'22Yes, I know they test the baby. Well, if I list who helped me conceive t his child, they are going to tell whoever it is.\'22 \par\par

\'22Yes, that is a distinct possibility.\'22 \par\par

\'22Well, then, what am I supposed to do? I just gave birth. How am I suppos ed to deal with that?\'22 \par\par

Okay, psychosocial issues. How are they going to deal with this? Is there fo

llow-up counseling for any of this? Have you seen anything apropos? Are people qualified to do it? Anyone funded to do it? I think it is a problem. \par\par

Okay, I am sixteen, I am sexually active, I have experimented with IV drugs. Friends suggest I get tested because rumor has it that Jack, who I hung out wi th last week, has been ill - I mean, in and out of the hospital. People do not know what the deal is with him. I should get tested. I go to an anonymous testi ng site. Test positive. Not only do I freak out, but after I test positive, I a m told - counseled - that I should access care - prophylactic measures, I shoul d talk to somebody. \'22There are ways to avoid becoming ill, so you should see a doctor.\'22 \par\par

Who do I go to? Are they going to tell me that if I go to a doctor, who is p robably my family doctor, because who else do I know, that he will have to do a confirmatory test and if positive report my name and the names of my known con tacts? I guess I could to Planned Parenthood; I guess I could go to GMHC; I gue ss I could go to a CBO; but when I go I am going to have a confirmatory test. M y argument, in this context, has consistently been a \'5B*424\'5D confirmat ory test of my HIV status is not an initial diagnosis and, therefore, it should not be reported and my name should not be reported. \par\par

Providers are not looking at it that way because they are nervous about bein g sanctioned. I mean, I do hospital-based legal services. They are telling us, \'22We are not sure that this is what it says. We want to comply with the law. We would probably err on the side of reporting rather than not.\'22 We need to educate, educate, educate, educate. \par\par

Okay, so I go. I now have an appointment with my doctor. I am nervous and sc ared. The doctor says to me, \'22You want to tell me who you have been with?\'2 2 It is important, because you should engage in partner notification, and you s hould not be engaging in at-risk behavior. You need to take care of yourself. I t is real, real important. And you, because you are feeling vulnerable at the a ge of sixteen and freaking out because you tested positive, share some informat ion. They, in turn, have to engage in contact tracing, and they may. \par\par

Now, it could be a problem and it could not be a problem. On the other hand, whoever you have been with may have already identified you as a partner. So yo u may already be on a list. Say you get a letter at home. You are sixteen, get a letter at home from the Department of Health, because of course their attempt s to reach you personally failed, and they were good-faith efforts. \par\par

They knock on your door. Maybe you are not home. Parents are home. They say, \'22Have your child get in touch with the Department of Health.\'22 Then they send the letter. You think Mom and Dad are not going to ask you why you are get ting letters from the Department of Health? Then they may even read the letter. \par\par

And then what happens? I have situations where I have sixteen-and seventeen-year-olds who call my office and say, \'22My Mom just found out that I am posit ive and kicked me out of the house. My father found out I am positive and said that I cannot touch anything in the house, I cannot touch my brother and sister , I have to get a job. I mean, I gotta take care of business. How can you help me?\'22 \par\par

Do we all know about the changes in the welfare laws? What do sixteen-year-o lds do if they are not hooked up with another adult, unless they are emancipate d? Remember, New York is not an emancipation state. You cannot go to court and get emancipated. \par\par

These are real problems, and they have far-reaching repercussions, and peopl

e do not think about it. \par\par
\'5B*425\'5D Say you are in a battering situation. Get tested. So you have been in counseling with a particular community-based agency that can provide comprehensive services. People know who the batterer is. They know who you are hooked up with. It may be a series of batterers that you have been with. I mean, it happens. It could be a historical situation. Is this agency now required to engage in contact tracing, and how much risk are you at this point? \par\par

So what is the point of getting tested? I would not. I would do the same things my clients tell me: \'22No. I would go to an anonymous site, and when I am really, really sick then I will get care.\'22 \par\par
Is that what this law was designed to accomplish? No. Allegedly, it was to do exactly the opposite, to encourage folks to access care early on, to alert people to the possibility that they may have been exposed to HIV and stem the tide of the epidemic. Well, I think it is going to do exactly the contrary, and I have real issues about informed consent. \par\par
What about a false/positive? Do you ever think about that? There are false/positives. I have a couple. People come in, tested positive, two years later come back and tell me, \'22No. You know what? They made a mistake. Thank you for helping me, and I am very happy.\'22 \par\par
Okay, the name is on a list now. How do you get it off? What do you do with contact tracing? People may have been contacted. Your life may be completely changed as a result of this. We thought about it enough. The folks who passed the law did not think about it enough. \par\par
I am trying to think if there are any other little scenarios that I have not talked about. Interesting questions. \par\par
I had a representative from one of those companies that does the HIV tests by mail - they are not New York-based. I forgot where they are. Is it Texas? There is one in Texas, and there is another one, because this gentleman was not from Texas - but anyway, say Texas. Okay, I do an HIV test by mail. This is supposed to be anonymous, except I do not understand, if they are so anonymous - I mean, you call in and you give them a number, but if there is some problem with the blood sample, then you are supposed to send another one, and they send you another kit, but by sending you another kit, they already know who you are. \par\par
AUDIENCE: But they do not have to link it to the - they could give you another kit with a new number. \par\par
MS. PINOT: Yes, but they send it to your home. Sure, you could send it to a Post Office box, assuming you have a Post Office \'5B*426\'5D box. You could send it to your place of employment. You can send it to a friend's house. \par\par
You could send it anywhere. All I am saying is that there is no guarantee of confidentiality - what is confidentiality? Let's be real, okay? \par\par
So, anyway, can we use these tests to avoid the law? My problem with it is, say, there is a problem with the blood sample and you then have to do it again and instead of going out and purchasing another one, you call in. They tell you that there was a problem with xyz2000 and \'22if you give us your address or an address where we can send this, we will send you another one.\'22 All right, that is okay. Give somebody else's. I will give my mother's address, okay? Fine. What then? What happens then? Say you are positive. What do you do? What do you do? \par\par
Do you access care? How do you document that you are positive? You have this thing with a number on it. How do you know it is you? You know, I can see doctors going \'22No, no, no. This will not do. You have to take an initial HIV tes

t here in the State of New York.\'22 And that is a problem because then there i
s disclosure; you know, you have to report. \par\par
Okay, I am trying to be creative. I am trying to think of as many scenarios
as possible. You want to help me out? \par\par
AUDIENCE: Well, who has access to the lists legally? \par\par
MS. PINOT: The Department of Health. \par\par
AUDIENCE: Does anybody else? I mean, insurance companies, criminal justice?
\par\par
MS. PINOT: Well, at the moment - \par\par
MS. HANSSENS: Illinois adopted a measure authorizing use of the state AIDS r
egistry to crosscheck with names of licensed heath care workers, although it ha
s not been implemented. So, in theory, laws can be adopted allowing access or u
se outside the state health department. The CDC currently is advancing the adop
tion of a model state privacy law that would allow health officials across the
country - local, state and federal - to all share identifiable information of p
ersons with HIV. Such use would not be considered a disclosure requiring affect
ed individuals' informed consent. Once names-based registries of those with HIV
have been created, the list of agencies and individuals who have access to thi
s information can be changed with the stroke of a legislative pen. \par\par
AUDIENCE: Could you file a Freedom of Information Act request, if you are in
litigation or anything like that? \par\par
\'5B*427\'5D AUDIENCE: Well, the law as it is written says that confidenti
ality will be maintained and will only be disclosed \'22as necessary to further
the provisions of this Title.\'22 n132 But then, we have questions about what
that really means, what is going to be necessary - especially when you see amen
dments that are pulling out things like a doctor before could make certain kind
s of disclosures if the doctor reasonably believed there was the risk of transm
ission. Well, they struck the word \'22reasonably.\'22\par
\par
----------Footnotes----------
- \par\par
n132. See id. 2139. \par
\par
----------End Footnotes----------
- \par\par
MS. HANSSENS: Well, there are two words which illustrate how officials might
define \'22necessary\'22: Nushawn Williams. Local officials responded by takin
g his picture into schools, and his mug shot broadcast on national television.
While health department officials may not have intended that broad a result, th
e incident demonstrates that health officials, both state and federal, either a
re unwilling or unable to control those kinds of disclosures, particularly in c
hanged situations. \par\par
AUDIENCE: And who is doing data entry? I mean, if we do not think that the C
ommissioner of Health is going to do this in a wrongful way - in the call that
I got in my office - I mean, who was this person? I do not believe - although I
do not know who it was - I do not believe that it was a high-ranking official
at the local Department of Health or at the Division of AIDS Services, but it w
as a data entry person or it was a caseworker or it was somebody who had access
to a computer screen. \par\par
AUDIENCE: In Florida last year there was this guy who worked for the Florida
Department of Health, took the records and threatened to publish them in two n
ewspapers. \par\par
AUDIENCE: Well, he sent them to the newspapers. \par\par
AUDIENCE: But the newspapers refused to publish it. \par\par

MS. HANSSENS: They prosecuted him and he got probation. \par\par
AUDIENCE: I am still confused on when you said the law presumes anonymous te sting and yet you have to have names reporting. That does not seem to go. \par \par
MS. PINOT: You can go to an anonymous testing site and be tested. That is yo ur option. \par\par
AUDIENCE: But once your doctor or someone else - \par\par
MS. PINOT: The big issue, or the big question, is if you go to a doctor to a ccess care and the doctor suggests - because you tell the doctor \'22I am HIV, having a confirmatory test done\'22 - the question is, is that test confirming your HIV diagnosis an initial test \'5B*428\'5D or not? Our argument is th at it is not and, therefore, your name should not be reported. \par\par
We do not know what the regulations are going to say, but they hear us talki ng, so in all likelihood it is going to say if you get tested anonymously, upon accessing care a confirmatory test will be deemed an initial test subject to t he requirements of the new law. \par\par
AUDIENCE: We should say as a baseline, though, - and maybe this goes to your question - that before this law, we had anonymous testing and we had confident ial testing. There were specially licensed sites to do anonymous testing, and t hen there was your confidential document if you go to your doctor, or something . So what they are saying, we think, is that those anonymous sites, specially f unded to give anonymous testing rather than confidential testing, will - \par\ par
AUDIENCE: Well, it is just that with the partner notification I am wondering - I do not mean this to sound funny, given the political climate today, but wh ere they say they have to contact your sexual partners, what is their definitio n of a \'22sexual partner?\'22 What kind of sex are they talking about? What if you refuse to give names, or what if you honestly do not know the name of the person you had sex with? \par\par
AUDIENCE: There are, in fact, no criminal penalties, and I would suggest tha t you identify Assemblyperson Nettie Meyersohn. \par\par
MS. PINOT: She is the one that is pushing the \'22unblinding\'22 of - she wa nts to make these lists of names available to other entities. \par\par
MS. HANSSENS: This happened with the newborn testing here in New York and th is is something that Liz Cooper worked on a lot. We had blinded seroprevalence surveys among newborns, and once that information was there, Assemblyperson Mey ersch was one of these people that pushed to say babies are going home and dyin g. So, with a stroke of the legislative pen, an anonymous survey turned into ma ndatory names reporting. \par\par
The bottom line is that once a list is there, then there will be this desire - this uninformed, usually politically driven desire - to use the data for oth er purposes. History supports us on this. \par\par
For folks that have money, these things are much less of a problem. There ha ve always been doctors, certainly in the gay community, that will allow you to test as Donald Duck and you could still test as Donald Duck in a names reportin g system. The problem is \'5B*429\'5D that, for individuals who rely on pub licly-funded benefits to survive, there may be some problems with continuing th rough the system as Donald Duck. \par\par
But there are certainly doctors - there always have been doctors - who will not report and who will do everything they can to protect their patients. So pa rt of what you do is for your own protection is identify those doctors, and you also try to work with clients. \par\par
Ultimately, a lot of these policies are driven by politics and funding, fund ing, funding. \par\par

The CDC wants these names and numbers for a variety of reasons unrelated to the ones that they are offering. Politician want names; government agencies want numbers to show that they deserve funding. There has been incredible pressure on the states, and it was clear even from members of the New York State HIV Advisory Council that they believed if they did not adopt a names-based reporting system, that we would lose funding. So a lot of the rhetoric supporting HIV reporting strikes me as an \'22emperor with no clothes\'22 situation. There are mainstream health officials and even some directors of aids service organizations in the receiving line for this naked king that are saying, \'22You look fabulous, you look fabulous.\'22 And then there are the rest of us in the crowd that are saying, \'22Excuse me, I think you are naked.\'22 \par\par

AUDIENCE: There is an interesting and very painful historical twist in all this, which is that there was sort of a concession early on, or an understanding early on in the epidemic, that with AIDS when people got sick, they really died very close to the time of diagnosis. And now, ironically enough, we have all these reasons to give people incentives to go ahead and get tested early so that they can go ahead and get treatment - the direct opposite of what a lot of Millie's clients talk about - and yet, we now are putting in a roadblock at exactly the time that we want to encourage people to go in to get tested, and possibly to get care. The irony of those things happening at the same time, quite frankly, on the backs of poor people and largely people of color, is just too painful in this epidemic. \par\par

AUDIENCE: And for data that is largely useless for the purposes that they are saying that they are collecting it. \par\par

AUDIENCE: A question and a comment. On unique identifiers, I mean, I realize that that has been thrown out as a way of trying to back off on names reporting. On the other hand, given all the risks to what happens to a database once it exists, and the fact \'5B*430\'5D that for unique identifiers to work somebody has to have a match of the name and the unique identifier somewhere - I mean, that exists physically somewhere in the world. \par\par

AUDIENCE: It does not have to, actually. Anna Forbes of Philadelphia is the most brilliant person who could explain why you do not actually have to have a master list. \par\par

AUDIENCE: My concern is that even using unique identifiers, (1) there is a reality of a risk of confidentiality being breached, and (2) perhaps more important, is that there is probably going to be the same perception by people who are going to be deterred from taking the test. \par\par

AUDIENCE: And that has been shown. \par\par

AUDIENCE: It just struck me through the whole debate that while there was sort of a political tactic to raising unique identifiers, does it really accomplish anything? Does it really accomplish what we want it to accomplish with respect to the problems with names reporting? \par\par

The second question is, has there been any enforcement of the provisions of Article 27-F, the confidentially provisions that have been in effect now for a number of years in New York State? I think there actually are criminal penalties attached, right? Has anyone anywhere in New York State been prosecuted? Is it enough for institutions to think that if they err on the wrong side of reporting - for example, if they decide something is initial and it is not - they could be running afoul of that law? \par\par

MS. PINOT: Not if they are acting in good faith. There are some handouts here, but one of the ones that I brought says \'22disclaimers.\'22 If you are acting in good faith in carrying out the provisions of the law, no criminal or civil liabilities attach - \par\par

AUDIENCE: So then the 27-F pressures just do not exist in that whole, so the

re is no incentive to err on that side. \par\par
The other thing I just wanted to mention is on the domestic violence point. The domestic violence provisions that are passed with respect to welfare are an abomination. The supposed domestic violence community was part of creating tha t abomination; they were part of creating the abomination as to the regulations , enforcing it. I would not trust either the administration, obviously, or peop le who call themselves domestic violence advocates to inform you on those provi sions, and I would certainly - (1) they did not consult any poor people advocat es, and certainly did not want consult poor people's advocates, because we are seen as pariah and likely to \'5B*431\'5D turn off the Governor because we actually care about the lives of poor people. \par\par
I would suggest - I am saying this very strongly, since it is absolutely tru e, and it has been a nightmare - that when it comes to domestic violence provis ions, expect the worse. And certainly do not limit your consultations to people who call themselves domestic violence advocates, because they are dangerous. \par\par
MS. HANSSENS: Can I just answer your first question? I think what you are su ggesting about unique identifiers is absolutely true. I think that the problems , the basic problems, with names reporting as surveillance - those are differen t things - are the same for unique identifiers as they are there. That is one o f the reasons Lambda has never actively supported unique identifiers - we do no t support HIV test reporting in any form as a way of getting a reliable picture of the epidemic. \par\par
In fact, the Latino Commission on AIDS did a phone survey with graduate stud ents calling people with Hispanic surnames, and found that there was not a subs tantial difference between unique identifiers and names reporting in deterring people from willingness to get tested. \par\par
This fear is not unfounded. If I had a choice of a name and I could say, use either \'22Donald Duck,\'22 or a unique identifier that includes the last four digits of my Social Security number - well, all I have to do is put those four numbers into a phone call to Visa and they say \'22Hi, Catherine Hanssens, how are you?\'22 I mean, it is particularly easy to track people down with a socia l security number, and then of course there are immigrants at risk who do not h ave a number at all. \par\par
I think that people supported unique identifiers because people believe we n eed a better picture of the epidemic and it is a preferable alternative to name s reporting. Fine, we do need a better picture - but none of the information we have about IV drug use has ever produced broad-based government support for n eedle exchanges. \par\par
In fact, in New Jersey when people involved in needle exchange programs are being chased down, prosecuted, arrested and programs are being shut down, and t he information we know about youth is rejected for abstinence-only-based preven tion education, what reason do we have to believe that more data will produce b etter programs? \par\par
\'5B*432\'5D AUDIENCE: Universal health coverage with confidentiality woul d do a lot more for giving a good picture of what is happening in the epidemic. \par\par
It also would be interesting to see - you know, there are unique identifiers in Massachusetts, starting in Massachusetts, and they have it in Maryland. It will be interesting if they are going to do a follow-up study, also to see nega tive impact, if any, and then do some sort of comparison in those states that h ave gone to name reporting and those that have gone to unique identifiers. \pa r\par
The problem with those systems, though, is that the systems - the Maryland s

ystem sucks. Excuse me, but it does. It is dumb. It is also based on using a po
rtion of the Social Security number, which leaves out - oh, who are we forgetti
ng? - oh, immigrants. There are those folks, of course, but they do not get HIV
, so we are not really losing anything. \par\par

MS. PINOT: And if they do, we do not care, right? \par\par

AUDIENCE: We do not care because we are not going to give them health care.
\par\par

And the system in Massachusetts is actually sort of scary, too, I think. \p
ar\par

Plus, any unique identifier system you did manage to put together would do n
othing for the contacts. If you are named as a contact, you are on the list. I
mean, you are there. There is no way you can manipulate that any other way. \p
ar\par

MS. PINOT: I mean, think of the potential for being on a contact list. I mea
n, I could be ticked off at all of you and put you all on my contact list. \pa
r\par

AUDIENCE: But the track-back thing, again, there is this whole sort of sugge
stion that we need to be able to indefinitely - I mean, because if you are HIV-
positive, it will be, as far as we know, it will be a pretty long time, somebod
y checking in on you. When you take a test, you do not, I think, envision that
somebody from the Health Department is going to have the ability to track you a
nd show up at your door - which, frankly, is not much better than a letter, and
in fact most of the data that we have - \par\par

On the off chance that New York did end up adopting a unique identifier syst
em, what additional obstacles would you see, considering the fact that New York
has such a higher seroprevalence compared to Maryland and Massachusetts? \par
\par

You mean in terms of that it is more difficult to do it? \par\par

I mean, in terms of if you are having the last four digits of the Social Sec
urity code. \par\par

\'5B*433\'5D MS. HANSSENS: Well, I never totally understood, first of all,
why numbers are viewed as inherently more difficult than letters. I mean, just
conceptually I do not understand that. My name is routinely misspelled. It is
misspelled here in the program. It is always wrong. There is this sort of notio
n that it has to be a Social Security number. How many people here have AOL or
use the Internet? \par\par

And you made up your own name, right, and you fed it in, and in nanoseconds
they told you if that name was taken. So if you wanted to be reddog69, and damn
, it was taken, you could become reddog70. \par\par

And that is your identifier. You have made up that name. The odds are - even
if you are drunk or forgetful - that you will remember your identifier because
it is your own special name named after your first love or your dog or whoever
. So the likelihood that people will remember that and give that and that can b
e keyed to that test and subsequent tests is pretty decent. We have the technol
ogy. \par\par

Health officials, they talk about traditional health methods as if tradition
al forms of medical treatment - you know, like attaching leeches to your body -
somehow have this kind of permanent value. And, in fact, as Matthew explained,
this epidemic is different than the ones that we adopted these methods for in
the 1920s and 1930s, where you slept with a few folks, you were tested, you wer
e treated, you were rendered noninfectious. If they found out who you were with
, they could treat you and render you noninfectious and that was the end of it.
\par\par

This is very different, but there is no reason why, with the technology that

we have, that we need or should rely on a names-based system to track people w
ith HIV, but this is the way it has always been done. They would have to change
some things, and bureaucrats hate change. \par\par
Acknowledgements\par
\par
Thanks to the following who helped organized the conference: Alexis Baden-Maye
r, Dan Brook, Jack Chen, James P. Colgate, Elizabeth Cooper, Timothy W. Donovan
, Marie Fabian, Walker Harman, Cynthia S. Kern, Robin Merrill, Daniel R. Schaff
er, Thomas Schoenherr, Leslie Williams, Fordham University School of Law and al
l the panelists and moderators. \par\par
\pard
\sect \sectd \sbknone
\page \f1 \f0 \fs20 \li000\ri000 \pard

\qc Fordham Urban Journal\par
\par
\pard
\qc \ul January,\ul0 1999\par
\par
\pard
\qc 26 Fordham Urb. L.J. 247\par
\par
\pard
LENGTH: 18661 words \par\par\pard
NOTE: MOTHER STILL KNOWS BEST: CANCER-RELATED GENE MUTATIONS, \par
FAMILIAL PRIVACY, AND A PHYSICIAN'S DUTY TO WARN \par\par\pard
Alissa Brownrigg* \par\par\pard
* J.D. Candidate, Fordham University School of Law, 1999; B.A., magna cum lau
de, Barnard College, 1996; A.D.N., University of Hawai'i, Manoa, 1988. I would
like to extend my appreciation to Professor Elizabeth Cooper for her valuable i
nsight and advice and Radford Small for providing endless encouragement. \par\
par\pard
SUMMARY: ... The patient's children particularly may benefit from the medical
information, especially where it reveals a genetic disease, because a forewarni
ng of their increased risk of the disease would give them the option of investi
gating and taking advantage of preventive measures. ... BRCA1 and BRCA2 are rec
ently discovered genetic mutations that signal that their carriers face a risk
of developing breast and ovarian cancer that is significantly higher than the r
isk the average woman faces. ... Part II reviews current legislation regulatin
g the dissemination of genetic information, existing exceptions to physician-pa
tient confidentiality, and recent court decisions regarding the physician's dut
y to warn family members of genetic disease. ... Other diseases, such as breas
t and ovarian cancer, insulin-dependent diabetes, and coronary artery disease,
develop if certain genetic mutations exist in combination with environmental fa
ctors that have not yet been identified. ... Women in the general population,
without either genetic mutation, face approximately a twelve percent risk of br
east cancer and a one and a half percent chance of developing ovarian cancer du
ring their lifetimes. ... One may argue that breast and ovarian cancer are so
serious that individuals should be aware of an increased risk so that they can
make informed personal choices about their own genetic testing, lifestyle, and
health management. ... \par\par\pard
TEXT: \'5B*247\'5D \par\par
\par
\par

Whatever, in connection with my professional service, or not in connection wit
h it, I see or hear, in the life of men, which ought not to be spoken of abroad
, I will not divulge, as reckoning that all such should be kept secret. n1\par

\par
----------Footnotes----------
\par\par
n1. Oath and Law of Hippocrates (visited Nov. 24, 1998) <ftp://ftp.std.com/o
bi/ Hippocrates/HippocraticOath>. \par\par
\par
\par
Introduction\par
\par
At the completion of medical school, graduates embarking on their careers as p
hysicians mark the moment by taking the Hippocratic Oath. n2 Although the oath
originated as early as the fifth century B.C., its vow to abstain from sharing
a patient's personal information remains an important tenet of medical care tod
ay. n3 The oath's assurance of privacy encourages patients to divulge personal
information, trusting that their doctors will keep it confidential, even from m
embers of the patients' families. n4\par
\par
----------Footnotes----------
\par\par
n2. See Robert D. Orr & Norman Pang, The Use of the Hippocratic Oath: A Revi
ew of 20th Century Practice and a Content Analysis of Oaths Administered in Med
ical Schools in the U.S. and Canada in 1993 (visited Feb. 19, 1998) <http://www
.sequel. net/-twilight/poath9.htm> (noting that while a majority of medical sch
ools do administer a version of the oath that omits outdated content of the tra
ditional oath, some schools do not administer the Hippocratic Oath at all). \p
ar\par
n3. See Charles Marwick, Medical Records Privacy a Patient Rights Issue, \i
276 JAMA 1861 (1996)\i0 (\'22A patient has a right to keep personal medical in
formation confidential .... The best guide for steering a path way through toda
y's computerized medical recordkeeping is the Hippocratic oath.\'22); American
Medical Association--Institute for Ethics, Principles of Medical Ethics (visite
d Nov. 24, 1998) <http://www. ama-assn.org/ethic/pome.htm> (\'22A physician sha
ll ... safeguard patient confidences within the constraints of the law.\'22).
\par\par
n4. See Marwick, supra note 3 (\'22Plans with a more cavalier attitude to pr
ivacy will not attract members, who will switch to other plans if they can or w
ithhold information about their health if they can't.\'22) (citation omitted);
Bernard Friedland, Physician-Patient Confidentiality; Time to Re-Examine a Vene
rable Concept in Light of Contemporary Society and Advances in Medicine, \i 15
J. Legal Med. 249, 256 (1994)\i0 (\'22The patient's most profound secrets are
kept confidential. This encourages patients to bare themselves fully to their p
hysicians so that an accurate diagnosis may be made and appropriate treatment i
nstituted.\'22). \par
\par
----------End Footnotes----------
\par\par
\'5B*248\'5D In situations where confidential medical information affects
the health of a patient's relatives, however, some assert that physicians shoul
d be required to share the information with the family, with or without the pat
ient's consent. n5 The patient's children particularly may benefit from the med

ical information, especially where it reveals a genetic disease, because a fore warning of their increased risk of the disease would give them the option of in vestigating and taking advantage of preventive measures. n6\par
\par
----------Footnotes----------
\par\par
n5. See Diana Brahams, Human genetic information: the legal implications, in Human Genetic Information: Science, Law and Ethics 111, 113-14 (Derek Chadwick et al. eds., 1990). \par\par
\par
\par
As against the duty of confidentiality which would be owed by a doctor, there may be a duty of disclosure to a partner or child which has to be weighed in th e legal balance, particularly if all concerned are patients of the same doctor who owes them all an equal duty of care. In this instance, unless the public ar e put at risk, any disputes which arise are likely to be private matters. \par
\par
\par
\par
Id. \par\par
n6. See Lori B. Andrews, Torts and the Double Helix: Malpractice Liability f or Failure to Warn of Genetic Risks, \i 29 Hous. L. Rev. 149, 180 (1992)\i0 \' 5Bhereinafter Double Helix\'5D (\'22The strongest case for a warning exists whe n there is a high likelihood that the relative has the genetic defect, the defe ct presents a serious risk to the relative and his or her children, and presuma bly the disclosure is necessary to prevent serious harm.\'22). \par
\par
----------End Footnotes----------
\par\par
This conflict between protecting the integrity of physician-patient confiden tiality and protecting at-risk third parties lies at the core of many medical-l egal conflicts. n7 For example, since the turn of the century, physicians treat ing patients for communicable diseases, such as tuberculosis, have had to decid e whether the interest of third parties (or the public at large) to be warned o f a risk of infection or harm from the disease supersedes the duty to maintain the confidentiality of the patient's information for the patient. n8 \'5B*249 \'5D Although respect for a patient's privacy generally compels doctors to re frain from sharing medical information with anyone uninvolved with the patient' s care, the physician must notify health officials when innocent third parties are at risk of certain diseases. n9 Recently, physicians who treat HIV-positive individuals have faced this conflict because they now may notify at-risk partn ers or contacts (i.e., intravenous drug users with whom the individual has shar ed needles) if the patient does not. n10 In the near future, genetic test resul ts may create another exception to physician-patient confidentiality because of their potentially valuable use to close patient relatives. n11\par
\par
----------Footnotes----------
\par\par
n7. See \i id. at 176\i0 (\'22A major exception to confidentiality, however , should be noted. A physician may, in certain instances, breach confidentialit y in order to protect third parties from harm, such as when the patient might t ransmit a contagious disease or commit violence against an identifiable individ ual.\'22); see generally Friedland, supra note 4 (examining the numerous circum stances where conflict arises between the legal and ethical obligations of phys

icians to protect the confidentiality of patients' information and the potentia
l benefit to third parties if such information is made available to them). \pa
r\par
n8. See Susan Fox Buchanan, Medical Ethics at the Millennium: A Brief Retros
pective, 26 Colo. Law. 141, 142 (1997) (\'22Urbanization in the late nineteenth
and early twentieth centuries led to a growing concern with public health and
epidemics in many American new cities .... Confidentiality had been tempered by
the exigencies of contagious disease.\'22); Philip R. Reilly, Public Policy an
d Legal Issues Raised by Advances in Genetic Screening and Testing, \i 27 Suffo
lk U.L. Rev. 1327, 1334-35 (1993)\i0 (comparing genetic privacy considerations
with those of HIV information; there, individual privacy rights often outweigh
disclosure to third parties with strong interest in information). \par\par
n9. See infra note 95 and accompanying text. \par\par
n10. See infra note 99 and accompanying text. \par\par
n11. See Sonia M. Suter, Whose Genes Are Those Anyway? Familial Conflicts Ov
er Access to Genetic Information, \i 91 Mich. L. Rev. 1854, 1854-55 (1993)\i0
(\'22The identification of disease genes has escalated dramatically .... Confli
cts of interest may arise between an individual and her relatives, who may pers
onally benefit from learning about the individual's genetic status.\'22); Genet
ics in the Courtroom: An Introduction, 36 No. 3 Judges' J. 1 (1997) (recognizin
g that genetic discoveries promise to introduce new types of evidence, causes o
f action and perspectives into courtrooms); Andrews, Double Helix supra note 6,
at 177. \par\par
\par
\par
One can make an argument that health care professionals working in the medical
genetics field have disclosure obligations similar to those of the physician w
hose patient suffers from an infectious disease or a psychotherapist whose pati
ent is a \'5Bsic\'5D potentially violent. Because of the inheritable nature of
genetic diseases, a health professional who, through research, counseling, exam
ination, testing, or treatment, gains knowledge about an individual's genetic s
tatus invariably has information valuable not only to the patient, but also to
his or her spouse or relatives. \par\par
\par
\par
Id. \par
\par
----------End Footnotes----------
- \par\par
Although genetic testing has existed for many years, n12 scientists are pres
ently attempting to identify the patterns created by all human genes. n13 Resea
rchers are linking these patterns with inher \'5B*250\'5D ited traits, disea
se, and even an individual's susceptibility to common adult-onset disease. n14
So far, genetic mutations have been identified and linked to several diseases,
such as Alzheimer's, various cancers, and Lou Gehrig's Disease. n15 Genetic tes
ting is frequently used in prenatal testing and will increasingly become availa
ble to the public as part of routine health care. n16\par
\par
----------Footnotes----------
- \par\par
n12. See Roger B. Dworkin, Limits: The Role of Law in Bioethical Decision Ma
king 85 (1996) (noting that since the 1953 discovery of DNA's structure, geneti
c screening, counseling, and prenatal diagnosis have become established in med
ical practices). \par\par

n13. Genes are the functional units of DNA that combine into various patterns and lead to different appearances and behaviors, or phenotypes, of cells. See Leroy Hood & Lee Rowen, Genes, Genomes, and Society, in Genetic Secrets 4 (Mark A. Rothstein ed., 1997); U.S. Congress, Office of Technology Assessment, Technologies for Detecting Heritable Mutations in Human Beings 6 (1986) (describing the human genome, which is the complete set of genetic information - each cell of the human body contains forty-six chromosomes, where groups of genes are arranged in sequence to form DNA and proteins). \par\par

n14. Adult-onset, or late-onset diseases are those that are present in an individual's DNA since conception, but do not manifest themselves until adult life. See Wendy C. McKinnon et al., Predisposition Genetic Testing for Late-Onset Disorders in Adults: A Position Paper of the National Society of Genetic Counselors, \i 278 JAMA 1217, 1217 (1997);\i0 Office of Technology Assessment supra note 13, at 30. \par\par

n15. See Michael J. Malinowski & Robin J.R. Blatt, Commercialization of Genetic Testing Services: The FDA, Market Forces, and Biological Tarot Cards, \i 71 Tul. L. Rev. 1211, 1224 (1997)\i0 (\'22Recent discoveries include genetic links to Alzheimer's, bladder cancer, cervical cancer, colon cancer, obesity, prostate cancer, and tumor growth associated with a spectrum of common cancers. Researchers are even developing an 'Ides of March' genetic test to serve as a crude indicator of a person's life span.\'22); Julie Holland, Should Parents be Permitted to Authorize Genetic Testing for their Children? \i 31 Fam. L. Q. 321, 324 (1997).\i0 \par\par

n16. See John Bell, Prenatal Diagnosis: Current Status and Future Trends, in Human Genetic Information: Science, Law and Ethics, Symposium on Human Genetic Information; Ciba Foundation Symposium 18, 19 (1992). \par\par

\par

\par

Genetic Screening, as it is currently applied, relates mostly to the prenatal diagnosis of the major monogenic disorders ... a number of technological advances ... will introduce the possibility of effectively screening for many common diseases. In turn, this will alter both the populations needing to be screened and the potential interventions that follow such screening procedures. \par\par

\par

\par

Id.; Benjamin S. Wilfond & Kathleen Nolan, National Policy Development for the Clinical Application of Genetic Diagnostic Technologies: Lessons from Cystic Fibrosis, \i 270 JAMA 2948, 2949 (1993)\i0 (\'22It may ... seem inevitable that virtually every test that is technically feasible will be routinely used. Commercial interests may promote testing; clinicians may use tests to allay fears of legal liability; and patients themselves may demand testing to obtain genetic information.\'22). \par

\par

----------End Footnotes----------\par\par

BRCA1 n17 and BRCA2 n18 are recently discovered genetic mutations that signal that their carriers face a risk of developing breast and ovarian cancer that is significantly higher than the risk the average woman faces. n19 As more women become aware of the BRCA mutations, there will be an increased demand for BRCA \'5B*251\'5D testing. n20 Accordingly, physicians will more frequently face the dilemma of whether to notify family members of their increased risk of developing cancer due to their genetic makeup. Geneticists, however, have been unable to decide whether genetic information should be disclosed to relatives bec

ause information has the potential for both great benefit and harm to its recip
ients. n21 Therefore, a balancing test is needed to govern the release of genet
ic data. n22\par
\par
----------Footnotes----------
\par\par
n17. See infra note 35 and accompanying text. \par\par
n18. See infra note 36 and accompanying text. \par\par
n19. See Wylie Burke, Recommendations for Follow-up Care of Individuals With
an Inherited Predisposition to Cancer: II. BRCA1 and BRCA2, \i 277 JAMA 997, 9
98 (1997)\i0 \'5Bhereinafter Recommendations II\'5D. Although BRCA1 is associa
ted with a six percent lifetime risk of colon cancer in women and men, and an e
ight percent lifetime risk of prostate cancer in men, both BRCA1 and BRCA2 are
blamed for significant increases in breast cancer, a disease most commonly expe
rienced by women, and ovarian cancer, a disease exclusively experienced by wome
n. See id. See infra notes 35 and 36 and accompanying text. Because I concentra
te on breast and ovarian cancers, I will use \'22patient\'22 to refer to female
s throughout the Note. \par\par
n20. See Nancy Press et al., How are Jewish Women Different From All Other W
omen?, 7 Health Matrix 135, 159 (1997). \par\par
\par
\par
We suggest that there is an implicit belief in the contemporary United States
that a probability statistic, accurately calculated and named, can eliminate it
s own most essential element - uncertainty. This belief makes Americans see ris
k information as inherently useful and may be one of the reasons there is often
insufficient attention paid to gaps between diagnostic sophistication and trea
tment options. This is particularly relevant in the case of genetic susceptibil
ity testing for breast cancer because this belief may drive both clinicians and
test consumers to opt for genetic testing even in the absence of proven effica
cy of treatment sequelae. \par
\par
Id. \par\par
n21. See Dorothy C. Wertz, Society and the Not-So-New Genetics: What are We
Afraid of? Some Future Predictions from a Social Scientist, 13 J. Contemp. Heal
th L. & Pol'y 299, 312 (1997) (\'22Whether or not to inform a patient's relativ
es that they may be at a genetic risk, against the wishes of that patient, was
one of the questions geneticists found most difficult to answer. There was no c
onsensus on this issue anywhere in the world.\'22). \par\par
n22. Although legislation is forward-looking, and a balancing test would be
used by a court after harm has occurred, solutions that succeed today will like
ly prove unworkable for a long term in the realm of rapid advances in genetic
technology. Therefore, physicians could consider factors in the balancing test
to determine whether or not to disclose genetic information. See Dworkin, supra
note 12, at 12 (\'22Changing values, advances in science, and unanticipated si
tuations combine to create the possibility that prospective, comprehensive lawm
aking will be fundamentally flawed.\'22). \par
\par
----------End Footnotes----------
\par\par
This Note focuses on the BRCA gene mutations and argues that physicians curr
ently have no duty to warn the children n23 of a known BRCA carrier, who has be
en diagnosed with breast or ovarian cancer, that they also may carry the BRCA m
utations that predispose them to cancer. Part I provides a background of curren

t genetic research and testing, including the significance of testing positive for BRCA1 or BRCA2, and the future of BRCA testing. Part II reviews current legislation regulating the dissemination of genetic information, existing exceptions to physician-patient confidentiality, and recent court decisions regarding the physician's duty \'5B*252\'5D to warn family members of genetic disease. Part III proposes a balancing test which should be used to determine whether a physician is required to notify a patient's children if she tests positive for a BRCA mutation. This test allows the physician's duty to warn to adapt to changes in professional education, cancer prevention, and legislation. This Note concludes that application of the balancing test to BRCA mutations under current conditions indicates that physicians should keep their patients' genetic information confidential because of the substantial harm posed by its release.\par

\par
----------Footnotes----------
\par\par
n23. Throughout this Note, references to a patient's children mean adult offspring. Warning minor children about the possibility that they may inherit genetically linked diseases raises numerous complex ethical issues that merit their own separate discussion. For an excellent overview of these issues, see Dorothy C. Wertz et al., Genetic testing for children and adolescents: who decides?, \i 272 JAMA 875 (1994);\i0 see also Holland, supra note 15. \par\par
\par
\par
----------End Footnotes----------
\par\par
I. A Background of Genetic Research\par
\par
A brief overview of recent genetic research and advances in biotechnology will illuminate areas where new exceptions in the confidential nature of the physician-patient relationship may be permitted. This Part reviews the developments in genetic research, particularly with respect to the BRCA1 and BRCA2 mutations.
\par\par
A. The Human Genome Project\par
\par
The Human Genome Project (\'22HGP\'22) is an international research effort designed to locate and map out all human genes, collectively known as the human genome. n24 Once the human genome is completely sequenced, scientists will have a \'22virtual instruction book\'22 for a human being. n25 Genetic information details an individual's behavioral and biological traits, and diagnoses and reveals \'5B*253\'5D predispositions to certain diseases. n26 The government, therefore, has recognized that many moral, ethical, and legal issues arising out of genetic research must be addressed in the near future. n27\par
\par
----------Footnotes----------
\par\par
n24. Hearings on the National Genome Research Institute, 105th Cong. (1997) \'5Bhereinafter Hearings on NHGRI\'5D (Testimony of Francis S. Collins, Director of the National Human Genome Research Institute) (\'22NHGRI\'22). In the United States, the project is carried out by the NHGRI and the Department of Energy. The NHGRI, which was established in 1989, funds research laboratories throughout the United States and also has its own in-house laboratories. The HGP researchers intend to sequence all human genes by the year 2005, and at the present time, have mapped out about two percent of human DNA. See Human Genome Project

Information (visited Nov. 14, 1997) <http://www.ornl.gov/TechResources/Human Genome/genetics.html> (estimating that about 5800 genes have been mapped to date). \par\par

n25. See Hearings on NHGRI, supra note 24. As researchers identify gene patterns and mutations of those patterns, they also hope to determine what role environmental influences may play in conjunction with inherited factors in the development of disease. With this information, scientists may reveal modes of preventing such diseases as cancer, heart disease and diabetes that do not yet exist. See id.; see also Eugene B. Brody, Biomedical Technology and Human Rights 129 (1993) (\'22A detailed chart of the genes is essential to ultimate progress in understanding the biology of living organisms and, specifically, to the clinical biotechnology aimed at the prevention and cure of genetic disease.\'22). \par\par

n26. McKinnon et al., supra note 14, at 1217 (noting that genetic tests which have, in the past, detected rare monogenic conditions, can now identify susceptibility to many complex, adult-onset diseases). \par\par

n27. See F. Collins & D. Galas, A new five-year plan for the U.S. Human Genome Project, 262 Science 43 (1993) (noting that the Department of Energy and the National Institute of Health devote three to five percent of their annual budgets towards ELSI, the world's biggest bioethics program). \par

\par

----------End Footnotes----------

\par\par

In an effort to identify and confront these questions, the National Human Genome Research Institute (\'22NHGRI\'22) created and funded the Ethical, Legal, and Social Implications Program (\'22ELSI\'22). n28 ELSI's priorities include ensuring privacy and fair use of genetic information, promoting responsible clinical integration of genetic technologies, addressing ethical issues in research, and educating professionals and the public about genetic issues. n29 The stated goals of ELSI are to identify issues resulting from genetic research and develop policies to address these issues. n30 The program also seeks to foster an acceptance of genetic variation, and to increase public and professional awareness of genetic testing and the appropriate use of test results. n31\par

\par

----------Footnotes----------

\par\par

n28. Id. \par\par

n29. See Hearings on NHGRI, supra note 24. Responding to the recommendations of the ELSI group and to the National Action Plan on Breast Cancer, President Clinton has stated that his administration will support legislation designed to prevent discrimination by insurance companies on the basis of genetic information. See id. \par\par

n30. See Francis S. Collins, Preparing Health Professionals for the Genetic Revolution, \i 278 JAMA 1285, 1285 (1997)\i0 \'5Bhereinafter Revolution\'5D. \par\par

n31. Commentators have expressed great concern about physicians anxious to provide genetic testing to their patients and about the public demanding testing before providers are adequately educated about interpreting test results and are trained to provide sufficient counseling and support for their patients. See Malinowski & Blatt, supra note 15, at 1245-1246. \par\par

\par

\par

Due to the absence of clinical data, health care providers cannot interpret the results of predictive genetic tests for most of their patients with any relia

bility even when they are knowledgeable about genetics. This interpretation pro
blem is exacerbated because the current generation of health care providers doe
s not possess such knowledge. \par\par
\par
\par
Id. \par
\par
----------End Footnotes----------
- \par\par
In addition to mapping normal gene patterns, the process of identifying gene
s and their components, called nucleotides, n32 also \'5B*254\'5D reveals m
utations in sequences that contribute to disease. n33 The ability to identify p
atterns associated with disease may enable scientists to develop treatments and
cures. n34 Some incurable diseases, such as cystic fibrosis, Huntington's Dise
ase, and Tay-Sachs, are caused by mutations in one chromosome, and thus the pro
bability that offspring will inherit these conditions can be accurately determi
ned. n35 Other diseases, such as breast and ovarian cancer, insulin-dependent d
iabetes, and coronary artery disease, develop if certain genetic mutations exis
t in combination with environmental factors that have not yet been identified.
n36 Therefore, \'5B*255\'5D the discovery of these mutations only signals a
n individual's potential for disease and does not guarantee its development. Mo
reover, the predictive value of many tests that identify predisposition to dise
ase is currently undetermined due to a dearth of data about the complex nature
of these gene mutations. n37\par
\par
----------Footnotes----------
- \par\par
n32. Nucleotides are the building blocks of genes. There are four different
components which bind together in pairs to form triplet formations called codon
s, which make up amino acids, the components of proteins. See Office of Technol
ogy Assessment supra note 13, at 6. When a mutation occurs, one nucleotide subs
titutes another in its place and creates a different protein. See id. \par\par

n33. See Hood & Rowen, supra note 13, at 8-9 (noting that alterations in gen
e patterns in chromosomes, known as polymorphisms, can identify genes that pred
ispose to disease). \par\par
n34. See Collins, Revolution supra note 30, at 1285. \par\par
\par
\par
Knowledge of basic biological alterations underlying illnesses also offers the
best hope for strategies to override or repair them. Promising gene- based str
ategies include drug therapy, which is used to nurture defective proteins, and
gene therapy, in which the gene is used as a pharmaceutical. Gene discovery als
o allows elucidation of interactions between genes and between genes and the en
vironment. \par\par
\par
\par
Id.; Reilly, supra note 8, at 1327-28. The human genome is organized as approx
imately one hundred pairs of genes patterned on twenty-three pairs of chromosom
es. About three billion nucleotides, the building blocks of DNA, encode the gen
es which instruct cells to produce proteins that carry out cell processes and d
irect our bodily functions. Mutations in the genes can create disease by sendin
g cells \'22wrong\'22 information. See id. Scientists are able to locate the mu
tations in genes, replicate the patterns, splice in desired arrangements, and i

ntroduce these into cells to correct errors resulting in some diseases. See id. Current research may allow scientists to develop this gene therapy for more mutations and make available treatment that will attack diseases in a manner that is more effective and less destructive to the body. See William J. Polvino & W. French Anderson, Medicine, Gene Therapy, and Society, in The Human Genome Project and the Future of Health Care 39, 40-42 (Thomas H. Murray et al. eds., 1996). \par\par

n35. See Paul M. Schwartz, Privacy and the Economics of Personal Health Care Information, \i 76 Tex. L. Rev. 1, 19 (1997)\i0 (\'22Such monogenic diseases, which affect only a tiny fraction of the population, can now be effectively predicted, although not cured.\'22). While Huntington's Disease results from a dominant gene and can be passed on from one parent, cystic fibrosis is caused by a recessive gene and is only manifest when both parents are carriers of the trait. See Robert Williamson & Anna M. Kessling, The Problem of Polygenic Disease, in Human Genetic Information: Science, Law and Ethics 63 (Ciba Foundation 1990). \par\par

n36. Carson Strong, Ethics in Reproductive and Perinatal Medicine 136 (1997). While certain genetic mutations determine that a person will develop a disease, such as Huntington's Disease, cystic fibrosis and hemophilia, other mutations are multifactorial, meaning that only in combination with other external factors, such as environmental influences, will a particular disease develop. See id. Accordingly, these mutations determine that their carriers are susceptible to certain diseases, but cannot conclusively predict their development. Before scientists can discover preventive measures with which to deter the onset of these conditions, the external factors which contribute to disease must also be ascertained. See id. \par\par

n37. See infra notes 138-139 and accompanying text. \par

\par

----------End Footnotes----------

\par\par

B. The BRCA Gene Mutations\par

\par

Both the BRCA1 and BRCA2 genetic mutations, identified in 1994 n38 and 1995 n39 respectively, are associated with breast and ovarian cancer. n40 Studies show that women carrying one of these mutations, whose families have a history of breast or ovarian cancer, face a seventy-six to eighty-seven percent risk of developing breast cancer, and a thirty-two to eighty-seven percent risk of developing ovarian cancer during their lifetimes. n41 Women in the general population, without either genetic mutation, face approximately a twelve percent risk of breast cancer and a one and a half percent chance of developing ovarian cancer during their lifetimes. n42 While \'5B*256\'5D only five to ten percent of all cases of breast cancer are attributed to the BRCA mutations, n43 a woman carrying one of these mutations is twenty times more likely than a woman without the mutations to develop breast cancer before the age of fifty. n44\par

\par

----------Footnotes----------

\par\par

n38. See Georgia L. Wiesner, Clinical Implications of BRCA1 Genetic Testing for Ashkenazi Jewish Women, 7 Health Matrix 3, 21-22 (1997) (\'22The BRCA1 gene is a large, novel gene of unknown function that extends over 100,000 bases of genomic DNA .... Early studies of breast tumors showed that the BRCA1 region was frequently deleted in approximately twenty percent of breast tumors during the process of tumorigenesis thereby indicating that it may function as a tumor suppressor gene.\'22). BRCA1 increases a woman's risk for both breast and ovaria

n cancer. Carriers who have had breast cancer also have a forty-four percent ch
ance of developing ovarian cancer by the age of seventy. See Burke et al., supr
a note 19, at 998. This mutation is also associated with prostate cancer in men
and colon cancer in both men and women. See id. \par\par
n39. Breast Cancer (Genetics): Full Sequence of BRCA2 Cancer Gene Published,
Cancer Biotechnology Wkly, Mar. 18, 1996 (\'22BRCA2 is believed to be responsi
ble for approximately 40 percent of early-onset, hereditary breast cancer.\'22)
; Wiesner, supra note 38, at 23 (\'22BRCA2 is associated with pre-menopausal fe
male and male breast cancer.\'22). \par\par
n40. See Burke et al., supra note 19, at 998. The BRCA2 mutation creates a s
imilar risk for breast cancer in women as BRCA1. See id. Researchers have obser
ved several cases of breast cancer in males carrying the BRCA2 mutation, with o
ne pedigree of the mutation linked to multiple cases of male breast cancer and
none in females. See id. The risk for ovarian cancer is increased to a lesser e
xtent for women carrying BRCA2 than for those with BRCA1. See id. \par\par
n41. See Wiesner, supra note 38, at 21 (stating that cumulative breast cance
r risk for BRCA1 carriers is about 50% by age 50 and 85% by age seventy while r
isk for ovarian cancer is 30-40% by age sixty); Jeffrey Struewing et al., The R
isk of Cancer Associated with Specific Mutations of BRCA1 and BRCA2 Among Ashke
nazi Jews, \i 336 New Eng. J. Med. 1401, 1401 (1997).\i0 \par\par
n42. See Deborah Schrag et al., Decision Analysis - Effects of Prophylactic
Mastectomy and Oophorectomy on Life Expectancy Among Women with BRCA1 or BRCA2
Mutations, \i 336 New Eng. J. Med. 1465, 1465 (1997).\i0 \par\par
n43. See Wiesner, supra note 38, at 15. \par\par
n44. See Burke et al., Recommendations II, supra note 19, at 997, 999. \par

\par
----------End Footnotes----------
- \par\par
C. Advantages of Undergoing Testing for the BRCAMutations\par
\par
Women identified as BRCA mutation carriers may take advantage of several sugge
sted measures that may prevent the onset of, or increase the chances of survivi
ng, breast or ovarian cancer. n45 These preventive steps range from simple diet
ary or activity changes to surgical intervention. n46 Low-fat, high-fiber diets
, regular exercise, and the avoidance of smoking may decrease the incidence of
breast cancer. n47 Because early detection greatly increases the chances of sur
viving breast cancer, women are encouraged to perform regular breast self-exams
to monitor for any changes in breast tissue. n48\par
\par
----------Footnotes----------
- \par\par
n45. See Jerome Groopman, Decoding Destiny, The New Yorker, Feb. 9, 1998, at
44 (stating that measures to prevent cancer range from avoiding alcohol and fa
ts, drinking herbal tonics, and taking megavitamins, to the removal of breasts
and ovaries). \par\par
n46. See id. \par\par
n47. See Wylie Burke et al., Recommendations for Follow-up Care of Individua
ls With an Inherited Predisposition to Cancer; I. Hereditary Nonpolyposis Colon
Cancer, \i 277 JAMA 915, 918 (1997)\i0 (emphasizing that lifestyle changes ha
ve not been proven effective, but may decrease risk of cancer for those with in
herited predisposition to cancer). \par\par
n48. See Burke, Recommendations II, supra note 19, at 998-99 (\'22The limite
d sensitivity of mammography, particularly in younger women, makes self-examina

tion potentially of greater value for BRCA1 and BRCA2 mutation carriers than fo
r women of average risk.\'22). \par
\par
----------End Footnotes----------
- \par\par
A health care provider also may perform breast exams during annual check-ups
and monitor for any tumorous growths through regular mammograms. n49 Women wit
h a family history of breast cancer are encouraged to have a baseline mammogram
when they reach the age of twenty-five, followed by routinely scheduled mammog
rams throughout the remainder of their lives. n50 Although drugs have been prop
osed as agents to help prevent breast cancer, n51 their efficacy is unproven, a
nd more research is necessary \'5B*257\'5D before this strategy is routinel
y implemented. n52 At the extreme, women at high risk for breast cancer may eve
n opt to undergo a prophylactic mastectomy. n53\par
\par
----------Footnotes----------
- \par\par
n49. See id. \par\par
n50. See id. at 999 (warning that, although early testing is recommended for
women at high risk of breast cancer, risks and benefits of mammography before
age fifty have not yet been established). \par\par
n51. See id. at 1001. \par
\par
Oral contraceptives may provide a means to reduce ovarian cancer risk. In addi
tion, ... tamoxifen\'5B \'5D has been shown to reduce rates of recurrent and co
ntralateral breast cancer, suggesting a role for this agent in primary preventi
on ... \'5Bbut it\'5D has been shown to increase endometrial cancer risk, cause
bone marrow suppression, promote thrombotic events, and produce an array of ot
her unpleasant adverse effects. \par\par
\par
\par
Id. See also Mendel E. Singer & Randall D. Cebul, BRCA1: To Test or Not to Tes
t, That is the Question, 7 Health Matrix 163, 182 (1997). \par\par
n52. See Joyce O'Shaughnessy, Chemoprevention of Breast Cancer, \i 275 JAMA
1349, 1353 (1996)\i0 (citing the identification of breast cancer susceptibilit
y genes and improved diagnostic tools for breast lesions as highlighting the ne
ed to develop effective intervention strategies against breast cancer). Because
there are more opportunities for women to recognize their increased risk for b
reast cancer, there is a greater push for scientists to develop pharmaceutical
agents that may help prevent the development of the disease. See id. While such
research is in progress today, much more must be conducted before drug therapy
is readily available to those at risk. See \i id. at 1352-53.\i0 \par\par
n53. A prophylactic mastectomy is the elective removal of one or both breast
s before any sign of tumor formation occurs for the purpose of preventing the o
nset of breast cancer. See Schrag et al., supra note 42, at 1465. If diagnosed
with cancer in one breast, a woman may choose to have her doctor remove both th
e affected and noncancerous breasts, so that she may avoid a recurrence of the
cancer in the healthy breast at some later time. See Diana Keough, Portraits of
Prevention; Women with Family History of Breast Cancer Choose to Have Mastecto
mies, The Plain Dealer, Sept. 1, 1997, at IF. Women from families at high risk
for breast cancer also may decide to have their breasts removed in an effort to
prevent cancer. See id. (\'22Although the procedure has been performed since 1
960 on women with a strong family history of breast cancer--defined as two or m
ore relatives with the disease--the number of procedures has increased since th

e identification of the breast cancer genes ....\'22). See also Schrag et al., supra note 42, at 1469 (\'22Until better methods of cancer prevention are devel oped, women and their physicians are likely to continue to consider the possibi lity and timing of prophylactic mastectomy and oophorectomy.\'22). \par
\par
----------End Footnotes----------
\par\par
Fewer preventive measures exist for ovarian cancer because women diagnosed w ith this disease usually do not exhibit symptoms until it significantly has adv anced. n54 Regular exercise and low-fat \'5B*258\'5D diets may help to prev ent ovarian cancer, n55 but there is no self- exam for physical changes (such a s the presence of lumps), and clinicians frequently do not detect abdominal mas ses before the cancer has spread to other areas of the body. n56 Surveillance f or women at high risk for ovarian cancer, however, includes routine ultrasounds and blood tests that may indicate tumor development. n57 These women also may elect to undergo a prophylactic oophorectomy, or removal of the ovaries. n58 I ndeed, one study shows that roughly one-third of women carrying the BRCA1 mutat ion who have a strong family history of breast or ovarian cancer plan to have t heir ovaries removed to prevent cancer. n59 This option is not available to wom en who wish either to start a family or have \'5B*259\'5D another child, ho wever, because the removal of the ovaries results in menopause. n60\par
\par
----------Footnotes----------
\par\par
n54. See Dennis S. Chi & William J. Hoskins, Ovarian Cancer Controversy: Whe n and How to Use Available Screening Methods (visited Feb. 11, 1998) <http://ww w. medscape.com/Medscape/womens.health/1996/vOl.nl1/wl72.chi/wl72.chi.html#Box1 >. \par\par
\par
\par
While screening is available for breast cancer (breast self-examination, clini cal breast examination, and mammography) and for colorectal cancers (stool test for occult blood and sigmoidoscopy), no effective method has been devised to s creen for ovarian cancer ... unfortunately, early in the course of the disease, patients are either asymptomatic or have nonspecific symptoms, such as abdomin al discomfort, dyspepsia, or urinary frequency, which may go unrecognized by bo th the patient and her physician for prolonged periods of time. Therefore, appr oximately 70% of patients present with advanced ... stage disease. \par\par
\par
\par
Id. \par\par
n55. See Burke et al., Recommendations II, supra note 19, at 1001 (\'22Dieta ry and exercise measures are an unproven means to reduce cancer risk, but have a broad range of other health benefits and do not pose the risks of pharmacolog ical or procedural interventions.\'22). \par\par
n56. See Chi & Hoskins, supra note 53. \par\par
\par
\par
The normal ovary is usually not palpable in postmenopausal women. Unfortunatel y, given the natural history of ovarian cancer, it has been estimated that one must perform more than 10,000 routine pelvic exams to detect 1 case of ovarian cancer ... such reports demonstrate that pelvic examination is too insensitive to serve as the sole screening method to detect curable stages of ovarian cance r. \par\par

\par
\par
Id. \par\par
n57. See id. (\'22Prospective trials have provided data supporting the use o
f serum tumor markers \'5Bfound in the blood\'5D and sonography in ovarian canc
er screening for at-risk patients.\'22). \par\par
n58. See Schrag et al., supra note 42, at 1470 (\'22In our analysis, prophyl
actic oophorectomy resulted in, at most, small gains in life expectancy, and p
ostponing oophorectomy until the completion of childbearing reduces its benefit
minimally.\'22). Prophylactic oophorectomy is the elective removal of both ova
ries before any sign of disease is detected. Id. Although this procedure curren
tly provides the best mode of prevention for ovarian cancer, it is not foolproo
f. See Chi & Hoskins, supra note 53. \par
\par
A woman from a family with a hereditary ovarian cancer syndrome should be offe
red the option of prophylactic oophorectomy after childbearing is completed or
by age 35. However, she needs to understand that although prophylactic oophorec
tomy is presently the only effective method of ovarian cancer prevention, there
have been case reports of patients with hereditary ovarian cancer syndromes wh
o have ... subsequently developed \'5Bcancer\'5D. \par\par
\par
\par
Id. \par\par
n59. See Caryn Lerman et al., BRCA1 Testing in Families With Hereditary Brea
st Ovarian Cancer; A Prospective Study of Patient Decision Making and Outcomes,
\i 275 JAMA 1885, 1891 (1996).\i0 When a parent or sibling carries the BRCA1
gene and develops breast or ovarian cancer, other close family members may deci
de to undergo genetic testing so that they can better determine how aggressive
their efforts at preventing the cancer should be. The decision whether or not t
o have breasts or ovaries removed, a measure some may consider quite drastic, m
ay hinge on the presence of genetic factors. Id. (\'22For members of HBOC \'5Bh
ereditary breast and ovarian cancer\'5D families who do not carry a BRCA1 mutat
ion, receipt of a negative test result may prevent unnecessary prophylactic sur
gery.\'22). \par\par
n60. See Burke et al., Recommendations II, supra note 19, at 1001 (\'22Balan
ced against the potential but unproven protective effect of oophorectomy are th
e risks and symptoms of surgical menopause .... Treatment with hormone therapy
to decrease these risks may increase risk of breast cancer.\'22). \par
\par
----------End Footnotes----------
- \par\par
D. The Future of BRCA Testing\par
\par
While significant attention has focused on the advances in genetic research an
d the availability of new genetic tests, there has been little discussion about
the potential harms that can result from testing and the appropriate ways to d
eal with genetic information. n61 Despite the lack of thorough analysis regardi
ng the complex social, ethical, and legal implications of genetic testing, the
demand for and occurrence of testing will continue to rise. n62 Breast cancer r
eceives enormous media attention and has been cited as the most important healt
h concern of American women. n63 As more women with relatives diagnosed with br
east or ovarian \'5B*260\'5D cancer learn about the tests for BRCA mutation
s, more physicians will be asked to provide such screening. n64\par
\par

----------Footnotes----------

- \par\par

n61. See Gail Geller et al., Genetic Testing for Susceptibility to Adult-Ons et Cancer; The Process and Content of Informed Consent, \i 277 JAMA 1467, 1468 (1997)\i0 (stating that professional societies recommend that genetic testing be confined to clinical research due to complex implications of results warran ting special attention for informed consent). Before health practitioners offer genetic testing to their patients, it is important that they are educated abou t interpreting results and the need to provide adequate counseling to ensure th at the decision to learn one's carrier status is fully informed. See also Susan Gilbert, Doctors Often Misread Results of Genetic Tests, Study Finds, N.Y. Tim es, Mar. 26, 1997, at C4. \par\par

n62. See Lerman et al., supra note 58, at 1891 (\'22To the extent that the p ublic is educated about BRCA1 testing and the potential benefits are emphasized , utilization of BRCA1 testing is likely to increase.\'22); Malinowski & Blatt, supra note 15, at 1217- 18 (stating that every person has four or five genetic mutations linked to serious health conditions, and continued research will unc over more links between genes and diseases). \par\par

n63. See Barbara Brotman, Fear of Breast Cancer Exaggerates its Impact, Chi. Trib., Oct. 5, 1997, at 9. Campaigns designed to increase the interest and awa reness of breast cancer have brought the disease to the forefront of public att ention. Sometimes criticized for taking the focus off of other serious threats to the health of American women, the attention paid to breast cancer by newspap ers, magazines and even political leaders has significantly increased concern a bout prevention and desire for early detection of the disease. See id. (\'22Bre asts are also far more visible than, say, lungs, sites of a cancer that kills m ore women than breast cancer. Women can hardly avoid their breasts, especially when public health campaigns have turned morning showers into diagnostic sessio ns.\'22); see also Clintons Promote Cancer Detection: President and Wife Share Radio Address, St. Louis Post-Dispatch, Oct. 26, 1997, at 06A (announcing highe r standards for breast cancer screening); Celebrating Survivorship: Making a Di fference in the Fight Against Breast Cancer, Newsweek, Oct. 13, 1997, at S1 (fi nding that outreach and educational resources for breast cancer encourage women to screen for and prevent cancer). \par\par

n64. See Press et al., supra note 20, at 153. \par\par

\par

\par

We have women, especially young, educated women, who are terrified of breast c ancer and overestimate their own vulnerability to the disease. Their sense of r isk is created and reinforced by media presentations of breast cancer which als o accustoms them to thinking in terms of 'risk factors.' Since many of the most frightened women also may be those with the best access to health care service s, we would suggest that a highly motivated set of consumers exists for anythin g which they believe may reduce their risk of breast cancer. \par\par

\par

\par

Id.; Many People Prefer Not to Know if They Have Gene Linked to Cancers, Cance r Wkly, July 15, 1996 (stating more requests for BRCA1 test results came from s tudy subjects with health insurance, more relatives affected with breast cancer and more knowledge about testing); but see George C. Cunningham, A Public Heal th Perspective on the Control of Predictive Screening for Breast Cancer, 7 Heal th Matrix 31, 47 (1997). \par\par

\par

\par

The media can contribute positively or negatively .... By reporting new discov
eries they raise expectations. By publicizing the commercial availability of te
sts, the media can create a demand for testing. However, by carefully reporting
the limitations of current testing knowledge, they can contribute to informed
participation by the public in the formation of policy. \par\par
\par
\par
Id. \par
\par
----------End Footnotes----------
- \par\par
Physicians soon will find that they have access to these tests, because biot
echnology companies already are marketing BRCA testing kits. n65 Moreover, as t
esting for BRCA mutations becomes more accessible, people likely will use the i
nformation to direct their life decisions, such as where to live, what occupati
on to choose, and whether to have children. n66 There even has been speculation
that women increasingly will ask to include screening for the BRCA mutations i
n their prenatal testing. n67\par
\par
----------Footnotes----------
- \par\par
n65. See Malinowski & Blatt, supra note 15, at 1212-13 (noting that OncorMed
, Genetics & IVF Institute and Myriad have begun marketing tests for the BRCA g
enes and other community and academic laboratories are introducing their own te
sts for genetic disorders to assess future disease risk). \par\par
n66. See Lori Andrews, Body Science: As Medical Research Unlocks the Secrets
of Genetics, the Battle Over Who Can Have Access to your Personal Life Story i
s Just Getting Under Way in Courts and Legislatures, \i 83 ABA Journal 44, 45 (
1997)\i0 (\'22People are starting to use genetic information to measure the co
nsequences of major life decisions.\'22). \par\par
n67. See Johnathon M. Lancaster et al., An Inevitable Dilemma: Prenatal Test
ing for mutations in the BRCA1 Breast-Ovarian Cancer Susceptibility Gene, 87 Ob
stetrics & Gynecology 306, 306 (1996). \par
\par
----------End Footnotes----------
- \par\par
\'5B*261\'5D \par\par
II. Genetics and the Law \par\par
A. Legislation Affecting the Dissemination\par
ofGeneticInformation\par
\par
Legislation addressing the use of genetic information is inadequate to deal wi
th the recent advances in biotechnology. Several laws attempt to protect indivi
duals from discrimination based on their genetic make-up, but the rights of the
family to a close relative's genetic information largely are left untouched. S
ome argue that the absence of regulation is appropriate and that medical ethics
issues are best dealt with by means other than legislation. n68 However, laws
intended to prevent discrimination directly affect the physicians' duty to war
n their patients' children of genetic disease. When disclosure of genetic infor
mation no longer threatens to subject its patients to discrimination by insurer
s and employers, a physician will sooner be required to share it with patients'
children.\par
\par
----------Footnotes----------

- \par\par
n68. See Dworkin, supra note 12, at 12. \par\par
\par
\par
Legislators are not oracles. They have no more ability to predict scientific a
nd technological developments than anybody else .... Those limitations also rai
se questions about the desirability of prospective lawmaking. While preventing
harm is more attractive than cleaning up after harm has occurred, the inability
to foretell the future or to envision every possible scenario suggests that ad
vance solutions may turn out to be unwise or even counter-\par
productive. \par\par
\par
\par
Id. \par
\par
----------End Footnotes----------
- \par\par
1. Federal Legislation\par
\par
Congress has attempted to protect those who have undergone genetic testing fro
m discrimination by both insurers and employers. The Health Insurance Portabili
ty and Accountability Act of 1996 n69 (\'22HIPAA\'22) prohibits group health in
surance plans from determining clients' eligibility and preexisting conditions
based on genetic information. n70 HIPAA, however, does not protect those who mu
st purchase individual insurance policies n71 and does not prohibit in \'5B*26
2\'5D surers from requiring prospective clients to undergo genetic testing or
disclose past test results. Under these circumstances, it would be difficult t
o prove that insurers used the information to discriminate against clients. n72
In addition, insurers still may increase policy rates and even deny coverage o
f specified procedures and treatments, such as prophylactic mastectomies or oop
horectomies. n73\par
\par
----------Footnotes----------
- \par\par
n69. Pub. L. No. 104-191, 5701, 110 Stat. 1936 (1996) (as codified at \i 29
U.S.C.A. 1181\i0 (Supp. 1998)). \par\par
n70. HIPAA also prohibits insurers from finding preexisting conditions from
genetic information \'22in the absence of a diagnosis of the condition related
to such information.\'22 Id. \par\par
n71. See id. \par\par
\par
\par
(a) Limitation on preexisting condition exclusion period; crediting for perio
ds of previous coverage ... a group health plan, and a health insurance officer
offering group health insurance coverage, may, with respect to a participant o
r beneficiary, impose a preexisting condition exclusion only if - (1) such excl
usion related to a condition ... for which medical advice, diagnosis, care, or
treatment was recommended or received within the 6 month period ending on the e
nrollment date ... (B) ... genetic information shall not be treated as a condit
ion described in subsection (a)(1) of this section in the absence of a diagnosi
s of the condition related to such information. \par\par
\par
\par
Id. \par\par

n72. See id.; see also Karen H. Rothenberg, Breast Cancer, The Genetic \'22Q uick Fix,\'22 And The Jewish Community: Ethical, Legal, and Social Challenges, 7 Health Matrix 97, 112 (1997) (noting the inadequacies of the Act to protect i ndividuals). \par\par

n73. See Rothenberg, supra note 71, at 112 (\'22Nor does it prevent a plan f rom increasing rates, excluding all coverage for a particular condition, or imp osing lifetime caps on all benefits or on specific benefits ... Absent other co ntractual and legal protections, plans could specifically exclude, for example, prophylactic surgery.\'22). \par

\par

----------End Footnotes----------

\par\par

Federal law addresses employment discrimination with the Americans with Disa bilities Act (\'22ADA\'22). n74 The ADA prohibits employers from denying employ ment on the basis of an individual's disability, n75 and requires that employer s provide reasonable accommodations in the workplace for those employees. n76 T he critical question is whether a predisposition to disease, or the diagnosis o f a condition without accompanying symptoms, constitutes a disability under the ADA. This issue currently is dividing the courts, n77 and until the United Sta tes Supreme Court rules on it, the ADA may not adequately protect individuals s usceptible to genetic disease from employment discrimination.\par

\par

----------Footnotes----------

\par\par

n74. See \i 42 U.S.C.A. 12101\i0 et seq. \par\par

n75. See \i 42 U.S.C.A. 12112\i0 (a) (\'22No covered entity shall discrimina te against a qualified individual with a disability because of the disability o f such individual in regard to job application processes, the hiring, advanceme nt, or discharge of employees, employee compensation, job training, and other t erms ....\'22). See also Mark A. Rothstein, Genetic Discrimination in Employmen t and the Americans with Disabilities Act, \i 29 Hous. L. Rev. 23, 52-68 (1992) \i0 (noting that the Act limits an employer's pre- employment inquiries to an applicant's ability to perform work-related duties). \par\par

n76. See \i 42 U.S.C.A. 12112\i0 (b)(5). See \i Abbott v. Bragdon, 107 F.3d 934 (1st Cir. 1997)\i0 (holding that HIV-positive status comprises physical im pairment under the ADA), cert. granted, \i 118 S. Ct. 554\i0 (Nov. 26, 1997). \par\par

n77. Compare \i Reichle v. Walsh Offshore, Inc., 1997 WL 728104\i0 (E.D. La . Nov. 20, 1997) (refusing to find HIV-positive employee terminated from job fo r unexcused absence physically impaired within definition of the ADA where no s ymptoms exhibited) with \i Hernandez v. Prudential Ins. Co. of America, 977 F.S upp. 1160 (M.D. Fla. 1997)\i0 (holding that HIV-positive employee had physical impairment that substantially limited major life activities of reproduction an d caring for himself, and was disabled within the meaning of the ADA). \par

\par

----------End Footnotes----------

\par\par

\'5B*263\'5D \par\par

2. State Legislation\par

\par

Roughly half of the states have enacted legislation designed to protect the pr ivacy of genetic information and to deter discrimination based on such informat ion. n78 Many states, for example, have legislation which combines protection a gainst discrimination with protection for the genetic privacy of both individua

ls and their families. n79 While these statutes are helpful, the range of their protection is restricted by the Employee Retirement Income Security Act (\'22ERISA\'22). n80 By exempting insurance policies provided by employers from the reach of state regulation, ERISA keeps more than one-third of the non-elderly insured out of the reach of state anti- discrimination and genetic privacy laws. n81 Therefore, despite the efforts of states to address the important issues generated by advances in genetic technology, ERISA prevents states from providing universal protection to their citizens.\par
\par
----------Footnotes----------\par\par
n78. See Robert Pear, States Pass Laws to Regulate Uses of Genetic Testing, N.Y. Times, Oct. 18, 1997, at A1 (\'22Concerned that the Federal Government is acting too slowly to protect the confidentiality of genetic information, states are passing their own laws to regulate the use of genetic test results to prevent discrimination by insurers and employers .... At least 26 states have adopted such laws.\'22). \par\par
n79. Cal. Ins. Code 10146 (West 1997) (requiring strict confidentiality of genetic information and establishing standards regarding unfair discrimination based on genetic information); C.R.S.A. 10-3-1104.7 (1)(c) (1997) (\'22To protect individual privacy and to preserve individual autonomy with regard to the individual's genetic information, it is appropriate to limit the use and availability of genetic information.\'22); GA. ST. 33-54-1 (1997) (limiting use and availability of genetic information to prevent insurance companies from denying access on basis of genetic information); N.J.S.A. 10:5-44 (1997) (requiring individual authorization to collect, retain, or disclose genetic information). \par\par
n80. \i 29 U.S.C.A. 1001\i0 -1461 (1988). \par\par
n81. See Rothenberg, supra note 71, at 109-10 (noting that ERISA exempts self- funded plans from state insurance laws and that more people will be affected by this exemption as more employers are likely to turn to self-funded plans in the future). \par
\par
----------End Footnotes----------\par\par
3. Proposed Federal Legislation\par
\par
Legislators recently have introduced several bills in Congress that protect individuals from discrimination based on genetic information and ensure that genetic information is kept private. n82 Only \'5B*264\'5D one bill, however, specifically addresses family members' access to genetic information, in addition to the access of insurers and employers. n83 The Medical Privacy in the Age of Technologies Act of 1997 permits health care providers to furnish an inpatient's next of kin or individual representative with protected health information, including genetic test results unless the patient objects to such disclosure. n84 Therefore, physicians would be allowed to notify a patient's family of genetic disease absent an explicit demand from the patient that such information be kept confidential. While this legislation would permit, and not require, a physician to disclose genetic information to a patient's children without her consent, it places the burden on the patient to deny disclosure of the information to her children if she wishes to protect her own privacy. n85\par
\par
----------Footnotes----------\par\par

n82. See, e.g., The Genetic Privacy and Nondiscrimination Act of 1997, H.R. 2198, 105th Cong. (enacted). The proposed act would give the individual undergoing genetic testing the authority to determine who may collect and analyze his DNA, and for what purposes the analysis is to be completed. See id. He may refuse to permit his DNA to be used for research or commercial activities, may inspect and obtain records of the test results, may order the destruction of the DNA, and also may delegate another person to order the destruction of the DNA in the event the tested individual dies. See id. Anyone providing a genetic test would be required to provide specific information to the individual undergoing testing before performing the DNA collection, obtain written authority to carry out the testing from the individual, and abide by instructions given regarding maintenance and destruction of the sample. In addition, the tester would have to restrict access to the genetic information to those authorized by the individual tested to have it. See id. \par\par

n83. See Medical Privacy in the Age of New Technology Act of 1997, H.R. 1815, 105th Cong. \par\par

\par

\par

\'5BA\'5D health care provider ... may disclose protected health information regarding an individual who is an inpatient in a health care facility to the individuals' next of kin, to an individual representative of the individual ... if (1) the individual who is the subject of the information (A) has been notified of the individual's right to object at the time of admission to the facility and has not objected to the disclosure. \par\par

\par

\par

Id. \par\par

n84. See id. \par\par

n85. See id. \par

\par

----------End Footnotes----------

\par\par

B. The Physician-Patient Relationship andConfidentiality\par

\par

An ancient principle requires that physicians keep confidential information they learn about a patient during treatment. n86 The rationale behind this tenet is to protect the privacy of the patient, and to encourage candid sharing of personal information so that the physician may render an accurate diagnosis and effect appropriate treatments. n87 Without an assurance that potentially embarrassing information will be maintained in confidence, those in need of medical advice or treatment may avoid visiting a health care provider until the problem is advanced and difficult, or perhaps impos \'5B*265\'5D sible to treat. n88 Therefore, the trust a patient develops in her health care provider may prove critical for health maintenance.\par

\par

----------Footnotes----------

\par\par

n86. See Buchanan, supra note 8, at 141-42 (reviewing the requirement in medical codes, starting with the Hippocratic Oath, that physicians are sworn to complete confidentiality); See Paul A. Lombardo, Genetic Confidentiality: What's the Big Secret? 3 U. Chi. L. Sch. Roundtable 589, 593 (1996) (\'22This ancient medical principle ... has been included in every physician's oath and code of ethics since Hippocratic times.\'22). See supra note 2 and accompanying text. \par\par

n87. See Friedland, supra note 4 at 256. \par\par
n88. See Elizabeth B. Cooper, Historical and Analytical Overview of Policy I
ssues Affecting Women Living with AIDS: A Blueprint for Learning from Our Past,
72 Bulletin of the New York Academy of Medicine 283, 290 (1995) (emphasizing t
he importance of confidentiality in the context of testing for HIV \'5Bthe viru
s that causes AIDS\'5D \'22women, like men, may choose not to know their serost
atus because of the many extant barriers to testing, including ongoing fears of
breaches of confidentiality, insufficient access to care and services for thos
e who test positive, and continuing discrimination against people (and families
) with HIV\'22). \par
\par
----------End Footnotes----------
- \par\par
Although physicians generally are prohibited from disclosing a patient's med
ical information without her consent, many exceptions to this rule apply. n89 I
n fact, so many exceptions have been made that it has been suggested that the c
oncept of physician-patient confidentiality is a dead letter. n90 Without direc
tion from federal law, health care providers depend on professional standards,
state legislation, and court decisions to determine when they must disclose med
ical information without the patient's consent. n91\par
\par
----------Footnotes----------
- \par\par
n89. See Buchanan, supra note 8, at 142. \par\par
\par
\par
There are occasions ... when a physician must determine whether or not his du
ty to society requires him to take definite action to protect a healthy individ
ual from becoming infected because a physician has knowledge, obtained through
the confidences entrusted to him as a physician, of other communicable disease
to which to the healthy individual is about to be exposed. \par\par
\par
\par
See id. \par\par
n90. See Lombardo, supra note 86, at 593 (\'22Medical confidentiality, as it
has traditionally been understood by patients and doctors, no longer exists. T
his ancient medical principle, which has been included in every physician's oat
h and code of ethics since Hippocratic times, has become old, worn-out, and use
less; it is a decrepit concept.\'22) (footnote omitted). Because medical inform
ation is so easily accessible through computer networks and from insurance prov
iders, confidentiality of medical records is significantly diminished. See Davi
d Orenlicher, Genetic Privacy in the Patient-Physician Relationship, in Genetic
Secrets 85-86 (Mark A. Rothstein ed., 1997). \par\par
n91. See Friedland, supra note 4, at 253-54. \par
\par
----------End Footnotes----------
- \par\par
Statutes determining when physicians must maintain or sacrifice confidential
ity vary from state to state. In New York, any health care provider authorized
to practice in the state may not disclose information obtained in such capacity
that is necessary to treat a patient, unless that individual consents to the d
isclosure. n92 New York statutes and regulations, however, allow for a number o
f exceptions to this requirement of confidentiality. For example, where \'5B*
266\'5D patients are diagnosed with communicable diseases, n93 sexually trans

mitted diseases, n94 and AIDS, n95 they are considered threats to the public or community, and thus health care providers must notify the Department of Health to prevent harm to third parties. n96\par
\par
----------Footnotes----------
\par\par
n92. See N.Y. C.P.L.R 4504(a) (McKinney 1992 & Supp. 1998). \par\par
\par
\par
Unless the patient waives the privilege, a person authorized to practice medicine, registered professional nursing, licensed practical nursing, dentistry, podiatry or chiropractic shall not be allowed to disclose any information which he acquired in attending a patient in a professional capacity, and which was necessary to enable him to act in that capacity. \par\par
\par
\par
See id. \par\par
n93. See N.Y. Pub. Health Law 2101 (McKinney 1993); N.Y. Comp. Codes R & Regs. tit. 10, 2.10 (1997). \par\par
n94. See N.Y. Pub. Health Law sec. 2300 (McKinney 1993); N.Y. Comp. Codes R. & Regs. tit. 10, 23.3 (1997). \par\par
n95. See N.Y. Pub. Health Law sec. 2782 (McKinney 1993 & Supp. 1998); N.Y. Comp. Codes R. & Regs. tit. 10, 24-1.2 (1997). \par\par
n96. See N.Y. Pub. Health Law 2101 (1) (McKinney 1993) (\'22Every physician shall immediately give notice of every case of communicable disease required by the department to be reported to it, to the health officer of the local health district where such disease occurs.\'22). \par
\par
----------End Footnotes----------
\par\par
As opposed to victims of communicable diseases, a patient with genetic disease may not create a risk for the public at large, but may pass on mutant genes to children who could benefit from genetic information. n97 For this reason, some argue that another exception to the physician-patient confidential relationship should apply in the context of genetic information. The privacy of genetic information is often analogized to the privacy of one's HIV status because of the potential for stigma and discrimination that is created when an individual is identified as infected or diseased. n98\par
\par
----------Footnotes----------
\par\par
n97. In order to establish the physician-patient privilege, three elements are essential: the existence of a doctor and patient relationship, the information at issue must be obtained in the course of treatment, and the information must be necessary for treatment. As discussed in Part II.C, where family members are the beneficiaries of genetic information, courts have construed the physician-patient relationship as extending to these individuals. See Vincent C. Alexander, Supplementary Practice Commentaries, N.Y. C.P.L.R. 4504(a) (McKinney 1993 & Supp. 1998); See infra Part II.C. \par\par
n98. See Scott Burris & Lawrence O. Gostin, Genetic Screening from a Public Health Perspective: Some Lessons from the HIV Experience, in Genetic Secrets 137, 148-49 (Mark A. Rothstein ed., 1997); see also Cooper, supra note 87 and accompanying text. \par
\par

----------End Footnotes----------
- \par\par
In New York, legislators have made great efforts to afford privacy to those undergoing HIV testing. n99 When a person tests positive for HIV, however, the law permits a physician to encourage the patient to notify his or her partners of their risk of contracting HIV. n100 If the patient refuses to do so, the physician has the discre \'5B*267\'5D tion to notify the person at risk or may arrange for a state health official to notify the patient's partner, even without the patient's consent. n101 With the advent of drug therapies shown to retard the progression of AIDS in people living with HIV, the public has become more receptive to a new exception to physician-patient confidentiality in these circumstances. n102 Apparently, where preventive measures are available to those who may be at risk for disease, the public is better able to accept breaches in the confidential relationship. n103\par
\par
----------Footnotes----------
- \par\par
n99. See N.Y. Pub. Health Law 2785(2) (McKinney 1993 & Supp. 1997). \par\par
n100. See N.Y. Pub. Health Law 2782(4)(a) (McKinney 1993 & Supp. 1998). \par\par
\par
\par
A physician may disclose confidential HIV related information under the following conditions: (1) the disclosure is made to a contact or to a public health officer for the purpose of making the disclosure to said contact; and (2) the physician reasonably believes disclosure is medically appropriate and there is a significant risk of infection to the contact; and (3) the physician has counseled the protected individual regarding the need to notify the contact, and the physician reasonably believes the protected individual will not inform the contact; and (4) the physician has informed the protected individual of his or her intent to make such disclosure to a contact and has given the protected individual the opportunity to express a preference as to whether disclosure should be made by the physician directly or to a public health officer for the purpose of said disclosure. If the protected individual expresses a preference for disclosure by a public health officer or by the physician, the physician shall honor such preference. \par\par
\par
\par
Id. \par\par
n101. See id. \par\par
n102. Exceptions to physician-patient confidentiality have been made where patients with infectious conditions, such as HIV, threaten the health of third parties, and counseling and treatment may benefit them. See AIDS: More Reporting of Virus Encouraged, American Political Network--Health Line, Aug. 21, 1997, at 13. \par\par
\par
\par
Until recently, there was a belief that patient privacy was necessary to encourage 'voluntary testing and counseling to help slow the spread of infection.' Now, however, 'new drug therapies make early detection and treatment more important,' and 'strong legal protections against discrimination have eased some of the pressure for confidentiality.' \par\par
\par

\par
Id.; Lawrence O. Gostin et al., The Public Health Information Infrastructure: A National Review of the Law on Health Information Privacy, \i 275 JAMA 1921 (1996)\i0 (discussing provisions in the law for disclosure of confidential medical information or partner notification where therapeutic measures are available to third parties at risk of infection). \par\par

n103. See Lynda Richardson, U.S. Urging Identification of Patients with HIV, N.Y. Times, Oct. 21, 1997, at B5 (\'22Many advocacy groups have softened their opposition to HIV reporting in recent months because of medical advances.\'22); <http://www. abcnews.com:80/sections/newsuse/hiv910/index.html> (noting that \'22mandatory \'5BHIV\'5D reporting has grown less controversial in recent years, especially with the advent of treatments for people who are infected but not yet sick\'22). \par

\par

----------End Footnotes----------

\par\par

C. Conflict in the Courts\par

\par

Courts have recognized an exception to the physician-patient privilege when revealing confidential medical information prevents foreseeable harm to identifiable third parties. n104 Courts also have \'5B*268\'5D determined that psychotherapists, who, while treating patients, learn that the patient is likely to attack or cause serious harm to a third party, have a duty to warn that endangered individual and even take steps to protect that third party from the risk that was revealed through confidential therapy sessions. n105 Moreover, courts have created new exceptions to the confidential physician- patient relationship that cover dangers ranging from acts of violence to exposure to contagious disease. n106 Courts have split, however, on whether to carve out another exception where genetic information may help a patient's family avoid harm. n107\par

\par

----------Footnotes----------

\par\par

n104. See \i Tarasoff v. Regents of University of California, 551 P.2d 334 (Cal. 1976)\i0 (en banc) (special relationship between physician and patient supports duty of reasonable care to protect identifiable third party from harm threatened by patient); see also \i Bradshaw v. Daniel, 854 S.W.2d 865 (1993)\i0 (holding that physician had duty to warn patient's wife of her risk of contracting Rocky Mountain Spotted Fever when he should have known patient had such disease); \i Hoffmann v. Blackmon, 241 So.2d 752 (Fla. Dist. Ct. App. 1970)\i0 (finding physician negligent for failing to diagnose tuberculosis in father, and failing to warn family of child's risk of contracting such disease). \par\par

n105. See \i Tarasoff, 551 P.2d at 345\i0 (requiring that a therapist who \'22reasonably should have determined, that a patient poses a serious danger of violence to others, \'5B \'5D bears a duty to exercise reasonable care to protect the foreseeable victim of that danger\'22). \par\par

n106. See supra note 103. \par\par

n107. Compare \i Pate v. Threlkel, 661 So.2d 278 (1995)\i0 (holding that physician's duty to warn patient's family members of genetic disease satisfied by notifying only patient) with \i Safer v. Pack, 677 A.D. 1188 (N.J.Super. 1996) \i0 (rejecting satisfaction of duty to warn with patient notification, but instead requiring that physicians take reasonable steps to ensure that family members are notified of genetic disease). \par

\par

----------End Footnotes----------
- \par\par
In Pate v. Threlkel, n108 the Florida Supreme Court decided whether physicia
ns caring for a woman diagnosed with medullary thyroid carcinoma owed her a dut
y to warn that her condition was genetically transferable. n109 One factor comp
licating the case was that the plaintiff was the patient's daughter, Heidi Pat
e. Only after learning that she also suffered from medullary thyroid carcinoma
did Pate learn that she inherited the disease from her mother. Holding that the
physicians had a duty to warn of the cancer's genetic nature, the court ruled
that Pate satisfied the privity require \'5B*269\'5D ment because she could
be considered the intended beneficiary of the duty. n110 The Pate court, howeve
r, specifically noted that the physician's duty to warn would be satisfied by n
otifying only the patient (who could be expected to share the information with
her children) and expressly rejected the requirement that the physician inform
the patient's children directly. n111\par
\par
----------Footnotes----------
- \par\par
n108. \i 661 So.2d 278 (1995).\i0 Heidi Pate, the adult daughter of a woman
diagnosed with medullary thyroid carcinoma, a genetically transferable cancer,
filed a complaint against her mother's physicians for failure to warn of the g
enetic nature of the cancer. Undergoing treatment for her own case of medullary
thyroid carcinoma, Pate claimed that the doctors should have been aware of the
disease's hereditary character and that given early warning, she could have be
en closely monitored for the cancer, and could have taken precautionary measure
s to prevent its onset. The trial court dismissed Pate's complaint for lack of
privity with her mother's physicians and the District Court affirmed. Recognizi
ng that in previous cases, intended beneficiaries of the prevailing standards o
f care were permitted to bring a cause of action against a professional despite
a lack of privity, the Florida Supreme Court decided that the more tenuous rel
ationship between plaintiff and defendant in this case did not foreclose liabil
ity. \par\par
n109. See \i 661 So.2d at 281\i0 (determining that health care providers we
re under a duty to warn Mrs. New of the importance that her children undergo ge
netic testing to identify their predisposition to same disease). \par\par
n110. \i Id. at 282\i0 (expanding requirement in past courts that privity e
xist between plaintiff end physician to maintain cause of action to third party
beneficiaries of relationship). \par\par
\par
\par
Here, the alleged prevailing standard of care was obviously developed for the
benefit of the patient's children as well as the patient. We conclude that when
the prevailing standard of care creates a duty that is obviously for the benef
it of certain identified third parties, then the physician's duty runs to those
third parties. \par
\par
Id. \par\par
n111. \i Id. at 282.\i0 \par\par
\par
\par
To require the physician to seek out and warn various members of the patient's
family would place too heavy a burden upon the physician. Thus, we emphasize t
hat in any circumstances in which the physician has a duty to warn of a genetic
ally transferable disease, that duty will be satisfied by warning the patient.

\par\par
\par
\par
Id. \par\par
\par
\par
----------End Footnotes----------
\par\par
In Safer v. Pack, n112 a New Jersey Superior Court reached a different concl
usion when faced with a similar case and held that a physician's duty to warn i
s not satisfied by informing the patient; rather, reasonable steps must be take
n to assure that the information reaches the parties at risk. n113 The Safer co
urt emphasized that individuals can begin any treatments or changes in lifestyl
e necessary to prevent the onset of the disease as soon as they learn that they
have a greater risk of developing it. n114 The court also noted that in the ca
se of genetic disease, the duty to warn of avertible risk is \'5B*270\'5D n
arrow enough to serve the interests of justice. n115 The court, in Safer, did n
ot define what \'22reasonable steps\'22 were, however, leaving open the questio
n of how the confidentiality between doctor and patient should be limited in ce
rtain circumstances. n116\par
\par
----------Footnotes----------
\par\par
n112. \i 677 A.2d 1188 (N.J. Super. 1996).\i0 Donna Safer, whose father was
treated for and died of colon cancer during the 1960s, sued the estate of her
father's physician for failure to warn of the genetic nature of the condition w
hich led to her father's fatal disease. At the time of the suit, Safer had been
diagnosed with multiple polyposis and colon cancer, which had metastasized to
her liver. Multiple polyposis is an inherited condition that, if left untreated
, leads to colorectal cancer. Because she was a child at the time of her father
's illness, Safer only learned that he suffered from the same disease after she
reviewed his medical records. The trial court dismissed Safer's case because i
t required that either a patient-physician relationship exist or that a threat
to the public health or community at large exist in order to bring a cause of a
ction in this situation. The New Jersey Superior Court permitted Safer's claim
against the physician's estate. \par\par
n113. See \i id. at 1192\i0 (\'22We decline to hold ... that, in all circum
stances, the duty to warn will be satisfied by informing the patient.\'22). \p
ar\par
n114. Id. (\'22The individual or group at risk is easily identified, and sub
stantial future harm may be averted or minimized by a timely and effective warn
ing.\'22). \par\par
n115. Id. (\'22Although an overly broad and general application of the physi
cian's duty to warn might lead to confusion, conflict or unfairness in many typ
es of circumstances, we are confident that the duty to warn of avertible risk f
rom genetic causes, by definition a matter of familial concern, is sufficiently
narrow to serve the interests of justice.\'22). \par\par
n116. Id. \par\par
\par
\par
We need not decide, in the present posture of this case, how, precisely, that
duty is to be discharged, especially with respect to young children who may be
at risk, except to require that reasonable steps be taken to assure that the i
nformation reaches those likely to be affected or is made available for their b

enefit. \par\par
\par
\par
Id. \par
\par
----------End Footnotes----------
\par\par
III. Aligning Legal Policy with the Current Status ofBiotechnology\par
\par
Although courts have long encountered breaches of confidentiality for the bene fit of at-risk third parties, disclosure of genetic information regarding predi sposition to cancer is a new issue to legislators and judges alike. Because dev elopments in genetics are far outpacing the legal system, it is necessary to up date the law to manage current conflicts and also anticipate the issues that wi ll accompany future advances. This Part evaluates the rationales employed by th e Pate and Safer courts, suggests other elements that courts should consider, a nd proposes a balancing test that will determine where disclosure of genetic in formation is appropriate. \par\par
A. Pate and Safer Reconsidered\par
\par
The courts in Pate v. Threlkel and Safer v. Pack reached disparate conclusions because of several significant factors. For example, when physicians diagnosed Heidi Pate's mother with medullary thyroid carcinoma, a genetically transferab le disease, Pate was an adult who would have been able to decide for herself ho w to use the information that she was at risk. n117 Donna Safer, however, was a minor at the time her father suffered from colon cancer, and discovered his co ndition only by researching his medical records after she was diagnosed with ca ncer. n118\par
\par
----------Footnotes----------
\par\par
n117. See \i Pate v. Threlkel, 661 So.2d at 279.\i0 \par\par
n118. See \i Safer v. Pack, 677 A.2d at 1189.\i0 \par
\par
----------End Footnotes----------
\par\par
The Pate court determined that, given the knowledge that her condition was g enetically transmissible, Pate's mother likely would \'5B*271\'5D have pass ed this information on to her adult daughter. n119 In Safer, however, notifying the plaintiff would have been much more complicated, and probably best left un til she became an adult. n120 The Safer court thus held that additional measure s should have been taken to assure that Safer eventually was informed about her father's condition. n121 Accordingly, where complicating factors exist with re spect to sharing genetic information with family members (e.g., where such fami ly members are minor children), courts may require additional support from heal th care professionals to ensure that the situation is handled appropriately.\pa r
\par
----------Footnotes----------
\par\par
n119. See \i Pate, 661 So.2d at 282\i0 (\'22Our holding should not be read to require the physician to warn the patient's children of the disease ... the patient ordinarily can be expected to pass on the warning.\'22). \par\par
n120. See supra note 115 and accompanying text. \par\par

n121. See id. \par
\par
----------End Footnotes----------
\par\par
The nature of the relationship between the physician and the family may be another important distinction for the courts. For example, Donna Safer's mother also was treated by the defendant physician who should have disclosed the genetic nature of her husband's cancer because she specifically asked about the risk to her family. n122 Heidi Pate, on the other hand, established no relationship with her mother's physicians, and requiring the doctors to seek out and share the genetic information with the patient's children would have been too great a burden. n123\par
\par
----------Footnotes----------
\par\par
n122. See \i Safer, 677 A.2d at 1190.\i0 Safer's mother claims that the physician reassured her that her husband was being treated for a condition that would not harm the children. See id. \par\par
n123. See supra note 110 and accompanying text. \par
\par
----------End Footnotes----------
\par\par
Moreover, the plaintiffs' parents were diagnosed with significantly different conditions. While the type of cancer from which Pate's mother suffered has no preliminary warning signals, n124 Safer's father had multiple polyposis, a genetically linked condition that later develops into colon cancer. n125 The knowledge of her father's condition would have alerted Safer to monitor closely for polyposis and to undergo the available treatment to avert the onset of colon cancer. The Safer court's decision likely was influenced by the fact that such information would have proven extremely useful to the plaintiff, and therefore it held that the treating physicians \'5B*272\'5D were obligated to take the necessary steps to provide the plaintiff with the information.\par
\par
----------Footnotes----------
\par\par
n124. See \i Pate, 661 So.2d at 279\i0 (noting that Pate's discovery of her condition occurred only after the cancer had reached an advanced stage). \par
\par
n125. See \i Safer, 677 A.2d at 1190\i0 (\'22Multiple polyposis is a hereditary condition that, if left undiscovered and untreated, invariably leads to metastatic colorectal cancer.\'22). \par
\par
----------End Footnotes----------
\par\par
Although Heidi Pate's disease was not preceded by a \'22warning\'22 stage, such as polyposis, she also would have benefitted tremendously from a warning from her mother's physicians, because medullary thyroid carcinoma may effectively be prevented. n126 Without a precancerous condition like polyposis, however, which would signal the need to take appropriate preventive measures, the Pate court may not have believed that breaking physician-patient confidentiality could have prevented Pate's cancer.\par
\par
----------Footnotes----------
\par\par

n126. See Leslie M. Alexandre, Genetic Testing for Cancer Susceptibility: Wh at Your Institution Needs to Know (visited Feb. 11, 1998) <http://www.medscape. com/ACCC/ OncIssues/1997/vl2.nO2/oil202.02.alexandre.html> (\'22\'5BA\'5D posit ive \'5Bgene\'5D test for mutations in the RET gene is a virtual guarantee of d eveloping medullary thyroid carcinoma, and prophylactic surgery is 100 percent effective in preventing this frequently fatal form of thyroid cancer.\'22).\par

\par
----------End Footnotes----------
\par\par
Both the Pate and Safer courts failed to consider several important factors that likely will prove critical to future cases. When testing for genes that in dicate a predisposition to disease, courts should consider the accuracy of the test performed and the ability of the physician to interpret its results. A tes t that cannot provide accurate results with reasonable certainty does not provi de physicians with information that will enable patients to make appropriate de cisions with respect to their physical and emotional well- being. n127 Even whe re genetic tests provide accurate results, to render beneficial counseling to t heir patients, physicians must adequately be educated about the significance of test results and how to interpret them (training which currently is lacking in primary care providers). n128\par
\par
----------Footnotes----------
\par\par
n127. See infra note 139 and accompanying text. \par\par
n128. See infra note 142 and accompanying text. \par
\par
----------End Footnotes----------
\par\par
The likelihood of gene transmission to the next generation and the severity of the corresponding condition also must be considered. Finally, the potential for discrimination against and stigmatization of the patient must be carefully restricted. \par\par
B. A Balancing Test\par
\par
Future cases involving the duty to disclose genetic information should be deci ded by using a balancing test. Where advances in technology and legislation occ ur so rapidly, a bright-line rule will not be effective for long. The weight at tributed to the elements on either side of this test will shift as scientists a dvance genetic technology, legislators further protect the privacy of genetic i nforma \'5B*273\'5D tion, and physicians and the public learn more about gen etic testing. Thus, the five factors in this proposed balancing test will have varying levels of significance and will allow for different results when appli ed to newly discovered mutations linked to diseases. \par\par
The following factors will best determine when to permit an exception to phy sician-patient confidentiality because they will allow courts to adapt to curre nt technological advances and legislation. Courts should weigh: \par\par
(1) the severity of the disease identified by testing; \par\par
(2) the availability of preventive or curative options for that disease; \p ar\par
(3) the accuracy and reliability of the test performed; \par\par
(4) the ability of the physician or health care provider to interpret and ad dress issues relevant to the test performed; and lastly, \par\par
(5) the protections afforded to the tested individual against discrimination

. \par\par
C. Applying the Balancing Test to the BRCA GeneMutations\par
\par
Although a carrier of genetic mutations diagnosed with breast or ovarian cance
r is likely to inform her children that they also may be at increased risk of c
ancer if they also carry the mutations, currently there is no legal duty to sha
re this information with family members. n129 Also, the patient may have her ow
n reasons for keeping it confidential. Therefore, the application of the balanc
ing test in the context of the BRCA mutations will provide a useful tool for ph
ysicians and courts in determining whether there is a duty to warn a patient's
children.\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n129. See Friedland, supra note 4, at 271 (\'22Even though genetic defects m
ay pose a threat of serious harm to others, the common law has never required a
n individual to come to the aid of another when the other's situation is not th
at of the individual's making.\'22). \par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - -
- \par\par
1. Severity of Disease\par
\par
The severity of the disease or condition to which an individual may be predisp
osed by inherited genetic mutations is a necessary consideration because breach
of confidentiality is a measure of last resort, and can be justified only if t
he threatened harm is imminent or serious. n130 A genetic mutation increasing a
n individual's risk for \'5B*274\'5D male pattern baldness must be treated
differently than one indicating susceptibility to an untreatable form of cancer
. Coping with the alterations in self-image that balding may create is less ser
ious than battling a life-threatening disease such as cancer. Statutes and case
s support measures other than unauthorized disclosure of a patient's medical in
formation to a third party, unless the disclosure is necessary to avert the thr
eat of substantial harm. n131 Therefore, in applying the proposed balancing tes
t, the more serious the condition, the more heavily it will weigh against maint
aining confidentiality.\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n130. See Lori B. Andrews, Gen-Etiquette: Genetic Information, Family Relati
onships, and Adoption, in Genetic Secrets 255, 269 (Mark A. Rothstein ed., 1997
) (noting that the National Research Council's Commission for the Study of Inbo
rn Errors of Metabolism, the President's Committee on Ethical Issues in Medicin
e, and the Institute of Medicine's Committee on Assessing Genetic Risks all rec
ommend limiting disclosure of genetic information to cases of life-threatening,
massively disabling, irreversible or fatal conditions). \par\par
n131. See id. at 269; \i DiMarco v. Lynch Homes, 583 A.2d 422 (Pa. 1990)\i0
(holding that a physician has a duty to teach safe sex practices to patient wi
th hepatitis in lieu of warning sex partners). \par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - -
- \par\par
For example, breast and ovarian cancer are serious diseases, ranking among t
he top five causes of death in American women, and are difficult to eradicate i

f not detected in an early stage of development. n132 Therefore, the applicatio
n of the severity element related to the BRCA mutations weighs heavily in favor
of disclosing this genetic information.\par
\par
----------Footnotes----------
- \par\par
n132. The serious nature of breast and ovarian cancer, coupled with more eff
ective treatment with early detection weigh in favor of notifying children of t
heir mother's BRCA carrier status. See \i Safer v. Pack, 677 A.2d 1188, 1192 (1
996)\i0 (\'22The individual or group at risk is easily identified, and substan
tial future harm may be averted or minimized by a timely and effective warning.
\'22); see also John Bell, Prenatal Diagnosis: current status and future trends
, in Human Genetic Information: Science, Law and Ethics 25 (noting that \'22scr
eening early in life ... would permit individuals at high risk to modify their
life styles so that they would be exposed to fewer environmental risk factors t
han otherwise\'22); but c.f. Daniela Altimari, 400 Women Attend Forum on Breast
Cancer, Hartford Courant, Sept. 26, 1997, at B1 (Bella Abzug argues that genet
ic testing deflects attention from environmental factors). \par
\par
----------End Footnotes----------
- \par\par
2. Availability of Preventive or CurativeOptions\par
\par
The second element to consider is the availability of effective preventive or
curative measures. Knowing that one is subject to an increased risk of developi
ng serious disease may create significant emotional distress, especially if the
re are no available means of treating or averting the onset of disease. Althoug
h some argue that the mere notification that one is at increased risk may provi
de some benefit, n133 if the available options are limited to \'22heroic\'22 or
\'5B*275\'5D drastic measures, this factor will weigh in favor of maintainin
g confidentiality. However, if researchers discover curative procedures (such a
s gene therapy or drug treatment) or determine that avoidance of exposure to sp
ecific external factors will effectively thwart the onset of disease, then this
element will weigh in favor of disclosure to offspring.\par
\par
----------Footnotes----------
- \par\par
n133. See Groopman, supra note 45, at 46 (noting that \'5Bthe awareness of o
ne's predisposition to disease\'5D \'22led many people to take better care of t
hemselves--stop smoking, end drug use, improve diet, take up exercise, seek str
ess reduction ... \'5Band\'5D the knowledge that one ... was mortal gave many y
oung people a precocious sense of maturity and wisdom\'22); Alexandre, supra no
te 126 (\'22When scientific discoveries venture into promising but uncertain ne
w realms, some people understandably react with caution. Although such apprehen
sion can be constructive and can lead to further education and knowledge, the r
eaction can be harmful when it discourages people from seeking a potentially li
fe-saving approach to health care.\'22). It is interesting to note that the aut
hor of this article, Leslie Alexandre, is Vice President of Corporate Affairs a
t OncorMed, one of the biotechnology companies currently marketing genetic test
ing kits. \par
\par
----------End Footnotes----------
- \par\par
Currently, there is no generally accepted method that has been proven to pre

vent breast or ovarian cancer, n134 although close surveillance n135 and measur
es such as drug therapy, prophylactic mastectomy and oophorectomy promise signi
ficantly to reduce the risk. n136 The removal of the breasts and ovaries may se
em like an extreme preventive procedure, but actually may serve to substantiall
y eliminate emotional distress and anxiety. n137 Many women, however, may elimi
nate either procedure as a viable option because they hope to have children or
decide that surgery is too drastic.\par
\par
----------Footnotes----------
\par\par
n134. See Wendy C. McKinnon et al., Predisposition genetic testing for late-
onset disorders in adults: a position paper of the National Society of Genetic
Counselors, \i 278 JAMA 1217 (1997)\i0 (\'22For many late-onset disorders, suc
h as cancer, much uncertainty surrounds the molecular biology of predisposition
genetic testing. Likewise, there is a dearth of data regarding appropriate med
ical management for gene mutation carriers and the psychological aspects of tes
ting.\'22). \par\par
n135. See Singer & Cebul, supra note 51, at 178 (\'22Although many women may
be reluctant to participate \'5Bin mammographic screenings\'5D due to cancer a
nxiety, compliance is generally improved when the patient is aware of the risk.
\'22). \par\par
n136. See id. at 179 (naming prophylactic mastectomy as the only established
preventive option currently available, but warning that cases of breast cancer
have occurred in women after having their breasts removed and that no studies
of the procedure's efficacy have been conducted yet). \par\par
n137. See Groopman, supra note 45, at 46 (relating a patient's difficult dec
ision to have her breasts and ovaries removed to reduce the anxiety felt by bot
h her family and herself). \par
\par
----------End Footnotes----------
\par\par
Once identified as a BRCA mutation carrier, an individual's decision about h
ow best to avoid cancer surely is excruciating and very personal. Although the
disclosure of genetic information would allow a carrier's children to engage i
n their own decision making processes, the limited options presently available
weigh against disclosure. \par\par
\'5B*276\'5D \par\par
3. Accuracy and Reliability of Test\par
\par
If the genetic test performed on an individual cannot be relied upon to provid
e accurate results, then such information threatens to bring more harm than ben
efit. Tests which produce false negative results likely will relieve anxiety an
d create a false sense of security in individuals who actually are at increased
risk for disease. A mistaken belief that they are free of the specific genetic
mutation may deter these individuals from obtaining the surveillance or treatm
ent that may save their lives. n138 On the other hand, false positive results a
re sure to create significant emotional distress in persons whose risk for dise
ase is no greater than those in the general population. Therefore, where geneti
c conditions cannot be identified with accuracy, genetic information should be
kept confidential.\par
\par
----------Footnotes----------
\par\par
n138. See Rothenberg, supra note 71, at 103 (fearing that \'22genetic determ

inism,\'22 where an individual believes her future is defined and predicted by genetic makeup and cannot be changed, will result from genetic testing). \par

\par
----------End Footnotes----------
\par\par
Today, there is no test available that has been proven to be accurate in identifying risk-predicting BRCA mutations. n139 Because numerous mutations of the BRCA1 and BRCA2 genes exist, and researchers have not determined which mutations correlate with manifestation of disease, it is quite possible that an individual identified as a BRCA mutation carrier may actually carry a mutation that does not contribute to the onset of cancer. n140 Until these tests \'5B*277\'5D have been shown to identify predisposition for cancer with sufficient accuracy, this factor will weigh against disclosure.\par
\par
----------Footnotes----------
\par\par
n139. See Malinowski & Blatt, supra note 15, at 1243 (\'22The predictive capability of many genetic tests remains scientifically undefined for the general population.\'22). \par\par
n140. See Cunningham, supra note 63, at 34. \par\par
\par
\par
Even after correctly detecting the presence of a mutation, there is only a probabilistic likelihood of the actual expression of malignancy. In screening terminology, this could be called a false screening positive for the women who have a mutation but are spared by failure of expression, or who have mutations which do not lead to an increased risk of cancer. \par\par
\par
\par
Id.; Singer & Cebul, supra note 51, at 175-76 (noting that there are no published data reporting the accuracy of tests for BRCA1 mutations, and that because mutations may be difficult to detect, false negatives could result from testing); See Ruth Hubbard & R.C. Lewontin, Sounding Board; Pitfalls of Genetic Testing, \i 334 New Eng. J. Med. 1192, 1192-93 (1996).\i0 Because the onset of breast or ovarian cancer depends on numerous factors, depending on DNA patterns to predict disease is problematic. Only a few of the several variants of BRCA1 and BRCA2 are associated with tumor formation. Additionally, even a woman with a family history of cancer who tests positive for one of the mutations may never develop cancer. At present, biotechnology companies that sell tests for the BRCA1 mutation are not required to involve the Food and Drug Administration, and thus there has been no external certification of the tests' quality or the interpretation of their results. See also Heather Bryant, Genetic Screening for breast cancer in Ashkenazi women, Commentary, 347 Lancet 1638 (1996). \par
\par
----------End Footnotes----------
\par\par
4. Education and Training ofPhysicians\par
\par
To render genetic testing beneficial for patients, physicians must have the ability to interpret test results and understand their significance and meaning. Because test results often are not clear, physicians delivering the results should be educated about the identification of gene mutations, as well as their significance. Critics of genetic testing in the clinical environment warn that fe

w primary providers have been adequately trained to determine what genetic test results mean, and what information must be provided to patients undergoing tes ting. n141 Any benefit to the individual being tested results from the physicia n's advice and direction. If physicians themselves have not learned how to inte rpret and use test results to promote better health, the patients are not likel y to benefit from such information, and thus this element would weigh in favor of maintaining confidentiality.\par
\par
----------Footnotes----------
\par\par
n141. See Malinowski & Blatt, supra note 15, at 1245. \par
\par
----------End Footnotes----------
\par\par
While plans to further educate physicians and other health care providers ab out genetic testing are underway, n142 the majority of physicians currently do not possess adequate knowledge or training to benefit their patients who wish t o undergo genetic testing. n143 \'5B*278\'5D When more physicians can provi de their patients with sufficient explanation and counseling with regard to BRC A testing, then disclosure to patients' offspring will be more acceptable. At t his time, however, this element must weigh against such disclosure.\par
\par
----------Footnotes----------
\par\par
n142. See Collins, Preparing Health Professionals, supra note 30 (noting tha t the National Coalition for Health Professional Education in Genetics plans to provide a national, systematic approach to educating health care providers thr ough internet programs, requiring the inclusion of genetic information on board and licensure exams, and standardized genetics curricula). \par\par
n143. See id. \par\par
\par
\par
Most health professionals are not prepared to integrate genetics into clinical practice. A study of DNA-based colon cancer susceptibility testing revealed th at nearly one third of physicians who delivered such test results did not fully understand their meaning. Surveys also show that many health professionals hav e insufficient knowledge of available genetic resources. \par\par
\par
\par
Id. Bernadine Healy, Editorial: BRCA Genes - Bookmaking, Fortunetelling, and M edical Care, \i 336 New Eng. J. Med 1448 (1997)\i0 (\'22It is too early to use BRCA gene testing in every day clinical practice, because it violates a common sense rule of medicine: don't order a test if you lack the facts to know how to interpret the results.\'22); Malinowski & Blatt, supra note 15, at 1245-46. \ par\par
\par
\par
Due to the absence of adequate clinical data, health care providers cannot int erpret the results of predictive genetic tests for most of their patients with any reliability even when they are knowledgeable about genetics. This interpret ation problem is exacerbated because the current generation of health care does not possess such knowledge. Their lack of genetic education and the novelty of the technology makes providers dependent upon the developers and manufacturer of these tests ... for information. \par\par

\par
\par
Id. \par
\par
----------End Footnotes----------
\par\par
5. Potential for Discrimination and Stigmatization\par
\par
If genetic testing reveals that an individual is susceptible to serious illnes
s, a court must consider the potential that such information will be used to de
ny that person health insurance or employment. This factor will depend upon the
progress made by legislators to enact laws that protect all individuals agains
t such discrimination. Moreover, without adequate protections against unauthori
zed disclosure of genetic information to third parties, carriers likely will be
perceived as \'22prediseased\'22 or disabled, even before they manifest any si
gns of illness. n144 Until firm protections are in place, this element should w
eigh against disclosure.\par
\par
----------Footnotes----------
\par\par
n144. See Joyce Wadler, Double Exposure, New York Magazine, Sept. 18, 1997,
at 24, 26 (\'22I looked after my health and it still didn't matter. I was my ow
n Unabomber, carrying my future from the time I was born, caught in a genetic a
ccident.\'22). The author of this article was a breast cancer survivor who desc
ribed her experience after being diagnosed with ovarian cancer and learning tha
t she carried genetic mutations which predisposed her to both diseases. \par\p
ar
\par
\par
----------End Footnotes----------
\par\par
Although some individuals may be protected by state laws prohibiting discrim
ination by employers and insurance providers, no current legislation assures th
at all who may benefit from BRCA testing will be protected from discrimination.
Therefore, it is improper to suggest that physicians should disclose genetic i
nformation to family members who then may be denied access to insurance or empl
oyment. The patients themselves are in the best position to know whether the be
nefit of disclosure will outweigh the harm to their children, and should, there
fore, decide the appropriate time and means to share genetic information with t
heir children. Until universal genetic privacy is afforded by federal legislati
on, this factor strongly weighs against disclosure by physicians. \par\par
The current status of genetic research, professional education, and legislat
ion results in the severity of disease as the only factor of the balancing test
that favors disclosure to children of a BRCA mutation carrier. One may argue t
hat breast and ovarian cancer are so serious that individuals should be aware o
f an increased risk so that they can make informed personal choices about their
own genetic testing, lifestyle, and health management. However, because \'5B
*279\'5D preventive measures are limited and unproven, such information may c
ause more emotional distress than physical benefit. \par\par
The information itself may not reveal as much about predisposition to cancer
as one may believe, due to either false positive or false negative results, or
simply the inexact nature of determining the probability of disease onset. Mor
eover, until educational programs for health care providers are implemented, it
is likely that the physician who delivers genetic information to a patient's c

hildren may not fully understand the meaning of the test results. The chance th
at the disclosure of genetic information may deny individuals health insurance,
and thus access to the medical attention critical to preventing or treating ca
ncer, threatens to cancel out any benefit inured to a patient's child. Therefor
e, application of the proposed balancing test would result in physician-patient
confidentiality outweighing a duty to warn the patient's children of their ris
k of inheriting the BRCA mutations. \par\par
Conclusion\par
\par
The ability to test for the BRCA1 or BRCA2 mutation is a significant achieveme
nt of genetic scientists and marks the start of a medical revolution. Such test
ing may provide those at risk for hereditary breast or ovarian cancer with inva
luable information that will enable them to better maintain health and an optim
um quality of life. It also threatens to cause serious harm, however, if offere
d without assurances of effective treatment for the cancer, accurate testing, a
dequately informed physicians, and protection against discrimination. \par\par

Courts should adopt this balancing test because it takes these important fac
tors into account. Currently, application of the proposed balancing test weighs
against requiring physicians to warn a patient's children that they may carry
BRCA mutations, and leaves the responsibility with the mother, who still knows
best. \par\par
\pard
\sect \sectd \sbknone
\page \f1 \f0 \fs20 \li000\ri000 \pard
\qc Copyright (c) 1999 Fordham University School of Law\par
\qc Fordham Urban Journal\par
\par
\pard
\qc \ul May,\ul0 1999\par
\par
\pard
\qc 26 Fordham Urb. L.J. 1635\par
\par
\pard
LENGTH: 19137 words \par\par\pard
NOTE: EXPANDING NEW YORK'S DNA DATABASE: THE FUTURE OF LAW ENFORCEMENT \par\pa
r\pard
Robert W. Schumacher II* \par\par\pard
* J.D. Candidate, Fordham University School of Law, 2000; B.A., magna cum lau
de, Villanova University, 1997. I would like to extend my appreciation to Profe
s sor Daniel Richman for his valuable insight and advice. I also wish to thank
my par ents, Robert Sr. and Rosemary, and sister, Melanie, for their steadfast
love, support and encouragement. \par\par\pard
TEXT: \'5B*1635\'5D \par\par
Introduction\par
\par
On a December morning in New York City, a young girl is found by authorities,
sexually molested and murdered. There is no evi dence present at the crime scen
e to produce a suspect. The victim's friends and family are questioned, but no
one is able to provide any leads. As the investigation continues, however, lab
reports un cover semen samples from the victim's body. With today's technol ogy
, such evidence can be run through New York State's deoxyribonucleic acid (\'22
DNA\'22) database, with the hope of finding a match between the semen found on

the victim's body and a sam ple already existing in the database. Currently, th
is database con tains DNA profiles from those previously convicted of certain s
ex offenses, homicide, assault and escape. n1\par
\par
----------Footnotes----------
- \par\par
n1. See N.Y. Exec. Law 995 (McKinney 1994). Specifically, felons are require
d to submit a DNA sample when convicted of an assault under N.Y. Penal Law sec
tions 120.05, 120.10 and 120.11, a homicide under sections 125.15-125.27 or a s
ex of fense under sections 130.25, 130.30, 130.35, 130.40, 130.45, 130.50, 130.
65, 130.67, 130.70 and 255.25. See id. 995.7. Also, submission is required when
a felon is con victed under sections 205.10, 205.15, 205.17 and 205.19 relatin
g to escape and other offenses, where the offender has been convicted within th
e previous five years of one of the other felonies enumerated. See id. \par
\par
----------End Footnotes----------
- \par\par
Unfortunately, the crime scene sample does not match any re corded in the da
tabase. The killer murders four more girls in the same way before being capture
d in the act with victim number six. \par\par
Upon detention, it is discovered that the killer had been con victed of two
misdemeanors in New York State within the last year- Sexual Misconduct and Rec
kless Endangerment in the Second De gree. Had New York's compulsory DNA statute
been more expan sive to mandate samples from all those arrested for fingerprin
table offenses, the initial sample collected would have matched this man's DNA
profile. The lives of five young girls could have been spared. \par\par
\'5B*1636\'5D This Note analyzes New York City Police Commissioner Howard
Safir's (\'22Safir\'22) proposal to expand New York's DNA Database to include p
rofiles from all persons arrested for a recordable offense. Part I discusses th
e admissibility of DNA identification technology in New York courts and gives a
n overview of the molecular biology of DNA, explaining the powerful investigati
ve advantage of DNA and the main profiling methods available. In addition, Part
I de scribes other DNA database programs currently in place and con cludes wit
h a detailed outline of Safir's proposal. Part II defines the controversy surro
unding Safir's proposal, specifically Fourth Amendment privacy concerns, as wel
l as fears of potential misuse of DNA profile information stored in a computer
database. Part III addresses these concerns and details New York's specific nee
d for an expanded statute in light of New York's recidivism rates, recent crime
trends, investigative efficiency and lower administra tive costs. This Note co
ncludes that Safir's plan is an effective, cut ting-edge law enforcement tool t
hat does not overly intrude upon an individual's Fourth Amendment privacy right
s. \par\par
I. Overview of DNA Uses\par
\par
DNA identification techniques are capable of assisting law en forcement offici
als in implicating the guilty and exonerating the in nocent. n2 In the early 19
90s, New York State recognized these inherent benefits and began admitting the
probative evidence in judicial proceedings.\par
\par
----------Footnotes----------
- \par\par
n2. Despite these apparent benefits in criminal prosecutions, opponents to t
he processes of DNA identification cite two main arguments against the admissib
ility of findings in criminal proceedings. First, because DNA profiling is a lo

ng complex pro cess, opponents attack relaxed testing protocols that could lead to error. See Robert J. Goodwin & Jimmy Gurule, Criminal and Scientific Evidence 285 (1997). Specifically, results are unreliable when mislabeling, contamination and comparison negligence occurs. See id. One illustration of the call for quality control and profi ciency standards in laboratory DNA testing can be found in \i New York v. Castro, 545 N.Y.S.2d 985, 997-98 (Sup. Ct. 1989),\i0 where the court held DNA evidence in admissable because those testing the sample failed to follow appropriate standards and controls. \par\par

Second, critics attack the accuracy of probability estimates concerning the chances of another person having a similar genetic make-up as the accused. See id. The probability figures, usually in the one-in-several million range, if wrongfully calcu lated, are \'22unreliable, misleading, and highly prejudicial.\' 22 Id. \par

\par

----------End Footnotes----------

\par\par

\'5B*1637\'5D In 1994, in People v. Wesley, n3 the New York Court of Appeals found Restriction Fragment Length Polymorphism (\'22RFLP\'22) n4 pro filing admissible in New York State. n5 The court ruled that the RFLP profiling method is generally accepted as reliable in the sci entific community, n6 using a test for admissibility of novel scientific evidence similar to that in Frye v. United States. n7 The majority de cision noted that questions of procedural negligence and probability inaccuracy were irrelevant to the issue of admissibility, but instead, were matters for jury consideration. n8\par

\par

----------Footnotes----------

\par\par

n3. \i 633 N.E.2d 451 (1994).\i0 This case involved the murder of seventy-nine year-old Helen Kendrick. See \i id. at 453.\i0 The investigation of her death led to Wesley when a bloodstained T-shirt with gray and white hairs on it, bloodstained underwear and bloodstained sweatpants were found in the defendant's apartment. See id. DNA comparisons provided inculpatory evidence, though the defendant was linked to the crime through a number of incriminating statements and nylon from Wesley's carpet found on the deceased's dress. See id. Wesley questioned whether DNA profiling evidence was admissible in New York and, if so, whether it should have been admitted against him. See \i id. at 452.\i0 \par

\par

n4. See infra text accompanying notes 29-52. \par\par

n5. See \i Wesley, 633 N.E.2d at 455.\i0 \par\par

n6. See id. \par\par

n7. \i 293 F. 1013 (D.C. Cir. 1923).\i0 The rule of Frye is that scientific expert testi mony is admissible only after the espoused theory has gained general acceptance in the scientific field. See \i id. at 1014.\i0 Specifically, the Frye court stated: \par\par

\par

\par

Just when a scientific principle or discovery crosses the line between the experimental and demonstrable stages is difficult to define. Somewhere in this twilight zone the evidential force of the principle must be recognized, and while courts will go a long way in admitting expert testimony deduced from a well-recognized scientific principle or discovery, the thing from which the deduction is made must be sufficiently established to have gained general acceptance in the particular field in which it belongs. \par\par

\par

\par
Id. The Wesley court felt \i Daubert v. Merrell Dow Pharmaceuticals, 509 U.S. 579 (1993),\i0 which held that Frye was superseded by the Federal Rules of Evi dence, was inapplicable here. See \i Wesley, 633 N.E.2d at 454 n.2.\i0 \par\p ar

n8. See \i id. 457-58.\i0 In concurrence, Chief Judge Kaye disputed the fin ding that RFLP was a reliable scientific technique in 1988, when conducted agai nst Wesley. See \i id. at 463\i0 (Kaye, J., concurring). \par

\par

----------End Footnotes----------

\par\par

Seven months after Wesley, a New York trial court held that Polymerse Chain Reaction (\'22PCR\'22) n9 profiling techniques were generally admissible in cri minal proceedings in People v. Palumbo. n10 Relying on universal acceptance in other jurisdic tions, n11 the Palumbo court found the PCR test to be \'22gener ally ac \'5B*1638\'5D cepted as reliable in the scientific community.\'22 n12 The Palumbo court further addressed opponents' concerns regarding probability issues in stating \'22that the PCR test may only show that the de fendant and t he assailant are part of a relatively large group of people having the same cha racteristic goes to weight of the evi dence, not its admissibility.\'22 n13\par

\par

----------Footnotes----------

\par\par

n9. See infra text accompanying notes 53-70. \par\par

n10. \i 618 N.Y.S.2d 197 (Sup. Ct. 1994).\i0 In a second-degree murder pro ceeding, the defendant requested a determination on the admissibility of a DNA profile taken using the PCR profiling method. See \i id. at 198.\i0 \par\par

n11. See \i id. at 200-01\i0 (citing \i Oregon v. Lyons, 863 P.2d 1303 (Or. Ct. App. 1993);\i0 \i Clarke v. Texas, 813 S.W.2d 654 (Tex. Ct. App. 1991);\i 0 \i Spencer v. Virginia, 393 S.E.2d 609 (1990);\i0 \i Washington v. Russell, 882 P.2d 747 (1994)).\i0 \par\par

n12. \i Palumbo, 618 N.Y.S.2d at 201.\i0 \par\par

n13. Id. \par

\par

----------End Footnotes----------

\par\par

While generally admissible in New York State, however, DNA evidence still ge nerates heated debate, specifically over its use as an identification tool in c onjunction with technological revolutions. In order for one to fully understand the relevant issues being raised, an overview of DNA science and profiling tec hniques is necessary. \par\par

A. Molecular Biology of DNA\par

\par

DNA is the fundamental material that defines the genetic char acteristics of a ll life forms. n14 DNA is present in most body cells, specifically those with n uclei, and can be carried in bodily fluids such as saliva, blood or semen. n15 DNA sequences vary in length and are composed of four organic bases, namely ade nine (\'22A\'22), cytosine (\'22C\'22), thymine (\'22T\'22) and guanine (\'22G\ '22), arranged in long chains that form a double helix. n16 Essentially, the st ructure resem bles a twisted ladder. n17 The sides of the ladder consist of rep eated sequences of phosphate and deoxyribose sugar. n18 The rungs of the ladder are formed by pairs of the aforementioned bases. n19 A single DNA molecule con

sists of over three billion base pairs where A matches only with T, while C exc
lusively pairs with G. n20 Thus, if a section of bases on one side of the ladde
r is ATTACAGGC, the opposite side would be TAATGTCCG. n21\par
\par
----------Footnotes----------
\par\par
n14. See Bruce Alberts et al., Glossary in Molecular Biology of the Cell G-8
(3d ed. 1994) (defining DNA as \'22serving as the carrier of genetic informati
on\'22). \par\par
n15. See Bruce Alberts et al., Molecular Biology of the Cell 385 (2d ed. 198
3); \i People v. Castro, 545 N.Y.S.2d 985, 988 (Sup. Ct. 1989)\i0 (detailing t
he scientific background behind the theory of DNA identification). Red blood c
ells, for instance, which do not have nuclei, do not carry DNA. See \i Castro,
545 N.Y.S.2d at 988.\i0 Also, DNA may be recoverable from other tissue through
a cell's mitochondria. See Barry Scheck, Privacy: The Impact of DNA Databases
33 (March 2, 1999) (transcript on file with Fordham Urban Law Journal) \'5Bhere
inafter Scheck Transcript\'5D. \par\par
n16. See Alberts et al., supra note 15, at 99. \par\par
n17. See \i People v. Wesley, 533 N.Y.S.2d 643, 646 (Albany County Ct. 1988)
.\i0 \par\par
n18. See \i Castro, 545 N.Y.S.2d at 988.\i0 \par\par
n19. See id. \par\par
n20. See Louis Levine, Biology of the Gene 11 (1969). \par\par
n21. See id. \par
\par
----------End Footnotes----------
\par\par
\'5B*1639\'5D Over ninety-nine percent of the base pairs described are the
same in all humans, responsible for a human's inherent form. n22 The remaining
base pairs, however, vary from person to person, n23 accounting for physical d
ifferences among humans that make each person unique. n24\par
\par
----------Footnotes----------
\par\par
n22. See Judith A. McKenna et al., Reference Guide on Forensic DNA Evidence,
in Reference Manual on Scienific Evidence 273, 281 (1994); Keith Inman & N ora
h Rudin, An Introduction to Forensic DNA Analysis 29 (1997). \par\par
n23. While DNA is unique to each individual, identical twins, with the same
genetic make-up, will posses identical DNA. See McKenna et al., supra note 22,
at 281. \par\par
n24. See id. Within a cell's nucleus, DNA is apportioned into forty-six sect
ions called chromosomes. See Simon Easteal et al., DNA Profiling: Principles Pi
tfalls and Potential 9 (1991). The ordinary human cell contains twenty-three p
airs of matching chromosomes, one chromosome per pair inherited from each paren
t. See id. Each human cell actually contains the same twenty-two pairs of chrom
osomes and a pair of sex chromosomes (male cells contain X and Y chromosomes, w
hile female cells contain two X chromosomes). See id. The portion of DNA involv
ed in produc ing certain physical traits is called a gene. See McKenna et al.,
supra note 22, at 281. Genes are located at specific sites, or loci, upon certa
in chromosomes. Alternate forms of genes are known as alleles. See id. at 282.
Alleles have a dramatic impact on cells, accounting for variant physical expres
sion among humans. See Easteal et al., supra note 24, at 12. A locus where the
allele differ among humans is called \'22polymorphic, and the difference is kno
wn as polymorphism.\'22 Mckenna et al., supra note 22, at 282. \par

\par
----------End Footnotes----------
\par\par
B. DNA Profiling n25\par
\par
DNA profiling technology provides law enforcement officials with a means of identifying individuals by detecting differences in cell structure. n26 DNA profiling involves three basic steps:\par
\par
----------Footnotes----------
\par\par
n25. In 1984, Alec Jeffreys discovered a unique application of technology for personal identification purposes. See Inman & Rudin, supra note 22, at 19. He termed the method \'22DNA fingerprinting,\'22 but scientists generally agree a better term for the process is \'22DNA typing\'22 or \'22DNA profiling.\'22 See id. \par\par
n26. See Mira Gur-Arie, The Science of DNA Profiling, in New York's DNA Databank and Commission on Forensic Science, An Analysis of Chapter 737 of the Laws of 1994, including the Complete Text of the New Statutory Provisions 16 (1994) \'5Bhereinafter Commission Analysis\'5D. \par
\par
----------End Footnotes----------
\par\par
\par
\par
(i) an analysis of both the known sample (taken from the suspect) and the unknown sample (recovered from the crime scene) to derive a series of DNA patterns present in each; (ii) a comparison of these profiles to determine if there is a match (indicating that an identity of source is possible) or an exclusion (indicating that such identity is unlikely); and (iii) if there is a match, a statistical analysis to determine what proportion of persons in the same population as the suspect have the same DNA patterns. n27\par
\par
----------Footnotes----------
\par\par
n27. Id. at 17 (citing National Research Council, DNA Technology in Forensic Science 51 (1992); Bruce S. Weir, Population Genetics in the Forensic DNA Debate, 89 Proc. Nat'l Acad. Sci. 11, 654 (1992)); see also \i Arizona v. Bible, 858 P.2d 1152, 1180 (Sup. Ct. 1993).\i0 \par
\par
----------End Footnotes----------
\par\par
\'5B*1640\'5D \par
\par
Identifying individuals for law enforcement purposes can be accomplished by utilizing one of several methods for comparing genetic variation. n28\par
\par
----------Footnotes----------
\par\par
n28. See Commission Analysis, supra note 26, at 17. \par
\par
----------End Footnotes----------
\par\par
1. RFLP Analysis\par

\par
RFLP analysis determines the size of a repetitive sequence of base pairs. n29 \'22Because the length of these sequences (sometimes called band size) of base pairs \'5Bcan vary greatly\'5D ... comparison of several corresponding sequence s of DNA from known (suspect) and unknown \'5Bcrime scene\'5D sources gives inf ormation about whether the two samples are from the same source.\'22 n30\par

\par
----------Footnotes----------
\par\par
n29. See M. Krawczak & J. Schmidtke, DNA Fingerprinting 27 (1994). Base pair sequences consistently repeat. See National Research Council, The Eval uation of Forensic Science 14 (1996). The repetitive sequences are known as Varia ble Number of Tandem Repeats. See id. \par\par
n30. McKenna et al., supra note 22, at 282. \par
\par
----------End Footnotes----------
\par\par
In the first step of RFLP analysis, DNA is separated from a sam ple of cells through the use of a centrifuge. n31 After extraction, the DNA is cleaned with organic solutions and divided into fragments with restriction enzymes. n32 Thr ough a procedure called \'22agarose gel electrophoresis,\'22 the fragments are then separated by length and placed adjacent to a positive electrode in a conta iner full of agarose gel. n33 Electric current is applied to the sample, causin g DNA fragments to separate by length. n34\par
\par
----------Footnotes----------
\par\par
n31. See Department of Criminal Justice, Forensic DNA Analysis: Issues 5 (19 91) \'5Bhereinafter Department Analysis\'5D. A centrifuge is \'22a machine \'5B used\'5D for whirling fluids rapidly to separate substances of different densit ies by centrifugal force.\'22 Webster's Third New International Dictionary 363 (1986). \par\par
n32. Restriction enzymes are virtual scissors used to cut DNA chains at spec ific sites. This stage is known as restriction digestion. See Commission Analys is, supra note 26, at 18. \par\par
n33. See id. Agarose Gel is a \'22gelatin-like material solidified in a slab about five inches thick.\'22 McKenna et al., supra note 22, at 282. \par\par

n34. See Commission Analysis, supra note 26, at 18. DNA carries a negative c harge and will, when electrocuted, move toward the positive electrode. See Depa r tment Analysis, supra note 31, at 5. The distance a single DNA fragment trave ls depends on its length, as shorter fragments travel farther than longer, heav ier frag ments. See id. \par
\par
----------End Footnotes----------
\par\par
After electrophoresis, the resulting DNA fragments are trans ferred from the gel to a nylon membrane, through a process called \'22Southern Blotting.\'22 n 35 The DNA is then unzipped by \'22heating \'5Band\'5D separating the double he lix into single strands\'5B,\'5D\'22 n36 exposing \'5B*1641\'5D the A, T, C and G base blocks. n37 Next, the unzipped fragments are exposed to radioactive probes, n38 \'22designed to be attracted only to polymorphic DNA segments, tho se that vary somewhat among individuals.\'22 n39\par

\par
----------Footnotes----------
\par\par
n35. See Department Analysis, supra note 31, at 5. \par\par
n36. McKenna et al., supra note 22, at 282. \par\par
n37. See Department Analysis, supra note 31, at 5. \par\par
n38. The probes are laboratory developed fragments carrying radioactive markers. See id. Each probe seeks out a matching sequence and binds to the complimentary strands. See id. \par\par
n39. Commission Analysis, supra note 26, at 18. This process is known as \'22hybridization.\'22 Id. The probes will seek out sequences with which they match and attach themselves to the strand. See Department Analysis, supra note 31, at 5. Therefore, a strand of \'22ATTGCA, for example, will bind with TAACGT.\'22 Id. at 6. \par
\par
----------End Footnotes----------
\par\par
The radioactivity of the probes allows for visual tracking via X-rays. n40 When film is developed, bands called \'22autorads\'22 are visible, representing an actual print of DNA band patterns. n41 The final stage of RFLP analysis involves band pattern comparison. n42 \'22Genetic differences between individuals will be identified by differences in the location and distribution of the band patterns, which correspond to the length of the DNA fragments present.\'22 n43 If two samples are from the same source, \'22hybridized DNA fragments of approximately the same length should appear at the same point in the suspect and evidence specimens.\'22 n44 This procedure, therefore, is not an actual comparison of genetic code, but is instead a measure of length of DNA fragments at a particular site on the DNA chain. n45\par
\par
----------Footnotes----------
\par\par
n40. See Department Analysis, supra note 31, at 6. \par\par
n41. See Commission Analysis, supra note 26, at 18. This image of bars is a comparable configuration to that found on a supermarket bar code. See Inman & Rudin, supra note 22, at 65. \par\par
n42. The autorads can be compared either visually or by computer. See Commission Analysis, supra note 26, at 18. Machine comparison converts the bar pattern into numeric code for purposes of analysis. See id. \par\par
n43. Department Analysis, supra note 31, at 6. \par\par
n44. McKenna et al., supra note 22, at 283. \par\par
n45. See Commission Analysis, supra note 26, at 18. Each fragment tends to vary in length among individuals. See id. While no single fragment is unique, an identical combination of lengths is extremely rare. See id. When a match is made, therefore, an estimate of the \'22frequency with which such a set of fragment length patterns is likely to appear in a given population\'5B \'5D\'22 is necessary to evaluate the significance of the match. Id. at 18-19. \par
\par
----------End Footnotes----------
\par\par
RFLP analysis is a useful technique because it is capable of discriminating between samples. n46 If at different markers there is band consistency, a high probability n47 exists that the DNA came \'5B*1642\'5D from the same source, thereby identifying a suspect. n48 Moreover, matching more bands increases the discrimination power of the analysis. n49 Conversely, inconsistency at marke

rs is dispositive that the suspect should be excluded. n50\par
\par
----------Footnotes----------
\par\par
n46. See Scheck Transcript, supra note 15, at 27. \par\par
n47. A five marker match would indicate that the same pattern could only be found in one-in-ten to one hundred million individuals. See id. at 27. \par\par
n48. See id. A commonly misunderstood point is that a DNA match via RFLP is not a declaration that a defendant is the source of the specimen tested. See Commission Analysis, supra note 26, at 19. Rather, the match of a DNA profile is merely an estimate of the frequency \'22with which this particular pattern of fragment lengths is likely to occur in the defendant's relevant ethnic population.\'22 Id. \par\par
n49. See Scheck Transcript, supra note 15, at 27. \par\par
n50. See id. at 28. \par
\par
----------End Footnotes----------
\par\par
One potential drawback to RFLP analysis is that a sufficient sample size is required to initiate the process. n51 Similarly, older samples cannot be utilized via this process because bacteria eats away at the DNA sample, rendering it useless for identification purposes. n52\par
\par
----------Footnotes----------
\par\par
n51. See Inman & Rudin, supra note 22, at 69. \par\par
n52. See Scheck Transcript, supra note 15, at 28. \par
\par
----------End Footnotes----------
\par\par
2. PCR Technique\par
\par
PCR is another effective identification technique available when there is an insufficient amount of DNA for RFLP analysis. n53 Essentially, the process replicates a minuscule DNA sample to enable genetic analysis. n54\par
\par
----------Footnotes----------
\par\par
n53. See Department Analysis, supra note 31, at 6. Another benefit of using this technique compared to RFLP is that one sample can be tested several times. See Scheck Transcript, supra note 15, at 30. Comparatively, RFLP analysis usually only permits but one test if a limited sample is present. See id. at 28. \par\par
n54. See Easteal et al., supra note 24, at 129. \par
\par
----------End Footnotes----------
\par\par
The first step, called denaturation, involves separating the two strands of the double helix so each can be used to generate a new strand. n55 Next, DNA primers n56 are used to establish a foundation on which DNA can replicate. n57 The primers must have a complimentary sequence of bases to the sample so that synthesis is possible. n58 An enzyme is applied to the sample, causing the primers to synthesize with their complimentary strands. n59 This process is per form

ed over and over, resulting in millions of copies of DNA iden \'5B*1643\'5D
tical to the original sample. n60 Finally, DNA is placed in a filter to evalua
te the amplified sample. n61\par
\par
----------Footnotes----------
- \par\par
n55. See Inman & Rudin, supra note 22, at 69. Separating the double helix re
quires heating the sample to 94 \'5Bdegrees\'5D C. See Easteal et al., supra n
ote 24, at 129. \par\par
n56. Primers are \'22short synthetic pieces of DNA that match defined locati
ons by complimentary base pairing.\'22 Inman & Rudin, supra note 22, at 70. \p
ar\par
n57. See Department Analysis, supra note 31, at 6. \par\par
n58. See id. \par\par
n59. See id. \par\par
n60. The process is also known as \'22molecular Xeroxing\'22 because of this
duplication effect. See Inman & Rudin, supra note 22, at 70. \par\par
n61. See \i People v. Lee, 537 N.W.2d 233, 251 (Mich. Ct. App. 1995).\i0 \p
ar
\par
----------End Footnotes----------
- \par\par
One manner of analysis is the DQ Alpha technique. Under this process, the am
plified DNA sample is placed over strips of probes containing DNA segments corr
esponding to a base known to exist at the studied site. n62 A reagent is then a
pplied that produces colored dots to appear where binding is successful between
the am plified DNA and the probe DNA, confirming the presence of targeted alle
les. n63 Because a high percentage of the population may carry a given allele,
n64 the analysis must be completed several times at different loci to narrow th
e percentage of people that could carry the fragments present in the DNA sample
. n65 The prob lem with this technique, therefore, is its lack of discriminatio
n, rais ing concerns over a coincidental match. n66\par
\par
----------Footnotes----------
- \par\par
n62. See Inman & Rudin, supra note 22, at 70-71. \par\par
n63. This comparison process is therefore known as \'22reverse-dot blot proc
edure or the blue-dot procedure.\'22 \i Lee, 537 N.W.2d at 251.\i0 \par\par

n64. At any given locus, for example, there may be alleles resulting merely
in brown or green eyes. See Department Analysis, supra note 31, at 6. \par\par

n65. See id. \par\par
n66. This method guarantees only that one of every 5000 individuals will pos
ses this genetic make-up. See Scheck Transcript, supra note 15, at 31. \par
\par
----------End Footnotes----------
- \par\par
Another analytic technique is the D1S80 method. Similar to RFLP, D1S80 analy
zes the variation present at a given locus of a defined DNA fragment. n67 Howev
er, because the sample size is small, it is amplified using PCR. n68 Like RFLP,
D1S80 distinguishes the sample manually using a chart resembling a supermarket
barcode. n69 Because only a limited number of loci are analyzed under this sys
tem, the power of discrimination is not as great as that of RFLP. n70\par

\par
----------Footnotes----------
\par\par
n67. See Inman & Rudin, supra note 22, at 47. \par\par
n68. However, unlike RFLP, the power of discrimination is limited because us
ually only one locus is analyzed. See id. \par\par
n69. See id. Another comparison method, Short Tandem Repeats (STR) is strik
ingly similar to the D1S80 system, except repeat units are shorter. See id. at
48. \par\par
n70. Also, the significance of the test may be further reduced if it analyze
s alleles common among individuals in particular racial groups. See id. at 47.
\par
\par
----------End Footnotes----------
\par\par
3. Mitochondrial DNA\par
\par
While both the RFLP and PCR methods analyze genetic mate rial residing within
a cell's nucleus, other bits of genetic material \'5B*1644\'5D exist in a c
ell's mitochondria. n71 The main advantage of analyzing mitochondrial DNA (\'22
mDNA\'22) is that it is available in hair and bone, materials that would prove
useless with other testing tech niques. n72 However, discrimination is a substa
ntial problem because mDNA, transmitted maternally, is identical in siblings an
d between mother and child. n73\par
\par
----------Footnotes----------
\par\par
n71. Mitochondria are subcellular compartments or organelles that supply pow
er to the cell. See National Research Council, supra note 29, at 72. \par\par

n72. See Scheck Transcript, supra note 15, at 34. \par\par
n73. See Easteal et al., supra note 24, at 136. \par
\par
----------End Footnotes----------
\par\par
C. DNA Databases\par
\par
DNA evidence has limited use as an identification tool without the utilization
of a computer database. n74 A DNA database is a computerized collection of DNA
profiles capable of being used for criminal identification purposes. n75 DNA p
rofiles are ideal for such storage because the information can be stored in num
eric code, thereby requiring minimal technology. n76 Essentially, a DNA test re
sult derived from a crime scene sample can be checked against the digital profi
les stored in the database. n77 Any matches made with database profiles can the
n be used as probable cause to obtain a sample from a suspect for further testi
ng. n78 This procedure guards against sampling errors that could have occurred
during data entry. n79\par
\par
----------Footnotes----------
\par\par
n74. Without the use of random DNA profiles to check it against, a sample of
DNA recovered from a crime scene would only be valuable if there were a suspec
t in cus tody who provided a sample matching the unknown sample. See generally
Kra wczak & Schmidtke, supra note 29, at 93 (acknowledging the limited impact o

f DNA evidence in a criminal justice system that does not utilize databases). T herefore, with out other evidence at a crime scene that produces a suspect, DNA evidence has little value. See id. \par\par

n75. See Inman & Rudin, supra note 22, at 133. \par\par

n76. See id. at 134. While DNA databases store the computerized DNA profile of an individual, the genetic samples from which the profiles are derived are o ften also kept in storage for future analysis. See Jean M. McEwen, DNA Databank s, in G enetic Secrets 231 (Mark A. Rothstein ed., 1997). \par\par

n77. See Department Analysis, supra note 31, at 25. This process is inherent ly similar to the one currently used to track latent fingerprints. See Inman & Rudin, supra note 22, at 133. The Automated Fingerprint Identification System (AFIS) con tains millions of citizens' fingerprints on computer file. See id. Fi ngerprints, like DNA, are unique to the individual and do not change over the c ourse of one's life. See National Research Council, supra note 29, at 57. Print s dusted at crime scenes can, therefore, be compared with those in the system t o generate suspects or lead to convictions. See id. \par\par

n78. See Inman & Rudin, supra note 22, at 134. \par\par

n79. See id. \par

\par

----------End Footnotes----------

- \par\par

\'5B*1645\'5D \par\par

1. Current State Laws on Criminal DNADatabases\par

\par

As of June 1998, all fifty states have passed legislation to create state DNA databases. n80 Generally, these laws require designated offenders to provide a genetic sample n81 for inclusion in the state DNA bank. n82 States usually cit e the assistance of law enforcement in identification and detection or exclusio n of individuals under criminal investigation as the main purpose of database l egislation. n83\par

\par

----------Footnotes----------

- \par\par

n80. See Ala. Code 36-18-20 (1994); Alaska Stat. 44.41.035 (Michie 1996); Ar iz. Rev. Stat. Ann. 31-281 (1993); Ark. Code Ann. 12-12-1101 (Michie 1994); Cal . Penal Code 290.2 (West 1994); Colo. Rev. Stat. Ann. 17-2- 201(5)(g)(I) (West 1995); Conn. Gen. Stat. Ann. 54-102g (West 1994); Del. Code Ann. tit. 29, 4713 (1994); Fla. Stat. Ann. 943.325 (West 1994); Ga. Code Ann. 24-4-60 (1992); Haw. Rev. Stat. Ann. 706-603 (Michie 1992); Idaho Code 19- 5504 (1996); 720 Ill. Co mp. Stat. Ann. 5/12-13 (West 1992); Ind. Code Ann. 10-1- 9-8 (West 1996); Iowa Code Ann. 13.10 (West 1991); Kan. Stat. Ann. 21-2511 (1991); Ky. Rev. Stat. Ann . 17.170 (Banks-Baldwin 1992); La. Rev. Stat. Ann. 15:605 (West 1999); Me. Rev. Stat. Ann. tit. 25, 1573 (West 1996); Md. Code Ann., Cts. & Jud. Proc. 10-915 (1994); Mass. Gen. Laws Ann. ch. 22E, 3 (Law. Co-op. 1997); Mich. Comp. Laws An n. 750.520m (West 1994); Minn. Stat. Ann. 299C.155 (West 1993); Miss. Code Ann. 45-33-15 (1995); Mo. Ann. Stat. 650.050 (West 1991); Mont. Code Ann. 44-6-102 (1995); Neb. Rev. Stat. 29- 4104 (1997); Nev. Rev. Stat. Ann. 176.0913 (Michie 1989); N.H. Rev. Stat. Ann. 632-A:22 (1996); N.J. Stat. Ann. 53:1-20.17 (West 1 994); N.M. Stat. Ann. 29- 16-2 (Michie 1997); N.Y. Exec. Law 995 (McKinney 1994); N.C. Gen. Stat. 15A- 266 (1993); N.D. Cent. Code 31-13-05 (1995); Ohio Rev. Code Ann. 2901.07 (West 1995); Okla. Stat. Ann. tit. 57, 584 (West 1996); Or. R ev. Stat. 181.085 (1998); 35 Pa. Cons. Stat. Ann. 7651.302 (West 1995); R.I. Ge n. Laws 12-1.5-4 (1998); S.C. Code Ann. 23-3-600 (Law. Co-op. 1995); S.D. Codif ied Laws 23-5- 14 (Michie 1990); Tenn. Code Ann. 38-6-113 (1991); Tex. Gov't Co

de Ann. 411.141 (West 1995); Utah Code Ann. 53-10-406 (1994); Vt. Stat. Ann. ti t. 20, 1931 (1998); Va. Code Ann. 19.2-310.2 (Michie 1993); Wash. Rev. Code Ann . 43.43.752 (West 1990); W. Va. Code 15-2B-1 (1995); Wis. Stat. Ann. 165.77 (We st 1993); Wyo. Stat. Ann. 7-19-402 (Michie 1997). \par\par

n81. Some states require a blood sample for testing. See, e.g., Haw. Rev. St at. Ann. 706-603(b) (Michie 1992); Okla. Stat. Ann. tit. 57, 584.A.2 (West 1996); Fla. Stat. Ann. 943.325(1)(a) (West 1994); Ga. Code Ann. 24-4-60 (1992); N.Y . Exec. Law 995-7 (McKinney 1994). Others, alternatively, call for a saliva swa b. See, e.g., Kan. Stat. Ann. 21-2511(a)(1991); Ark. Code Ann. 12-12-1103(7) (M ichie 1994). \par\par

n82. See McEwen, supra note 76, at 232. \par\par

n83. See, e.g., Ark. Code Ann. 12-12-1103(2) (Michie 1994); Alaska Stat. 44. 41.035(a) (Michie 1996); Ky. Rev. Stat. Ann. 17.175(2) (Banks-Baldwin 1992). \p ar

\par

----------End Footnotes----------

- \par\par

The scope of criminals included in DNA databases varies from state to state. Most statutes simply require a DNA sample from persons convicted of sex offens es and violent felonies. n84 Mean \'5B*1646\'5D while, other states have in creased the legislative scope to include persons convicted of any felony. n85\p ar

\par

----------Footnotes----------

- \par\par

n84. See, e.g., Haw. Rev. Stat. Ann. 706-603(3) (Michie 1992); Kan. Stat. An n. 21-2511(a) (1991); Ark. Code Ann. 12-12-1103(10-11) (Michie 1994); N.J. Stat . Ann. 53:1-20.20(a) (West 1994); N.Y. Exec. Law 995-c.3. (McKinney 1994). \pa r\par

n85. See, e.g., Va. Code Ann. 19.2-310.2 (Michie 1993); W. Va. Code 15-2B-1 (1995). \par

\par

----------End Footnotes----------

- \par\par

2. National DNA Database Policy\par

\par

The federal government also has taken steps in conjunction with states to appl y technology to national criminal investigations. The DNA Identification Act of 1994 n86 authorized the FBI to establish the Combined DNA Index System (\'22CO DIS\'22). n87 CODIS is a three-tiered n88 computer system used to facilitate th e exchange of DNA profile information across the nation. n89 The national tier of the CODIS network, the National DNA Index System (\'22NDIS\'22), is \'22a re pository for DNA profiles submitted by participating states. The NDIS allows st ates to exchange DNA profiles and perform inter-state \'5Bsearches\'5D.\'22 n90 To aid in administration, DNA profiles are stored in three indices: convicted offenders, unknown suspects and a population file used for statistical purposes . n91 States there fore are not limited to their own databases, and can search more effectively for suspects who cross state lines. n92\par

\par

----------Footnotes----------

- \par\par

n86. \i 42 U.S.C. 14131\i0 (1994). \par\par

n87. See id. 14132. \par\par

n88. CODIS' three hierarchical levels include local, state and national tier

s. See What's the Difference Between NDIS and CODIS (visited Jan 20, 1999) <htt
p://www.fbi.gov/pressrel/diff> \'5Bhereinafter FBI Release\'5D. All three conta
in DNA profiles, but each are flexible to meet the specific legislative or tech
nical needs of state and local enforcement agencies. See id. The Local DNA Inde
x System (LDIS) is \'22installed at crime laboratories operated by police depar
tments or sheriff's offices. All DNA profiles originate at the local level, the
n flow to the state and national levels.\'22 Id. The State DNA Index System (\'
22SDIS\'22), \'22allows laboratories within a state to exchange DNA profiles. T
he SDIS is also the communications path between the local and national tiers. T
he SDIS is typically operated by the agency responsible for implementing as a s
tate convicted offender statute.\'22 Id. \par\par
n89. See McEwen, supra note 76, at 233. \par\par
n90. FBI Release, supra note 88. \par\par
n91. See Howard Safir, Remarks to the Students of Bronx High School of Scien
ce (Dec. 14, 1998) at 9-10 (transcript on file with Fordham Urban Law Journal)
\'5Bherein after Safir's Plan\'5D. \par\par
n92. See McEwen, supra note 76, at 233. For example, in December 1997, withi
n minutes of networking eight states into CODIS, a perpetrator in a 1989 Wiscon
sin rape and attempted murder was identified as a convicted Illinois sex offend
er. See Safir's Plan, supra note 91, at 10. Also, by September 1996, databases
accounted for matching 58 profiles where unknown DNA from a crime scene was fo
und to be the same as a criminal profile of a known offender in another state.
See McEwen, supra note 76, at 233. \par
\par
----------End Footnotes----------
\par\par
\'5B*1647\'5D \par\par
3. More Intrusive DNA Databases\par
\par
The theory behind more expansive databases, storing the profiles of all those
arrested, is not an unprecedented concept. Great Brit ain currently permits its
law enforcement officials to collect non- intimate samples, such as hair and s
aliva, from all individuals ar rested for a recordable offense. n93\par
\par
----------Footnotes----------
\par\par
n93. See Criminal Justice and Public Order Act, Pt. IV, 55 (1994) (Eng.). Th
e samples taken include non-intimate tissue such as hair or saliva. Louisiana a
lso au thorized a similar system to begin in the Fall of 1999. See Eric Fettman
n, Isn't Crime the Worst Privacy Invasion of All?, N.Y. Post, Dec. 20, 1998, at
81.\par
\par
----------End Footnotes----------
\par\par
The British system, operational since April 1995, has met with resounding in
vestigative success. n94 Approximately 135,000 samples were collected within th
e system's first year n95 and 463,000 samples currently are included. n96 To da
te, over 38,000 suspect to crime matches have been obtained in investigations,
with a success rate of three to five hundred matches per week. n97 Over the las
t five years, 40,000 crimes have been solved with the help of DNA database prof
iles and more than 51,000 suspects have been exonerated. n98 Additionally, over
6,000 links have been made between separate crime scenes, proving crimes were
being committed by the same individual. n99 These statistics exemplify the inve
stigative benefits offered by an expansive DNA database.\par

\par
----------Footnotes----------
\par\par
n94. In addition to using its database, Great Britain also practices \'22Blo odings\'22 in circumstances where an offender is known to live among a certain population. Law enforcement officials will collect blood from every person in t he area to ferret out the guilty. See Scheck Transcript, supra note 15, at 42. Such DNA samples, however, are not placed into the State databank. See id. \pa r\par

n95. See McEwen, supra note 76, at 236. \par\par

n96. See Scheck Transcript, supra note 15, at 45. \par\par

n97. See Safir's Plan, supra note 91, at 13. The greatest number of hits in a week was over 1000. See Scheck Transcript, supra note 15, at 47. \par\par

n98. See Today: Police Commissioner Howard Safir and Norman Siegel of New Yo rk Civil Liberties Union Debate Proposed Policy of Taking DNA Sample and Other Tests on Everyone Arrested in New York City (NBC television broadcast, Dec. 15 , 1998) \'5Bhereinafter Today Debate\'5D (quoting Safir's comments on Great Bri tain's inves tigation success). \par\par

n99. See Fettmann, supra note 93, at 81. \par
\par
----------End Footnotes----------
\par\par

D. Safir's Proposal\par
\par

On December 14, 1998, New York City Police Commissioner Howard Safir launched a bold campaign to widen the scope of New York's compulsory DNA statute to enco mpass aspects of Great Britain's system. n100 Safir's plan calls for the univer sal DNA testing \'5B*1648\'5D of all those arrested so that the individual' s DNA can be included in a DNA database. n101 If passed, such an amendment woul d ex pand section 995 of the New York Executive Law, n102 which cur rently perm its involuntary DNA samples to be taken from designated offenders for inclusion into a statewide database. n103 This DNA database includes DNA identification information from persons convicted of assault, homicide and certain sex offense s. n104\par
\par
----------Footnotes----------
\par\par

n100. Safir introduced the initiative for the first time while addressing th e students of the Bronx High School of Science. See Safir's Plan, supra note 91 , at 1. \par\par

n101. See id. \par\par

n102. See N.Y. Exec. Law 995 (McKinney 1994). \par\par

n103. See id. 995-c.3. \par\par

n104. See id. 995.7.; see also supra note 1 (detailing specific offenses enu merated within the statute). This current program covers only eight percent of felony offend ers. See Gary Spencer, Action Predicted on Bills on DNA, Ending P arole, N.Y. L.J., Feb. 8, 1999, at 7. Blood samples have been taken from about 6000 offenders since the program began in 1996. See id. \par
\par
----------End Footnotes----------
\par\par

In short, Safir's plan is to begin taking DNA samples from all individuals a rrested for a recordable offense, as opposed to limiting testing to designated offenders under section 995. n105 Under the proposal, police would swab a suspe

ct's mouth for about thirty seconds to collect DNA present in saliva. n106 The DNA sample would then be used to create a computerized DNA profile, which would then be stored in a statewide database. This information would aid in suspect identification by matching genetic material found at crime scenes against a poo l of known offenders, similar to the method currently employed in matching late nt fingerprints against criminal records. n107 According to Safir, creation of a uni versal DNA database will enable police to narrow the field of pos sible s uspects in a crime more quickly (exposing the guilty and exonerating the innoce nt), efficiently arrest repeat offenders and save costs. n108\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n105. See Today Debate, supra note 98. Safir wants to assure the public that unre cordable offenses, such as traffic infractions, would not fall within the scope of this proposal. See id. \par\par
n106. See Safir's Plan, supra note 91, at 13. \par\par
n107. See \i Spencer, supra \i0 note 104, at 7. \par\par
n108. See Safir's Plan, supra note 91, at 14-17. \par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - - -
- \par\par
Meanwhile, Safir assures steps would be taken to minimize the risk of abuse of the collected specimens. n109 First, the computerized DNA profile would be e xpunged and the DNA sample destroyed upon acquittal or pardon of an offense. n1 10 Second, access to the database would be limited so the information could not be misap \'5B*1649\'5D propriated, but instead used exclusively for law en forcement iden tification purposes. n111\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n109. See infra text accompanying notes 204-205. \par\par
n110. See Safir's Plan, supra note 91, at 13. \par\par
n111. See id. \par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - - -
- \par\par
Publicly, Safir's plan has been met with mixed reaction. New York City mayor Rudolph Giuliani wholly endorses the plan as a novel, effective law enforcemen t tool. n112 A number of other politi cians likewise support the program, but t o varying degrees. n113 For instance, some would simply prefer to expand the st atute to include DNA from only convicted felons, and not those convicted of all offenses as Safir suggests. n114 On the other hand, some are ada mantly oppose d to amending the statute altogether. n115\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n112. See Mayor Rudolph W. Giuliani: Celebrating Our Progress in Building a Safer City, and Moving Forward (WINS Radio Broadcast, Jan. 3, 1999) (visited Ja n. 14, 1999) <http://www.ci.nyc.ny.us/html/om/html/99a/me990103.html>. Specific ally, Mayor Giuliani stated: \par\par
\par
\par
\'5BA\'5D few weeks ago Police Commissioner Safir called for what we believe c an be another important tool to continue reducing crime in the City: DNA test i

ng. Sampling the DNA of all those who are arrested-through a very simple, non-i
nvasive procedure that involves briefly placing a swab in the mouth to collect
saliva is essentially a more advanced and more precise form of finger printing.
In concert with strict privacy protections so that the process cannot be misu
sed, DNA represents an important new tool in policing that can help convict the
guilty and, equally important, keep the innocent free. \par
\par
Id. \par\par
n113. For example, State Senator Roy Goodman hails the proposal as offering
a high-tech crimefighting tool. Senator Goodman states, \'22This is a better fi
ngerprint. Call it a throat print. I think it makes all sorts of sense.\'22 Tra
cey Tully, Democrats Rip Safir's DNA Plan, Politicians See 'Police State' Tacti
c, N.Y. Daily News, Dec. 16, 1998, at 8. \par\par
n114. State Senator Dale Volker feels Safir's idea has a more realistic chan
ce of be coming law if it limits DNA testing to suspects arrested on felony cha
rges. See Mat thew Cox, Cool Response to Safir DNA Plan, N.Y. Newsday, Dec. 16,
1998, at A30. New York Governor George Pataki plans to propose such an idea al
ongside Safir's Plan to the State Assembly. See \i Spencer, supra \i0 note 104,
at 7. \par\par
n115. See infra text accompanying note 117. \par
\par
----------End Footnotes----------
\par\par
II. Conflict Surrounding Safir'sPlan \par\par
A. Constitutional Argument Against Safir'sPlan\par
\par
Opponents of DNA extraction for use in a universal database argue that the pro
cedure violates the Fourth Amendment guaran tee against unreasonable searches a
nd seizures on the grounds that such bodily searches are conducted in the absen
ce of individualized suspicion. n116 For instance, Norman Siegel, executive dir
ector of the New York Civil Liberties Union contends that the practice is un co
nstitutional because \'22in order to get DNA under the Fourth \'5B*1650\'5D
Amendment, \'5Bthe government\'5D would have to show that the gath ering of th
e DNA is relevant to the crime. That means that \'5Bthe government has\'5D to s
how that there was blood, semen, \'5Bor\'5D saliva at the crime scene in order
to make the match.\'22 n117 Proponents of such plans, however, observe that if
individualized suspicion must exist before a suspect is required to submit a sa
mple, an effective DNA database would be impossible to implement. n118 DNA data
bases refute the idea of individualized suspicion because the collection of sam
ples is intended to \'22solve future cases for which no present suspicion can e
xist.\'22 n119\par
\par
----------Footnotes----------
\par\par
n116. See \i Jones v. Murray, 962 F.2d 302, 305 (4th Cir. 1992);\i0 \i Boli
ng v. Romer, 101 F.3d 1336, 1338 (10th Cir. 1996);\i0 \i State v. Olivas, 856
P.2d 1076, 1081 (1993).\i0 \par\par
n117. Today Debate, supra note 98. \par\par
n118. See \i Jones, 962 F.2d at 305.\i0 \par\par
n119. Id. \par
\par
----------End Footnotes----------
\par\par
I. The Fourth Amendment Standard\par

\par
The primary function of the Fourth Amendment is to ensure a citizen's personal privacy against unwarranted State intrusions. n120 Specifically, the Fourth Amendment reads, in pertinent part: \'22The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated and no Warrants shall issue, but upon probable cause, ... particularly describing the place to be searched, and the per sons or things to be seized.\'22 n121 This federal guarantee also prohib its unreasonable searches and seizures conducted by state officers via the Fourteenth Amendment. n122 To prove an action violates Fourth Amendment rights, therefore, one must first show that the government action constituted a search, then prove it lacked the requisite amount of reasonableness.\par
\par
----------Footnotes----------
\par\par
n120. See \i United States v. Martinez Fuerte, 428 U.S. 543, 554 (1975);\i0 \i Schmerber v. California, 384 U.S. 757, 767 (1966).\i0 \par\par
n121. U.S. Const. amend. IV. \par\par
n122. See \i New Jersey v. T.L.O., 469 U.S. 325, 334 (1985);\i0 \i Mapp v. Ohio, 367 U.S. 643, 655 (1961)\i0 (holding that \'22since the Fourth Amendment's right of privacy has been declared enforceable against the States through the Due Process Clause of the Fourteenth \'5BAmendment\'5D, it is enforceable against them by the same sanction of ex clusion as is used against the Federal Government\'22). \par
\par
----------End Footnotes----------
\par\par
2. The Search Requirement\par
\par
Implication of Fourth Amendment protection first requires the determination of whether a government official's action constitutes a search. n123 In Katz v. United States, n124 the Supreme Court intro \'5B*1651\'5D duced the appropriate standard as to what actions constitute a \'22search\'22 within the dictates of the Fourth Amendment. n125 The Court held:\par
\par
----------Footnotes----------
\par\par
n123. See Hon Charles E. Moylan, Jr., A Conceptualization of the Fourth Amendment, in William W. Greenhalgh, The Fourth Amendment Handbook, A Chronological Survey of Supreme Court Decisions 6 (1995). \par\par
n124. \i 389 U.S. 347 (1967).\i0 \par\par
n125. In Katz, FBI agents, without first obtaining a warrant, used electronic eaves dropping equipment to record Charles Katz's conversation in a public telephone booth. Officials recorded Katz's voice as he transmitted wagering information over the telephone. It was clear the agents violated Katz's Fourth Amendment rights be cause they did not obtain a court order for placement of the equipment. The issue, however, was whether the Fourth Amendment even covered such a situation without a physical intrusion into a constitutionally protected area. See \i Katz v. United States, 369 F.2d 130 (9th Cir. 1966).\i0 \par
\par
----------End Footnotes----------
\par\par
\par
\par

The Fourth Amendment protects people, not places. What a person knowingly expo
ses to the public, even in his own home or office, is not a subject of Fourth A
mendment protection. But what he seeks to preserve as private, even in an area
accessible to the public, may be constitutionally protected. n126\par
\par
----------Footnotes----------
\par\par
n126. See \i Katz, 389 U.S. at 351.\i0 The Court then found \'22the Governm
ent's activi ties in electronically listening to and recording \'5BKatz's\'5D w
ords violated the privacy upon which he justifiably relied while using the tele
phone booth and thus constituted a 'search and seizure' within the meaning of t
he Fourth Amendment.\'22 \i Id. at 353.\i0 \par
\par
----------End Footnotes----------
\par\par
\par
\par
In a concurring opinion, Justice Harlan refined the Court's analy sis, definin
g a \'22search\'22 as a government intrusion into an area where an individual h
as a \'22reasonable expectation of privacy.\'22 n127\par
\par
----------Footnotes----------
\par\par
n127. \i Id. at 360\i0 (Harlan, J., concurring). \par
\par
----------End Footnotes----------
\par\par
Given this framework, the Supreme Court has determined the withdrawal of blo
od to be a search under the Fourth Amend ment. n128 Specifically, in Schmerber
v. California, n129 the Court de finitively stated, \'22it could not reasonably
be argued ... that the administration of the blood test in this case was free
of the con straints of the Fourth Amendment. Such testing procedures plainly co
nstitute searches ... within the meaning of that Amendment.\'22 n130 \'5B*1652\
'5D Since Schmerber, the withdrawal of blood consistently is referred to as a
\'22search.\'22 n131\par
\par
----------Footnotes----------
\par\par
n128. See \i Schmerber v. California, 384 U.S. 757 (1966).\i0 In Schmerber,
the Supreme Court held a state could withdraw blood from a motorist suspected
of drunk driving, despite his refusal to consent to the search. See \i id. at 7
58-59.\i0 The Court felt the action did not violate the motorist's Fourth Amen
dment rights because the Fourth Amendment's proper use is to protect only again
st intrusions that are not justified under the circumstances or made in an impr
oper manner. See \i id. at 768.\i0 The blood test was performed properly, \'22
taken by a physician in a hospital environment accord ing to accepted medical p
ractices.\'22 \i Id. at 771.\i0 The intrusion, meanwhile, was classi fied as i
nsignificant since \'22tests are a commonplace in these days of periodic physic
al examination and experience with them teaches that the quality of blood extra
cted is minimal, and that for most people the procedure involves virtually no r
isk, trauma, or pain.\'22 Id. \par\par
n129. See \i id. at 757.\i0 \par\par
n130. \i Id. at 767.\i0 \par\par
n131. See, e.g., \i Skinner v. Railway Labor Executives' Ass'n, 489 U.S. 602

, 616 (1989)\i0 (\'22We have long recognized that a 'compelled intrusion into the body for blood to be analyzed for alcohol content' must be deemed a Fourth Amendment search.\'22); Win ston v. \i Lee, 470 U.S. 753, 760 (1985)\i0 (reaff irming the Schmerber analysis); \i Rise v. Oregon, 59 F.3d 1156, 1159 (9th Cir. 1995)\i0 (\'22Non-consensual extraction of blood im plicated Fourth Amendment privacy rights.\'22); \i Jones v. Murray, 962 F.2d 302, 306 (4th Cir. 1992)\i0 (noting that \'22the bodily intrusion resulting from taking a blood sample co nstitutes a search within the scope of the Fourth Amendment\'22). \par
\par
----------End Footnotes----------
\par\par
Collection and analysis of urine similarly has been deemed a Fourth Amendmen t search by the Court. n132 In Skinner v. Railway Labor Executives' Ass'n, n133 the Supreme Court announced, \'22it is clear that the collection and testing o f urine intrudes upon expecta tions of privacy that society has long recognized as reasonable ... and ... these intrusions must be deemed searches under the F ourth Amendment.\'22 n134 Skinner further documents unanimous recogni tion of t his principle among the Federal Courts of Appeals. n135\par
\par
----------Footnotes----------
\par\par
n132. See \i Skinner, 489 U.S. at 617.\i0 In Skinner, the Court upheld the Federal Rail road Administration's drug and alcohol tests as constitutional. Se e \i id. at 634.\i0 The Court concluded the testing was reasonable under the F ourth Amendment even in the absence of a search warrant or reasonable suspicion of any particular employee due to the compelling government interest served by the mandate, which outweighed the voiced privacy concerns. See id. \par\par

n133. See \i id. at 602.\i0 \par\par
n134. \i Id. at 617.\i0 \par\par
n135. See id. (citing, for example, \i Lovvorn v. Chattanooga, 846 F.2d 1539 , 1542 (6th Cir. 1988);\i0 \i Copeland v. Philadelphia Police Dep't, 840 F.2d 1139, 1143 (3d Cir. 1988);\i0 \i National Treasury Employees Union v. Von Raab , 816 F.2d 170, 176 (5th Cir. 1987)).\i0 \par
\par
----------End Footnotes----------
\par\par
3. The Reasonableness Requirement\par
\par
Finding a practice to be a \'22search\'22 under the Fourth Amend ment is only the first step toward setting the standard governing such intrusions. n136 \'22 The Fourth Amendment does not proscribe all searches and seizures but only thos e that are unreasonable.\'22 n137 \'5B*1653\'5D Reasonableness \'22depends on all of the circumstances surrounding the search or seizure and the nature of the search or seizure it self.\'22 n138 Therefore, the viability of a search \ '22'is judged by balanc ing its intrusion on the individual's Fourth Amendment interests against its promotion of legitimate governmental interests.'\'22 n139 \par
\par
----------Footnotes----------
\par\par
n136. See id., at 618-19; \i New Jersey v. T.L.O., 469 U.S. 325, 337 (1985). \i0 \par\par
n137. \i Skinner, 489 U.S. at 619\i0 (citing \i United States v. Sharpe, 4

70 U.S. 675, 682 (1985));\i0 \i Schmerber v. California, 384 U.S. 757, 768 (19 66).\i0 This reasonableness re quirement arises from the Constitutional langua ge itself. See U.S. Const. amend. IV. (guaranteeing security against \'22unreas onable searches and seizures\'22). Schmerber also articulately stresses the nee d for a reasonable search: \par\par

\par

\par

The Fourth Amendment's proper function is to constrain, not against all intrus ions as such, but against intrusions which are not justified in the cir cumstan ces, or which are made in an improper manner. In other words, the question\'5B \'5D we must decide in this case \'5Bis\'5D ... whether the means and proce dur es employed in \'5Bthe search\'5D respected relevant Fourth Amendment stan dard s of reasonableness. \par\par

\par

\par

\i Schmerber, 384 U.S. at 768.\i0 \par\par

n138. \i United States v. Montoya de Hernandez, 473 U.S. 531, 537 (1985);\i 0 \i T.L.O., 469 U.S. at 337\i0 (\'22What is reasonable depends on the contex t within which a search takes place.\'22). \par\par

n139. \i Skinner, 489 U.S. at 619\i0 (quoting \i Delaware v. Prouse, 440 U .S. 648, 654 (1979));\i0 see also, \i T.L.O. 469 U.S. at 337;\i0 \i Bell v. W olfish, 441 U.S. 520, 559 (1979);\i0 \i Jones v. Murray, 962 F.2d 302, 305 (4t h Cir. 1992).\i0 \par

\par

----------End Footnotes----------

\par\par

The Skinner n140 Court recognized that in most criminal cases the aforementi oned balance is struck by requiring a search warrant in the Fourth Amendment. n 141 When non-consensual extraction of bodily fluids is performed without a warr ant or individualized sus picion, the Court demands that the state have \'22'sp ecial needs' be yond normal law enforcement that may justify departures from th e usual warrant and probable-cause requirements.\'22 n142 Specifically, the Cou rt stressed:\par

\par

----------Footnotes----------

\par\par

n140. \i 489 U.S. at 602.\i0 \par\par

n141. See \i id. at 619.\i0 \par\par

n142. \i Id. at 620\i0 (quoting \i Griffin v. Wisconsin, 483 U.S. 868, 873 -74 (1987)).\i0 See supra note 132 (summarizing Skinner). The Court stated the scrutinized regulation furthered the government's special need to prevent acci dents and casualties in rail road operations that result from railroad employee s under the influence of drugs or alcohol. See \i Skinner, 489 U.S. at 620-21. \i0 Once this \'22special need\'22 for testing was found, the Court concluded the warrant requirement in this case would not further traditional purposes of a warrant because drugs and alcohol dissipate quickly from the body. See \i id. at 623.\i0 Requiring a warrant would, therefore, frustrate the govern ment's interest in the search. See id. \par

\par

----------End Footnotes----------

\par\par

\par

\par

\'5BA\'5D showing of individualized suspicion is not a constitutional floor, b

elow which a search must be presumed unreasonable. In limited circumstances, wh ere the privacy interests implicated by the search are minimal, and where an im portant government in terest furthered by the intrusion would be placed in jeop ardy by a requirement of individualized suspicion, a search may be rea sonable despite the absence of such suspicion. n143\par
\par
----------Footnotes----------
\par\par
n143. \i Skinner, 489 U.S. at 624.\i0 \par
\par
----------End Footnotes----------
\par\par
\par
\par
B. Potential for Misuse of ObtainedInformation\par
\par
In addition to the documented constitutional arguments, n144 op ponents of DNA databanking also highlight the serious risk of abusing the vast amount of info rmation available in an individual's \'5B*1654\'5D DNA. n145 The DNA of an individual, serving as the human code, n146 is a virtual blueprint of genetic m ake-up that carries a map of that person's biological past and future. n147 Opp onents cite numerous instances where such information, when misappropriated, ca n be used for nefarious purposes. n148 For instance, some are concerned that em ployers would use private genetic information in a discrimi natory manner. n149 Also, there is a fear that insurance companies might use the information of di sease propensity to raise health in surance premiums or deny coverage altogethe r. n150 Even the gov ernment is cited as a potential candidate for misappropria tion of the information. n151 These arguments are further supplemented by Justi ce Brennan's n152 concurrence in Whalen v. Roe, n153 stating pro \'5B*1655\'5D phetically: \'22The central storage and easy accessibility of computer ized data vastly increase the potential for abuse of that information, and I am not prepared to say that future develop ments will not demonstrate the necessity o f some curb on such technology.\'22 n154\par
\par
----------Footnotes----------
\par\par
n144. See supra text accompanying note 116. \par\par
n145. See C. Teddy Li, Boling v. Romer: Federal Courts Condone Forced Withdr awal of Blood for DNA Databanks Despite Constitutional Concerns, \i 1 J. Health Care L. & Pol'y 421, 431 (1998)\i0 (citing Yale H. Yee, Note, Criminal DNA Da tabanks: Revolution for Law Enforcement or Threat to Individual Privacy?, \i 22 Am. J. Crim. L. 461, 462 (1995)).\i0 \par\par
n146. See id. \par\par
n147. See Karen Ann Jensen, Note, Genetic Privacy in Washington State: Polic y Considerations and a Model Genetic Privacy Act, 21 Seattle U. L. Rev. 357, 35 9-60 (1997). This commentary utilizes the term \'22future diary\'22, which is a pplicable to the instant contentions. See id. at 360. Acknowledging a diary con tains past information of a personal and private nature, genetic information st ored in DNA can be called a \'22future diary\'22 because it carries information about future health. See id. \par\par
n148. See Fettmann, supra note 93, at 81. \par\par
n149. See Kathy Day, Genetic Testing Leads to Discrimination Questions, San D iego Daily Transcript, Aug. 4, 1992, at 1 (raising the issue of whether emplo yers who possess knowledge of an individual's high susceptibility to an occupat

ional dis ease would deny a job); see also Michael Kirby, Genetic Testing and D
iscrimination: The Development of Genetic Testing Confronts Humanity with Urgen
t Challenges, UNESCO Courier, May 1, 1998, at 29 (stressing that an employer's
desire to know of a worker's disease susceptibility in light of potential costs
such as disability bene fits, sick leave and replacement pay). \par\par

n150. See Kirby, supra, note 149, at 29. Insurance in the past was relativel
y fixed by analyzing the risks of the \'22onset of a multitude of genetic disor
ders amongst all mem bers of the insuring public.\'22 Id. Kirby argues that now
the insurance company will gain an upper hand in offering higher premiums or f
latly denying coverage because of the availability of particular genetic inform
ation of inherited orders. See id. Insurers merely argue they should be able to
obtain such information because it is merely \'22substituting the latest scien
tific information for the old-fashioned medical check-ups and replacing general
ized data of life expectancy with accurate predictive data of ge netic disorder
s.\'22 Id. \par\par

n151. See George J. Annas, Privacy Rules for DNA Databanks: Protecting Coded
'Future Diaries', \i 270 JAMA 2346, 2348 (1993).\i0 Annas envisions law enfor
cement or child protection agencies using DNA information to ensure parents of
children with inherent genetic conditions are providing proper medical care. Se
e id. \par\par

n152. See \i id. at 2346.\i0 \par\par

n153. \i 429 U.S. 589 (1977).\i0 This case concerned an action brought by
physicians and patients challenging a New York statute requiring the state to b
e provided with a copy of a prescription for certain drugs. See id. The Court h
eld the statute to be a reason able exercise of the state's broad police power,
responding to concerns that drugs were being appropriated for unlawful use. Se
e id. \par\par

n154. \i Id. at 607\i0 (Brennan, J., concurring). \par
\par
----------End Footnotes----------
\par\par

While \'22genetic redlining\'22 n155 may be easy to dismiss as an alarm ist
or extremist reaction, n156 a simple look at American genetic prac tices over t
he last century illustrate why there is a cause for concern. During the 1920s,
for example, strong judicial support was lent to the eugenics movement, callin
g for sterilization of citi zens deemed undesirable. n157 Specifically, the Sup
reme Court up held a Virginia statute compelling sterilization for those judged
to be \'22manifestly unfit from continuing their kind.\'22 n158\par
\par
----------Footnotes----------
\par\par

n155. \'22Genetic Redlining\'22 is \'22differentiated treatment based on app
arent or per ceived human variation.\'22 Janet C. Hoeffel, Note, The Dark Side
of DNA Profiling: Unreliable Scientific Evidence Meets the Criminal Defendant,
\i 42 Stan. L. Rev. 465, 534 (1990).\i0 \par\par

n156. See Today Debate, supra note 98. (including Safir's classification of
the liberal view as \'22alarmist\'22). \par\par

n157. See Hoeffel, supra note 155, at 534 (citing Philip Reilly, Genetics, L
aw and Social Policy 124 (1977)). \par\par

n158. \i Buck v. Bell, 274 U.S. 200, 207 (1927).\i0 \par
\par
----------End Footnotes----------
\par\par

Evidence of genetic redlining is not so dated, however. In fact, during the

1970s, states enacted legislation to identify carriers of the sickle cell anemi
a gene to discourage them from bearing chil dren. n159 African-Americans, as th
e primary carriers of the gene, immediately felt discriminatory repercussions i
n the form of de creased job opportunities and higher insurance premiums. n160\
par
\par
----------Footnotes----------
- \par\par
n159. See Hoeffel, supra note 155, at 534. \par\par
n160. See id. at 534-35; see also Day, supra note 149, at 1 (describing how
the identi fication of sickle cell anemia carriers led to exclusion of opportun
ities in the military from amphibious and flight assignments). \par
\par
----------End Footnotes----------
- \par\par
III. Analysis \par\par
A. DNA Extraction Under Safir's Plan is a Search Within the Meaning of the F
ourthAmendment\par
\par
Under the analyses of Schmerber and Skinner, Safir's plan, call ing for swabbi
ng an accused's cheek to obtain a saliva sample for DNA analysis, n161 should b
e deemed a Fourth Amendment search. \'5B*1656\'5D Although a relatively new
analysis, n162 saliva sampling is favorably comparable with the testing of blo
od and urine. n163 First, the proce dure involves an intrusion reaching \'22bey
ond the physical charac teristics exposed to the public and into the security o
f the person.\'22 n164 Second, a saliva sample can, like blood and urine, pro v
ide significant amounts of genetic identity information. n165 Over the last dec
ade, courts utilized these factors in asserting that an oral swabbing procedure
, like the one suggested by Safir, impli cates the Fourth Amendment. n166 At le
ast one New York Federal District Court is among those in compliance. n167\par

\par
----------Footnotes----------
- \par\par
n161. See Safir's Plan, supra note 91, at 13. \par\par
n162. See \i Henry v. Ryan, 775 F. Supp. 247, 253 (N.D. Ill. 1991)\i0 (comm
enting that while no court to date had explicitly held saliva extraction to be
a Fourth Amendment search, this court would make the assertion). \par\par
n163. See \i Schlicher v. Peters, 103 F.3d 940, 943 (10th Cir. 1996);\i0 \i
United States v. Nicolosi, 885 F. Supp. 50, 55 (E.D.N.Y. 1995);\i0 \i Henry,
775 F. Supp. at 255.\i0 \par\par
n164. \i Henry, 775 F. Supp. at 253\i0 (citing \i Cupp v. Murphy, 412 U.S.
291, 295 (1973)).\i0 \par\par
n165. See \i Nicolosi, 885 F. Supp. at 55.\i0 \par\par
n166. See \i Shelton v. Gundmanson, 934 F. Supp. 1048, 1050 (W.D. Wis. 1996)
\i0 (involv ing swabbing the inside of an individual's mouth cheek with a spon
ge-like tooth brush); \i Nicolosi, 885 F. Supp. at 55\i0 (assuming the saliva
sample would be obtained by swabbing the inside of the subject's mouth with a p
ad of some sort). \par\par
n167. See \i Nicolosi, 885 F. Supp. at 55.\i0 This case involved a prosecut
ion for sending threatening communications through the mail in violation of \i
18 U.S.C. 876.\i0 See \i id. at 51.\i0 The government obtained a \'22so-order
ed\'22 subpoena directing the accused to provide a saliva sample. See id. The d
efendant refused, claiming the prosecution must first obtain a valid search war

rant in conformance with the requirements of the Fourth Amendment. See id. The District Court was asked to decide whether the Fourth Amendment applied to the ability of the Government to obtain saliva samples. See id. The court held that , in light of the facts that the search implicated a dignity interest by swabbi ng the inside of the defendant's mouth and the sample can provide a significant amount of genetic information not within the public domain, proper com pliance with the Fourth Amendment is necessary. See \i id. at 55.\i0 \par
\par
----------End Footnotes----------
- \par\par
B. Safir's Plan is Reasonable\par
\par
Because saliva extraction can be considered a \'22search\'22 under the Fourth Amendment, the next question is whether the practice is reasonable and can be a nswered by balancing the intrusion against the promotion of legitimate governme nt interests. The constitu tional challenge to DNA databanks consistently has b een over ruled through consideration of a number of factors. Limited privacy ri ghts, strong government interest and minimal bodily in trusion each prove the v alidity of the practice in question. \par\par
\'5B*1657\'5D \par\par
1. Limited Privacy Right Upon Arrest\par
\par
In Jones v. Murray, n168 perhaps the definitive authority on the constitution ality of body fluid extraction for use in DNA databases, n169 the Fourth Circui t Court of Appeals concluded the DNA testing statute in question did not violat e an inmate's Fourth Amendment privacy right. n170 The court reasoned, in part: \'22prob able cause had already supplied the basis for bringing the person wit hin the criminal justice system. With the person's loss of liberty upon arrest comes the loss of at least some, if not all, rights to per sonal privacy otherw ise protected by the Fourth Amendment.\'22 n171 The Supreme Court has recognize d this principal in holding both body cavity searches of prisoners n172 and pen itentiary cell searches n173 constitutional. Accordingly, while a free citizen need not expect such routine searches, that same individual cannot raise privac y objections upon arrest. n174\par
\par
----------Footnotes----------
- \par\par
n168. \i 962 F.2d 302 (4th Cir. 1992).\i0 This case involved the challenge that a Virginia statute requiring DNA testing for all felons violated the indi vidual's civil rights. See \i id. at 305.\i0 \par\par
n169. See \i State v. Olivas, 856 P.2d 1076, 1085 (1993)\i0 (\'22Jones v. M urray ... is persua sive authority for the proposition that drawing of blood fr om convicted felons to es tablish a DNA data bank for use in future prosecution of recidivist acts does not violate the Fourth Amendment.\'22). \par\par
n170. See \i Jones, 962 F.2d at 311.\i0 \par\par
n171. \i Id. at 306\i0 (emphasis added). \par\par
n172. See \i Bell v. Wolfish, 441 U.S. 520 (1979).\i0 In Bell, prisoners in a federal peniten tiary questioned the constitutionality of visual body cavity searches in light of their Fourth Amendment rights. See \i id. at 558.\i0 The Court upheld the searches, concluding the limited privacy rights of prisoners to be outweighed substantially by the govern ments' need for penal security. Se e \i id. at 559.\i0 \par\par
n173. See \i Hudson v. Palmer, 468 U.S. 517 (1984).\i0 In Hudson, an inmate brought an action against an officer for destruction of his property during a

prison cell search. See \i id. at 520.\i0 In rejecting the prisoner's claim, t
he Court declared: \'22We conclude that prisoners have no legitimate expectatio
n of privacy and that the Fourth Amend ment's prohibition on unreasonable searc
hes does not apply in prison cells\'5B.\'5D\'22 \i Id. at 530.\i0 \par\par
n174. See James P. O'Brien, Jr., Note, DNA Fingerprinting: The Virginia Appr
oach, \i 35 Wm. & Mary L. Rev. 767, 801-2 (1994).\i0 \par
\par
----------End Footnotes----------
- \par\par
2. Strong Government Interest\par
\par
Upon arrest, a suspect's identification becomes a matter of legiti mate state
interest, relevant to solving the crime for which the arrest took place and for
establishing a record to aid in solving past and future crimes. n175 As such,
criminals remain willing to take cer tain steps to hamper positive identificati
on by law enforcement of ficials by disguising faces, changing names or even a
ltering \'5B*1658\'5D features. n176 As the Jones court reasons, however, D
NA databases can play a pivotal role in aiding officials with legitimate pursui
t of suspect identification:\par
\par
----------Footnotes----------
- \par\par
n175. See \i Jones, 962 F.2d at 306.\i0 \par\par
n176. See \i id. at 307.\i0 \par
\par
----------End Footnotes----------
- \par\par
\par
\par
DNA ... is claimed to be unique to each individual and cannot, within current
scientific knowledge, be altered. The individual ity of the DNA provides a dram
atic new tool for the law en forcement effort to match suspects and criminal co
nduct. Even a suspect with altered physical features cannot escape the match th
at \'5Bhe\'5D ... left at the scene of a crime within samples of blood, skin, s
emen, or hair follicles. The governmental justification, ... therefore, relies
on no argument different in kind from that tra ditionally advanced for taking f
ingerprints and photographs, but with additional force because of the potential
ly greater precision of DNA sampling and matching methods. n177\par
\par
----------Footnotes----------
- \par\par
n177. Id. \par
\par
----------End Footnotes----------
- \par\par
\par
\par
Along with the government's interest in identification, deter rence of both cr
iminal and harmful actions is also a documented government interest in DNA data
banking. n178 DNA databases can address this national interest by serving as a
significant deterrent against recidivist activity. n179 In theory, those with p
rior arrests who previously submitted a DNA sample would be deterred from fu tu
re criminal behavior due to an increase in likelihood of capture accompanying t
he strong identification power of DNA evidence. n180\par

\par
----------Footnotes----------
\par\par
n178. See, e.g., \i Skinner v. Railway Labor Executives' Ass'n, 489 U.S. 602, 620-21 (1989)\i0 (upholding mandatory drug testing of railroad employees because of the importance of preventing harmful accidents and casualties); \i National Treasury Employees Union v. Von Raab, 489 U.S. 656 (1989)\i0 (highlighting the need for sober customs officials to protect national borders from contraband smuggling). \par\par
n179. See \i State v. Olivas, 856 P.2d 1076, 1085-86 (1993)\i0 (disclosing the rationale behind the Virginia compulsory DNA statute at issue in Jones). \par\par
n180. Accord O'Brien, supra note 174, at 797 (asserting that \'22DNA fingerprints on file ... deter future criminal behavior and ... increase the likelihood of capturing repeat offenders\'22). \par
\par
----------End Footnotes----------
\par\par
3. Minor Intrusion in DNA Extraction\par
\par
The bodily intrusion requested under Safir's plan, namely extracting DNA with a swab of the oral cavity to obtain a saliva sample, n181 must be evaluated against the aforementioned governmental interests. In People v. Wealer, n182 upholding a correctional code provision for mandatory blood and saliva sampling from state prisoners, the court presented a persuasive argument about the intru\'5B*1659\'5D sive levels of saliva extraction. n183 The Wealer court reasoned the procedure involved in taking saliva samples is inherently less intrusive than that required for extracting blood. n184 Therefore, if taking blood samples withstands constitutional scrutiny, taking saliva samples likewise is reasonable. n185 It thus follows that if blood sampling no longer is to be considered an overly intrusive procedure, n186 saliva sampling cannot be an inherently violative process either. n187\par
\par
----------Footnotes----------
\par\par
n181. See Safir's Plan, supra note 91, at 13. \par\par
n182. \i 636 N.E.2d 1129 (Ill. App. Ct. 1994).\i0 \par\par
n183. See \i id. at 1132.\i0 \par\par
n184. See id. \par\par
n185. See id. \par\par
n186. See supra note 131, at 771 (chronicling reasons why blood testing is not an overly intrusive procedure). \par\par
n187. See \i Wealer, 636 N.E.2d at 1136.\i0 Where blood testing involves actually piercing skin, a saliva extraction gently swabs the inside of an individual's mouth cheek to gain the necessary sample. See \i United States v. Nicolosi, 885 F. Supp. 50, 55 (E.D.N.Y. 1995).\i0 \par\par
Similarly, an argument can be made that the swabbing procedure is less physically intrusive than the constitutionally protected fingerprinting process. While swabbing invades the oral cavity, it is a quick, pain-free action. During fingerprinting, however, arestees may need to be physically guided to mark the inkpad and print card. Accord \i People v. Sallow, 165 N.Y.S. 915, 924 (Ct. Gen. Sess. 1917)\i0 (acknowledging the constitutionality of the fingerprinting process while stressing the importance of an arestee's freedom from torture or duress). This ordeal presents a constitutional physical intrusion greater than sw

abbing for saliva. \par
\par
----------End Footnotes----------
\par\par
C. Safeguards Can Protect Against MisuseofInformation\par
\par
Learning valuable lessons from the dark moments of genetic red lining in Amer ican history, legislators may consider several alterna tives to ensure DNA info rmation stored in a database will only be used for the stated purposes. \par\p ar
1. Unambiguous Legislative Drafting\par
\par
Clear, unambiguous legislation such as the DNA Identification Act of 1994, n18 8 is one solution. n189 This particular federal law pro vides that the results of DNA tests performed for a federal law enforcement agency may be disclosed on ly to criminal justice agen cies for the purpose of law enforcement identificat ion, n190 judicial \'5B*1660\'5D proceedings, n191 criminal defense, n192 i nclusion in a population statis tics database, identification research and prot ocol development for quality control. n193 The DNA Identification Act then outl ines spe cific penalties for unauthorized disclosure of DNA information availab le in a federal database and for unauthorized possession of DNA samples indexed in a database or individually identifiable DNA information. n194 Violation of any of these mandates may be punishable with a fine up to 100,000 dollars. n195 States, including New York, with DNA databank statutes in place have modeled t heir legislation to mirror the federal act in this regard. n196 In draft ing mo re expansive legislation to replace section 995, New York could easily pattern the statute to reflect that currently in place. n197\par
\par
----------Footnotes----------
\par\par
n188. \i 42 U.S.C. 14131\i0 (1995). \par\par
n189. See Annas, supra note 151, at 2349 (\'22Data protection principles sug gest that there should be ... stringent rules for the ... distribution of ... i nformation derived from \'5BDNA molecules\'5D because of the unique characteris tics of genetic information, including the fact that DNA molecules contain an i ndividual's probabilistic future diary.\'22). \par\par
n190. \i 42 U.S.C. 14133\i0 (b)(1)(A). \par\par
n191. Results of DNA tests performed for law enforcement purposes may be dis closed in judicial proceedings only if \'22otherwise admissible pursuant to ap plicable statutes or rules.\'22 Id. 14133(b)(1)(B). \par\par
n192. Id. 14133(b)(1)(C). \par\par
n193. Test results may only be used for these three purposes where personal identifi able information is removed. See id. 14133(b)(2). \par\par
n194. See id. 14133(c)(1)-(2). \par\par
n195. See id. \par\par
n196. See, e.g., La. Rev. Stat. Ann. 15:612, 15:617-18 (West 1999). \par\pa r
n197. See N.Y. Exec. Law 995-c.-f. (McKinney 1994). New York law currently m andates that records in its state DNA index only be released for law enforcemen t identification purposes to a federal, state or local law enforcement agency, district attorney's office, for criminal defense purposes, to a defendant or re presentative or for inclusion into a population statistical database, developme nt of identification re search and protocol or quality control when personal i dentifiable information has been removed. See id. 995-c.6.(a)-(c). Also, confid

entiality requirements stipulate such information may not be released to \'22in surance companies, employers, or poten tial employers, health providers, employ ment screening or personnel companies, or ... private investigation services.\' 22 Id. 995-d.1. Any person who intentionally dis closes a DNA record or results of a DNA test to an unauthorized agency or intention ally uses such informatio n for unauthorized purposes is guilty of a class A misdemeanor and, upon convic tion, subject to a fine of up to 10,000 dollars. See id. 995-f. \par
\par
----------End Footnotes----------
\par\par
2. Anti-Discrimination Legislation\par
\par
Anti-discrimination legislation is another alternative to combat genetic redli ning. n198 For example, New York amended its anti-dis crimination laws to deem it an unlawful, discriminatory practice for an employer to refuse employment or to discharge an employee based on \'22genetic predisposition or carrier status .\'22 n199 The specter \'5B*1661\'5D of criminal prosecution or civil liabi lity can serve to deter possible offenders and pacify liberal activists.\par
\par
----------Footnotes----------
\par\par
n198. See generally, Michael M.J. Lin, Conferring a Federal Property Right i n Genetic Material; Stepping into the Future with the Genetic Privacy Act, \i 2 2 Am. J. L. & Med. 109, 128 (1996).\i0 \par\par
n199. N.Y. Exec. Law 296.1.(a) (McKinney 1993) (amended 1996); see also, N.J . Stat. Ann. 10:5-12a. (West 1994) (amended 1996) (\'22It shall be an unlawful employ ment practice, or, as the case may be, an unlawful discrimination for an employer, because of ... genetic information ... \'5Bto\'5D refuse to hire or employ or to bar or discharge ... from employment such individual.\'22). \par

\par
----------End Footnotes----------
\par\par
3. Manner of Storage\par
\par
The nature of the DNA information stored in a databank can also quell the conc ern for misappropriation of information. Stan dard DNA profiles, capable of bei ng stored as a mere numeric code, will provide little information regarding inh erited medical or physical traits. n200 The privacy issues in databanking arise instead from retention of samples themselves, once identification informa tion is entered into the database. n201 These samples are where the wealth of genet ic information is stored because further testing could be performed on them in the future. n202 In light of these pri vacy risks, one suggestion for preservin g confidentiality more effec tively would be to destroy genetic samples after a nalysis. n203 Such an approach would provide law enforcement officials with dat a necessary for identification purposes, while addressing the obvious concerns for abuse of any other readily obtainable information.\par
\par
----------Footnotes----------
\par\par
n200. See Paul B. Ferrara, DNA Benefits Outweigh Any Risk, N.Y. Newsday, Feb ruary 11, 1999, at A49. \par\par
n201. See McEwen, supra note 76, at 237. \par\par
n202. See id. \par\par

n203. See id. at 238. McEwen, however, questions the feasibility of this app roach in light of a crime lab's need to save samples for reanalysis as technolo gy improves, the needs of a defendant to challenge the sample itself in a futur e case or the need for routine quality control checks. See id. To solve this pr oblem, perhaps, an additional sample could be recollected at a future date, ret ested for identification purposes and subsequently destroyed. See Jensen, supra note 147, at 382. \par

\par

----------End Footnotes----------

\par\par

Additionally, Safir's plan recognizes the debate surrounding ge netic inform ation available in a DNA sample. n204 Wanting to avoid comparisons to a virtual police state, where all citizens' profiles are available for identification pu rposes, Safir proposes that an ar rested citizen's sample would be destroyed an d the DNA profile erased from the databank once the person is found innocent or exempt from prosecution. n205 This practice succeeds in being sensi tive to co ncerns of information misappropriation by taking an af firmative step in assuri ng certain information is unobtainable (via expungement) to unauthorized partie s.\par

\par

----------Footnotes----------

\par\par

n204. See Safir's Plan, supra note 91, at 13. \par\par

n205. See id. Under the current New York law, upon reversal of a conviction or grant of a pardon of an individual whose DNA record has been stored in the s tate database, the DNA record is expunged from the index and all samples, analy ses and other documents are destroyed. See N.Y. Exec. Law 995-c.9. (McKinney 19 94). \par

\par

----------End Footnotes----------

\par\par

\'5B*1662\'5D \par\par

D. New York City's Need for an Expanded DNADatabase\par

\par

While Safir's plan withstands constitutional scrutiny, n206 as well as questio ns involving misappropriation, n207 the benefits of the practice for New York C ity also support passage into legislation.\par

\par

----------Footnotes----------

\par\par

n206. See supra text accompanying notes 161-187. \par\par

n207. See supra text accompanying notes 188-205. \par

\par

----------End Footnotes----------

\par\par

1. Suspect Identification\par

\par

Perhaps the greatest benefit an expanded DNA database yields is the increased number of suspects identifiable under a more in clusive law who, under current legislation, are not being profiled. In his proposal, Safir provides one examp le of how identification information becomes more useful under the proposed sys tem. n208 In examining the last one hundred forcible rape or sodomy cases in wh ich arrests were made, seventy-five arrestees had prior ar rests. n209 Accordin g to Safir, however, \'22in only eighteen of the cases did the perpetrator have

prior arrests and convictions for crimes that would place them in ... \'5Bthe\
'5D convicted offender DNA database.\'22 n210 The logical conclusion, therefore
, is that a significant number of investigations and apprehensions could be con
ducted with greater speed and efficiency if New York collected DNA profiles fro
m all those arrested. n211\par
\par
----------Footnotes----------
- \par\par
n208. See Safir's Plan, supra note 91, at 15. \par\par
n209. See id. \par\par
n210. Id. \par\par
n211. See id. at 16. Safir then goes on to cite the program in Great Britain
as evi dence of this theory. See id. Safir states that over an eighteen-month
period ending in October 1998, British law enforcement identified 175 rape susp
ects, 46 murder sus pects and over 19,000 burglary suspects with help from thei
r expansive DNA database. See id. \par
\par
----------End Footnotes----------
- \par\par
A consultation of New York State inmate profiles supports this assertion. n2
12 Across New York State, only 7.9% of inmates had no prior convictions and onl
y 12.9% had no prior arrests. n213 These statistics show an overwhelming majori
ty of inmates serving time who had prior infractions with the law n214 and woul
d therefore have been eligible for a DNA profile under Safir's plan, perhaps ex
pe \'5B*1663\'5D diting the investigation and arrest for each inmate for hi
s or her criminal commission.\par
\par
----------Footnotes----------
- \par\par
n212. See State of New York Department of Correctional Services, Div ision o
f Program Planning, Research and Evaluation, The HUB System: Profile of Inmates
Under Custody on January 1, 1998 (1998) \'5Bhereinafter 1998 Profile\'5D. \pa
r\par
n213. See id. at 32. \par\par
n214. Statewide, a majority of inmates (69.0%) had either served a prior jai
l term (23.8%) or a prior prison term (35.2%) and 20.1% had a prior conviction
without jail or prison. See id. at 32. \par
\par
----------End Footnotes----------
- \par\par
Meanwhile, in light of the total number of inmates under cus tody, n215 a la
rge percentage of DNA profiles could be taken for use in future investigations.
While those persons serving terms for se lect homicides, assaults and sexual
offenses are already included in the state DNA database under current law, a ma
jority of inmates in New York State prisons are not being profiled. n216 Specif
ically, al most a third of inmates (32.8%) are committed for drug offenses, 18.
8% for robbery and 5.9% for burglary. n217 If each of these of fenders were to
be profiled under Safir's plan, approximately 40,000 more DNA profiles would be
available to law enforcement statewide to aid in future investigations. n218\p
ar
\par
----------Footnotes----------
- \par\par
n215. As of January 1, 1998, there were 69,099 inmates under custody in New

York State. See id. at 2. \par\par
n216. According to the 1998 Profile, of all those inmates under custody in N ew York State currently eligible for inclusion in the state's DNA databank, 9.1 % are serving for Murder, 2.6% for Attempted Murder, 4.6% for Manslaughter, 2.9 % for Rape in the First Degree, 1.9% for Assault in the First Degree, 1.6% for Assault in the Second Degree, 1.5% for Sodomy in the First Degree and 1.0% for Sodomy in the Second Degree. See id. at 26. \par\par
n217. See id. at 25-26. These percentages represent the largest commission s tatistics, with others, such as kidnapping, weapons offenses, arson, etc. round ing out the rest of the prison population. See id. \par\par
n218. 40,000 represents 57.5% of the 69,099 inmates under custody listed in the 1998 Profile. See id. at 2. \par
\par
----------End Footnotes----------
- \par\par
The relevance of these 40,000 additional profiles comes to light when recidi vism rates in New York are provided. While there are many ways to measure recid ivism, it will be defined as the return or recommitment to New York State Depar tment of Correctional Services' custody for purposes of this Note. n219\par
\par
----------Footnotes----------
- \par\par
n219. See State of New York Department of Correctional Services, Div ision o f Program Planning, Research and Evaluation, 1993 Releases: Three Year Post Rel ease Follow-Up 3 (1997) \'5Bhereinafter 1993 Releases\'5D. There are several fo rms of releases such as release of an inmate to a health facility, parole or co mpletion of sentence. See id. at 1. The 1993 Releases includes only re leases o n parole and sentence completion. See id. Therefore, readmission to a New York correctional facility and, thus recidivism, is measured by either parole violat ion, occurring when a released inmate violates rules of parole and is returned to prison to continue serving time on a remaining sentence, or new felony commi tment, occurring when an inmate commits a new crime within the community and re ceives a new sen tence for it. See id. at 4. Essentially, the 1993 Releases pro vides return to custody statistics for all inmates released from New York State prisons in 1993 during a three- year follow-up period. See id. at 1. \par
\par
----------End Footnotes----------
- \par\par
Approximately forty-four percent of the inmates released in 1993 were recomm itted within three years of their release. n220 Sta \'5B*1664\'5D tistics f or return rates of those originally serving time for offenses not currently cov ered by section 995 prove the benefits of including all offenders in a statewid e DNA database. n221 For example, the category defined as \'22Property and Othe r Offenses,\'22 which includes inmates committed for Burglary in the Third Degr ee, Grand Lar ceny, Forgery, Stolen Property, Driving While Intoxicated and oth er crimes, demonstrated that within three years, fifty percent of offenders wer e recommitted for another offense. n222 Similarly, of those who served time for drug offenses, forty percent returned. n223 Among other current crimes not cov ered by section 995, \'22offenses that demonstrated high return rates were Robb ery 3rd (fifty-six percent), Burglary 3rd (fifty-five percent), Stolen Property (fifty- two percent) and Grand Larceny (fifty-one percent).\'22 n224\par
\par
----------Footnotes----------
- \par\par

n220. See id. at 3. \par\par

n221. Interestingly, homicide releases, currently covered by section 995, de mon strated one of the lowest recidivism rates. See id. at 16. Of 176,991 inmat es released during 1985-1993, 6399 had been committed for a homicide offense (M urder, At tempted Murder, Manslaughter and all other Homicide offenses), only 2 5% returned to prison within three years. See id. \'22Approximately 9% of those released with homi cide offenses returned as new court commitment; only 6% ret urned for a new homi cide offense.\'22 Id. Similarly, sex offenders (i.e. Rape, Sodomy, Sexual Abuse and all other Sex Crimes), covered under section 995, ret urned 33% within three years, an other lower return rate. See id. at 18. \'22Of the sex offenders who returned to prison for the commission of new crime, 25% returned for the commission of another sex offense, 19% returned for a drug off ense, and 17% returned for robbery.\'22 Id. \par\par

n222. See id. at 11. \par\par

n223. See id. \par\par

n224. Id. at 10. Offenses currently included under section 995 showed compar able percentages, but represented a smaller number of inmates. For example, whe re Rape in the First Degree had a 46.8% return rate, 124 violators out of 265 w ere recommit ted. See id. at 11. Comparatively, Robbery in the First Degree, wi th a 46.2% return rate, represents the return of 995 out of 2217 violators. See id. \par

\par

----------End Footnotes----------

\par\par

Indeed, these numbers suggest a striking trend: the same indi viduals consta ntly are being recycled through New York's prisons for repeat offenses. If DNA samples were taken from all arrestees, these individuals' computerized profiles would be included upon their first sentence. While obviously not helpful in al l investiga tions, DNA database profiles would be immensely helpful in those in vestigations which include genetic samples left behind at crime scenes. Because many of the same individuals are recommitting crimes, proliferation of this in vestigative tool can help ease the bur den on police, thereby reducing the time and cost of investigations. \par\par

2. Maintaining New York City's Low LevelofCrime\par

\par

Over the past decade, New York City has undergone a social renaissance, transf orming itself into an inherently safer metropo \'5B*1665\'5D lis. n225 A br ief consultation of crime rate statistics over this period lends weight to this assertion. For example, in 1998, only 628 homi cides were reported in New York City, n226 less than a third of the number of homicides in 1990, when a record 2262 were commit ted. n227 Overall, major crimes in the city dropped approxima tely eleven percent from 1997, with the most drastic declines recorded in homic ides, down nineteen percent, and car thefts, which dropped fifteen percent. n22 8 Also, in 1998, \'22there were fewer re ported robberies, assaults, burglaries , grand larcenies and car thefts, and - despite early indications that the drop in rape was leveling off - \'5Bthere has been an\'5D 11 percent ... \'5Bdrop i n\'5D rapes.\'22 n229\par

\par

----------Footnotes----------

\par\par

n225. See David Kocieniewski, Murders Drop 25% as Violent City Crime Falls A gain, N.Y. Times, July 2, 1998, at B3 (quoting Mayor Rudolph Giuliani's charact erization: \'22Over the past four years, New York City has been transformed fro m the crime capi tal of the world to the safest large city in the United States

\'22). \par\par
n226. See Micheal Cooper, Chicago Logs More Killing than New York City in '9 8, N.Y. Times, Jan. 1, 1999, at B3 (observing that New York City, with an estim ated 7.3 million population logged 69 less homicides than did Chicago, a city w ith a 2.7 million population). \par\par
n227. See Micheal Cooper, Homicides Decline Below 1964 Level in New York Cit y, N.Y. Times, Dec. 24, 1998, at A1 (stating homicide levels today are the lowe st since 1964, when 636 homicides were reported). \par\par
n228. See id. \par\par
n229. Id. Between 1990 and 1997, the total number of felony convictions has de creased 19.1%. See Division of Criminal Justice Services, Criminal Justice I ndicators by Percent Change, New York City: 1990-1997 (visited Jan. 10, 1999) < http://criminaljustice.state.ny.us>. \par\par
Criminologists debate the causes of the consistent and dramatic drop in New York City's crime rates. Some cite factors such as the booming economy, the dro p in the number of people in their late teens and early twenties, the decline o f drug use and the increase of incarceration as reasons for the decline. n230 O thers even suggest that the current generation of teens witnessed first hand th e effect of lawlessness on their families and have become weary of its costs. n 231\par
\par
----------Footnotes----------
\par\par
n230. See id. \par\par
n231. See David Kocieniewski, Crime in City Down in '97 by 9.1 Percent, N.Y. Times, Jan. 3, 1998, at B1. Kocieniewski refers to this reason as the \'22litt le brother factor.\'22 Id. \par
\par
----------End Footnotes----------
\par\par
One factor resulting in the dramatic crime rate drop, however, can be found in the aggressive policing of New York City's popu lace. n232 Among other imple mented strategies, the move away from community policing, calling for officers to simply walk neighbor hood beats, towards utilizing modern technology to figh t crime has \'5B*1666\'5D been very helpful in lowering crime. n233 Moreove r, Mayor Giu liani's constant call for a proliferated police force, n234 the de votion of police resources to an anti-drug campaign, n235 and the work of the d epartment's street crime unit n236 each play a role in addressing criminal prob lems.\par
\par
----------Footnotes----------
\par\par
n232. See Kocieniewski, Murders, supra note 225, at B3. \par\par
n233. For example, police are using computer maps to chart crimes and assign of ficers where they will be used most effectively throughout the five borough s. See Cooper, Homicides, supra note 227, at A1. \par\par
n234. The size of the New York City police force has swelled to nearly 40,00 0 of ficers. See Kocieniewski, Murders, supra note 225, at B3. \par\par
n235. The anti-drug initiative seeks to exile narcotics dealers from neighbo rhoods by saturating high-crime areas with law enforcement officials. See id. \par\par
n236. This police unit seizes illegal weapons, helping to reduce the number of shoot ings from 2500 in the first half of 1993 to fewer than 1000 in the fir st half of 1998. See id. \par

\par
----------End Footnotes----------
\par\par
The expansion of New York's DNA database is another aggres sive police tacti c that can help keep crime rates in New York City at these low levels. While so me would question the allocation of funds toward more policing, n237 expansion of law enforcement tac tics and crime reduction play too crucial a role in New York City's revitalization, from the growth in tourism to \'22the impressionist ic sense that residents feel better about their hometown.\'22 n238 Plans to inc rease police efficiency, such as Safir's plan, cannot be dismissed because the city can not lose its momentum if there is an expecta tion to drive down crime. n239\par
\par
----------Footnotes----------
\par\par
n237. For example, Peter F. Vallone, the Speaker of the City Council, and Gl enn Passman, the Associate Director of the Public Policy Organization, City Pro ject, ques tion whether the Mayor is already doing too much with law enforcemen t at the ex pense of other city services such as education, health care and soc ial services. See Dan Barry, Mayor Says Adding Officers is Key to City's Health , N.Y. Times, Jan. 29, 1999, at B10. \par\par
n238. Id. \par\par
n239. See id. (quoting Eli Silverman, a professor at John Jay College of Cri minal Justice). \par
\par
----------End Footnotes----------
\par\par
Meanwhile, due to the investigative efficiency posed by Safir's plan, costs associated with lengthy police investigations (such as in terviewing multiple s uspects, attempts to uncover inculpatory evi dence and preparing eyewitnesses f or prosecution) would drastically decrease, as a profile match in a database wo uld prove highly probative in either exonerating the innocent or convicting the guilty. n240 Cost and time aside, a review of the success of a simi lar progra m in Great Britain n241 proves the effects of the practice on crime fighting, s howing the strategy would aid in maintaining (or bettering) the low crime rate existing in New York City today.\par
\par
----------Footnotes----------
\par\par
n240. See Safir's Plan, supra note 91, at 15. \par\par
n241. See supra text accompanying notes 93-99. \par
\par
----------End Footnotes----------
\par\par
\'5B*1667\'5D \par\par
3. Backlog Caveat\par
\par
While the positive logical effects of an expanded DNA database are apparent, o ne prevalent administrative issue must be addressed before New York can serious ly consider putting Safir's plan into action. That problem is state DNA laborat ories lack the funds, fa cilities and personnel to type enough cases. Consequen tly, a signif icant backlog results, even under the current, less expansive, DN A collection statute. n242\par
\par

----------Footnotes----------
- \par\par
n242. See Barry C. Scheck, Getting Smart About DNA (US Does Not Use DNA Tech nology to Full Advantage), Newsweek 69 Nov. 16, 1998; Mike Pezzella, FBI DNA D ragnet to Track Fugitives in 50 States, Biotechnology Newswatch, Oct. 19, 1998, at 1. Nationally, over 450,000 samples exist at crime laboratories that have n ot yet been analyzed. See Kendall Anderson, Panel Debates Taking DNA Upon Arres t; Some at Dallas Meeting Say Samples Backlogged, The Dallas Morning News, Marc h 2, 1999, at 13A. \par
\par
----------End Footnotes----------
- \par\par
According to Professor Barry C. Scheck, n243 the backlog results from sample s that have been collected but not profiled due to sheer volume. n244 Similarly , New York has a significant number of rape kits from unsolved sexual crimes th at include genetic samples that have not been profiled and checked against the state databank. n245 Yet another problem resulting from the overload is the lar ge number of owed samples that have yet to be collected from convicted felons u nder the current statute because they are out on parole. n246\par
\par
----------Footnotes----------
- \par\par
n243. Barry C. Scheck is a law professor and co-director of the Innocence Pr oject at the Benjamin N. Cardozo School of Law in New York City. See Scheck, DN A, supra note 242, at 69. The Innocence Project utilizes DNA testing to aid in defending in mates wrongfully convicted of crimes. See id. Professor Scheck is also a commis sioner on New York's Forensic Science Review Board, which created and maintains the state's DNA databank. See id. \par\par
n244. See Scheck Transcript, supra note 15, at 54. \par\par
n245. Professor Scheck estimates there are approximately 10,000 such kits in New York, which were formerly being thrown away before a change in policy. See id. at 59. \par\par
n246. See id. at 56. \par
\par
----------End Footnotes----------
- \par\par
The effects of backlog in New York are numerous. Databases are not being uti lized to their full investigative advantage because they are not being kept cur rent. n247 Even when labs are able to ana lyze a profile, it takes months to pr oduce results, n248 by which time a suspect may already be awaiting trial, ther eby creating unnecessary expenses for the judicial system n249 and overall inju stice to the de \'5B*1668\'5D tained. n250 Comparatively, the British, who have made the invest ment in sufficient personnel and facilities, are able to p rofile their crime scene DNA within two weeks because they do not have backlog problems. n251\par
\par
----------Footnotes----------
- \par\par
n247. See id. at 54. \par\par
n248. See Scheck Transcript, supra note 15, at 62; see also Cellmark to Use New DNA Test to Link Criminals to Unsolved Crimes, PR Newswire, Feb. 15, 1999. \par\par
n249. \'22Defendants are likely to plead guilty quickly after getting bad DN A re sults.\'22 Cellmark, supra note 248. \par\par

n250. \'22Indigent defendants, unable to make bail, spend time in jail for c
rimes they did not commit.\'22 Id. \par\par
n251. See id.; See also Scheck Transcript, supra note 15, at 62. \par
\par
----------End Footnotes----------
- \par\par
The solution to the problem of backlog simply would be to fund the state lab
oratories so that they are able to efficiently transform incoming evidence into
computerized profiles, as well as eliminate the current backlog at these labs.
n252 In a recent budget proposal, President Clinton set aside federal funds to
aid anti-crime initia tives. n253 Recognizing the backlog issue, the proposal
allots fifteen million dollars to eliminate over one million backlogged convict
ed offender DNA samples at state laboratories. n254 When these old samples are
digitized, states can allocate funds to provide facilities and personnel to ha
ndle the volumes of incoming samples and thus prevent future backlog.\par
\par
----------Footnotes----------
- \par\par
n252. See Scheck, DNA, supra note 242, at 69; see also Anderson, supra note
242, at 13A. \par\par
n253. See Juan Otero, Clinton Focuses Funds on Anti-Crime Initiatives, Natio
n's Cities Wkly. Feb. 8, 1999, at 13. \par\par
n254. See id. \par
\par
----------End Footnotes----------
- \par\par
Conclusion\par
\par
The ability to store the genetic records of criminals in a database is an inva
luable tool when used for law enforcement identification purposes. Such a techn
ique, however, is not used to its utmost po tential when only selected criminal
s are included in the database. The implementation of a system where DNA is tak
en from all those arrested for inclusion in a statewide DNA database would stre
ngthen the fight against crime in New York by detering recidi vism, assisting i
n maintaining record low crime rates and easing in vestigative burdens on law e
nforcement agencies. \par\par
The proposed system, in light of inherent government interest in crime fight
ing, does not violate an arrestee's privacy rights. Although steps first should
be taken to address the misappropria tion of information and backlog, the New
York State Legislature should adopt Safir's plan into law because of its potent
ial as an invaluable law enforcement tool. \par\par
\pard
\sect \sectd \sbknone
\page \f1 \f0 \fs20 \li000\ri000 \pard

\qc Harvard Journal of Law & Public Policy\par
\par
\pard
\qc Spring, 1999\par
\par
\pard
\qc 22 Harv. J.L. & Pub. Pol'y 751\par
\par

\pard
LENGTH: 10999 words \par\par\pard
NOTE: Is HIV Really a \'22Disability\'22?: The Scope of the Americans with Disa
bilities Act after \i Bragdon v. Abbott, 118 S. Ct. 2196 (1998).\i0 \par\par\
pard
Christiana M. Ajalat\par
\par
\pard
SUMMARY: ... Congress enacted the Americans with Disabilities Act of 1990 (\'22
ADA\'22) to protect individuals with disabilities from discrimination in such c
ritical areas as employment, housing, public accommodations, education, transpo
rtation, and communication. ... The Court thus concluded that HIV infection sa
tisfies all three prongs of the definition of disability under the ADA: it is \
'22a physical impairment\'22 which \'22substantially limits\'22 the \'22major l
ife activity\'22 of reproduction. ... He noted that the Justice Department, af
ter adopting a Rehabilitation Act regulation verbatim, added \'22'HIV infection
(symptomatic and asymptomatic)' to the list of disorders constituting a physic
al impairment.\'22 ... Finally, the Court turned to Dr. Bragdon's contention th
at, even if HIV infection is a disability under the ADA, the mandate not to dis
criminate might be qualified by what is referred to as the \'22direct threat\'2
2 provision of the ADA. ... The reason that an HIV-positive individual experie
nces discrimination is because she has a deadly and infectious disease which ma
y present a direct threat to the health and safety of others in some circumstan
ces. ... The Court apparently adopted Ms. Abbott's novel approach towards inte
rpreting the ADA and found - without conducting an individualized inquiry - tha
t HIV infection substantially limits an individual's major life activity of rep
roduction. ... \par\par\pard
TEXT: \'5B*751\'5D \par\par
Congress enacted the Americans with Disabilities Act of 1990 (\'22ADA\'22) n
l to protect individuals with disabilities from discrimination in such critical
areas as employment, housing, public accommodations, education, transportation
, and communication. n2 The ADA defines disability as \'22a physical or mental
impairment that substantially limits ... \'5Ba\'5D major life activity ....\'22
n3 According to this definition, suffering from a physical or mental impairmen
t does not render an individual conclusively disabled. Rather, the individual m
ust show that the impairment \'22substantially limits a major life activity.\'2
2\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n1. \i 42 U.S.C. 12101\i0 et seq. (1994). \par\par
n2. See id. 12101(a)(3). Section 12101 addresses congressional findings that
over 43 million Americans have physical or mental disabilities and that these
individuals compose a \'22discrete and insular minority\'22 who have \'22been f
aced with restrictions and limitations ... and \'5Bwho have been\'5D relegated
to a position of political powerlessness in our society, based on characterist
ics that are beyond the control of such individuals ....\'22 Id. 12101(a)(1), (
7). Through the ADA, Congress sought to provide legal remedy for a group that h
as \'22often had no legal recourse to redress such discrimination.\'22 Id. 1210
1(a)(4). \par\par
n3. Id. 12102(2)(A). The statute also covers individuals who have a \'22reco
rd of\'22 or are \'22regarded as\'22 having such an impairment. Id. 12102(2)(B)
, (C). \par
\par

----------End Footnotes----------
- \par\par
Last term, in Bragdon v. Abbott, n4 the Supreme Court offered its first inte
rpretation of the ADA's definition of \'22disability,\'22 an interpretation whi
ch drastically expanded the scope of what constitutes a \'22major life activity
\'22 under the ADA. The Court held that asymptomatic HIV infection is a \'22dis
ability\'22 under the ADA because it \'22substantially limits\'22 the \'22life
activity of procreation ....\'22 n5 The Court further considered whether requir
ing a dentist to treat an individual with HIV presents a \'22direct threat\'22
to the \'22health and safety of others,\'22 thus qualifying the ADA's protectio
n. n6 The Court failed to reach a conclusion on this issue, remanding the decis
ion with \'5B*752\'5D instructions to the United States Court of Appeals fo
r the First Circuit. n7 Although Bragdon's goal of protecting HIV-infected indi
viduals from discrimination is laudable, the majority's reasoning unjustifiably
expands the scope of the ADA and establishes a doctrine that is both over-incl
usive and under-inclusive.\par
\par
----------Footnotes----------
- \par\par
n4. \i 118 S. Ct. 2196 (1998).\i0 \par\par
n5. \i Id. at 2207.\i0 \par\par
n6. \i Id. at 2210\i0 (citing \i 42 U.S.C. 12182\i0 (b)(3) (1994)). If a \'
22direct threat\'22 is present, the dentist could refuse treatment notwithstand
ing the protection offered by the ADA. See id. The ADA defines a direct threat
to be \'22a significant risk to the health or safety of others that cannot be e
liminated by a modification of policies, practices, or procedures or by the pro
vision of auxiliary aids or services.\'22 \i 42 U.S.C. 12182\i0 (b)(3) (1994).
\par\par
n7. Because the Court did not reach a definitive ruling on this issue, this
note will focus primarily on whether HIV infection should be considered a disab
ility under the ADA and not on the \'22direct threat\'22 issue in depth. \par

\par
----------End Footnotes----------
- \par\par
Sidney Abbott, a woman infected with HIV but manifesting no outward symptoms
of the virus, went to dentist Randon Bragdon's office in Bangor, Maine, for a
routine checkup. n8 On a patient registration form, she disclosed her HIV statu
s. n9 After Dr. Bragdon discovered that she had a cavity, he informed her that
he would not fill the cavity in his office, but instead offered to treat her at
a hospital, pursuant to his infectious disease policy. n10 He stated that he w
ould not charge an additional fee for his services, though she would have to pa
y any cost for using the hospital's facilities. n11 Ms. Abbott sued Dr. Bragdon
under state law and Section 302 of the Americans with Disabilities Act, n12 al
leging discrimination on the basis of her disability as an HIV-positive indivi
dual. n13\par
\par
----------Footnotes----------
- \par\par
n8. See \i Bragdon, 118 S. Ct. at 2201.\i0 \par\par
n9. See id. \par\par
n10. See id. \par\par
n11. See id. \par\par
n12. See id. Respondent Abbott relied on Section 302 of the ADA which provid

es that \'22no individual shall be discriminated against on the basis of disabi
lity in the full and equal enjoyment of the goods, services, facilities, privil
eges, advantages, or accommodations of any place of public accommodation by any
person who ... operates a place of public accommodation.\'22 \i 42 U.S.C. 1218
2\i0 (a) (1994). \par\par
The term \'22public accommodation\'22 is defined to include the \'22professi
onal office of a health care provider.\'22 Id. 12181(7)(F). \par\par
n13. See \i Bragdon, 118 S. Ct. at 2201.\i0 \par
\par
----------End Footnotes----------
- \par\par
The United States and the Maine Human Rights Commission intervened as plaint
iffs. n14 The plaintiffs and the defendant both filed cross-motions for summary
judgment, and the United States District Court for the District of Maine ruled
in favor of the plaintiffs, holding that respondent's HIV infection satisfied
the ADA's definition of disability and that the defendant raised no genuine iss
ue of material fact as to whether respondent's HIV infection would have posed a
direct threat to the health or safety of others during the course of \'5B*75
3\'5D dental treatment. n15 The First Circuit affirmed on both counts. n16\pa
r
\par
----------Footnotes----------
- \par\par
n14. See id. \par\par
n15. See id. (citing \i Abbott v. Bragdon, 912 F. Supp. 580, 584-91 (D. Me.
1995)).\i0 \par\par
n16. See \i Bragdon, 118 S. Ct. at 2201.\i0 \par
\par
----------End Footnotes----------
- \par\par
In a five-to-four opinion, the United States Supreme Court affirmed the deci
sion that HIV infection constitutes a disability under the ADA and remanded on
the issue of whether the ADA's protection in this case is qualified because its
application would pose a direct threat to the health and safety of others. n17
Writing for the majority, n18 Justice Kennedy found that HIV infection satisfi
es the ADA's statutory definition of disability. He stated that it is (1) \'22a
physical impairment\'22 that (2) \'22substantially limits\'22 a (3) \'22major
life activity.\'22 n19 Justice Kennedy's opinion relied almost exclusively on
regulatory and judicial interpretations of the Rehabilitation Act of 1973 n20 a
nd the Fair Housing Amendments Act of 1988, n21 statutes from which the ADA's d
efinition of disability was drawn almost verbatim. n22 He argued that Congress'
s repetition of a well-established term carries the implication that Congress i
ntended the term to be construed in accordance with these pre-existing regulato
ry and judicial interpretations. n23\par
\par
----------Footnotes----------
- \par\par
n17. See \i id. at 2213.\i0 \par\par
n18. Justice Kennedy was joined by Justices Stevens, Souter, Ginsburg, and B
reyer. \par\par
n19. \i Bragdon, 118 S. Ct. at 2207.\i0 \par\par
n20. \i 29 U.S.C. 706\i0 (8)(B) (1994). \par\par
n21. \i 42 U.S.C. 3602\i0 (h)(1) (1994). \par\par
n22. See \i Bragdon, 118 S. Ct. at 2202.\i0 \par\par

n23. See id. Justice Kennedy referred to an even more compelling reason to a
pply the Rehabilitation Act regulations to the ADA. He pointed to 12201(a) of t
he ADA, which directs that \'22except as otherwise provided in this chapter, no
thing in this chapter shall be construed to apply a lesser standard than the st
andards applied under title V of the Rehabilitation Act of 1973 \i (29 U.S.C. 7
90\i0 et seq.) or the regulations issued by Federal agencies pursuant to such
title.\'22 Id. (citing \i 42 U.S.C. 12201\i0 (a) (1994)). \par
\par
----------End Footnotes----------
- \par\par
Examining step-by-step how HIV infection would fit under the ADA definition
of disability, the Court's opinion began by inquiring whether HIV infection con
stitutes \'22a physical impairment.\'22 n24 Justice Kennedy pointed to regulati
ons issued by the Department of Health, Education and Welfare - the regulations
that interpreted the Rehabilitation Act. n25 These regulations define \'22phys
ical or mental impairment\'22 to include\par
\par
----------Footnotes----------
- \par\par
n24. \i Bragdon, 118 S. Ct. at 2202.\i0 \par\par
n25. See \i id. at 2203.\i0 When the Justice Department took over responsib
ility for implementation and enforcement of the Rehabilitation Act in 1980, it
adopted those regulations almost verbatim. See id. \par
\par
----------End Footnotes----------
- \par\par
\par
\par
any physiological disorder or condition, cosmetic \'5B*754\'5D disfigureme
nt, or anatomical loss affecting one or more of the following body systems: ne
urological; musculoskeletal; special sense organs; respiratory, including speec
h organs; cardiovascular; reproductive, digestive, genito-urinary; hemic and ly
mphatic; skin; and endocrine .... n26\par
\par
The commentary accompanying these regulations contained a list of representati
ve disorders including cancer, heart disease, and diabetes, but failed to menti
on HIV infection or AIDS. Justice Kennedy explained this omission by noting tha
t the regulation and its commentary were enacted before HIV was identified as t
he cause of AIDS. n27 His opinion then examined in detail the mechanics of HIV
infection: how it begins to invade the body, how it progresses, and how it even
tually develops into AIDS. Through this description, Justice Kennedy establishe
d that there is no latent phase to the disease. n28 In particular, his majority
opinion stressed the fact that during the asymptomatic phase (which lasts on a
verage from seven to eleven years), the virus is migrating from the circulatory
system to the lymph nodes. n29 As a result of these factual findings, the Cour
t concluded that the virus has a \'22constant and detrimental effect on the inf
ected person's hemic and lymphatic systems from the moment of infection\'22 n30
and thus clearly satisfies the regulatory definition of a physical impairment.
n31\par
\par
----------Footnotes----------
- \par\par
n26. 45 C.F.R. 84.3(j)(2)(i) (1998), quoted in \i Bragdon, 118 S. Ct. at 220
5.\i0 \par\par

n27. See \i Bragdon, 118 S. Ct. at 2203.\i0 See also infra note 77. \par\p
ar
n28. See \i id. at 2203-04.\i0 \par\par
n29. See \i id. at 2204.\i0 \par\par
n30. \i Id. at 2204.\i0 \par\par
n31. See 45 C.F.R. 84.3(j)(2)(i) (1998). \par
\par
----------End Footnotes----------
- \par\par
The Court next addressed whether this physical impairment affects a major li
fe activity because \'22the statute is not operative, and the definition not sa
tisfied, unless the impairment affects a major life activity.\'22 n32 Responden
t Abbott's claim was that her HIV infection placed a substantial limitation on
her ability to reproduce and that reproduction is a major life activity. n33 Th
e Court had \'22little difficulty\'22 finding that reproduction is a major life
activity and cursorily explained its \'5B*755\'5D reasoning. Relying heavi
ly on the First Circuit's statement that \'22the plain meaning of the word 'maj
or' denotes comparative importance ...,\'22 n34 the majority held that \'22repr
oduction and the sexual dynamics surrounding it are central to the life process
itself.\'22 n35 Referring to regulations issued to implement the Rehabilitatio
n Act, n36 the Court held that if working and learning are major life activitie
s, reproduction should surely be as well. n37\par
\par
----------Footnotes----------
- \par\par
n32. \i Bragdon, 118 S. Ct. at 2204.\i0 \par\par
n33. See \i id. at 2204-05.\i0 The Court limited its inquiry to respondent
Abbott's claim that reproduction constitutes a major life activity although it
noted, in dicta, that HIV's impact on so many phases of life could have made ma
ny major life activities relevant to its examination. See id. \par\par
n34. \i Id. at 2205\i0 (citing \i Abbott v. Bragdon, 107 F.3d 934, 939-40 (
1997)).\i0 \par\par
n35. Id. \par\par
n36. These regulations define working and learning as illustrative major lif
e activities. See id. (citing 28 C.F.R. 84.3(j)(2)(ii) (1998)). See also infra
pp. 12-13. \par\par
n37. See \i Bragdon, 118 S. Ct. at 2205.\i0 \par
\par
----------End Footnotes----------
- \par\par
Having established that HIV is \'22a physical impairment\'22 and that it imp
acts reproduction, which the decision construed as a \'22major life activity,\'
22 Justice Kennedy turned to the final factor in the ADA definition to address
whether HIV \'22substantially limits\'22 the major life activity of reproductio
n. n38 The majority decided that, even though conception and childbirth are not
impossible for an HIV victim, they are \'22substantially limited\'22 by the ri
sk of transmission of HIV to the child during pregnancy. n39 The Court thus con
cluded that HIV infection satisfies all three prongs of the definition of disab
ility under the ADA: it is \'22a physical impairment\'22 which \'22substantiall
y limits\'22 the \'22major life activity\'22 of reproduction. n40\par
\par
----------Footnotes----------
- \par\par
n38. See \i id. at 2205-06.\i0 \par\par

n39. \i Id. at 2206.\i0 Based on scientific and medical studies, the Court determined that the risk of transmission to the child is approximately twenty-five percent on average, but that it could be reduced to eight percent with antiretroviral therapy. The Court did not decide which of the percentages was more appropriate to consider when determining whether the major life activity of reproduction is substantially limited. See id. and infra note 93 and accompanying text. \par\par

n40. See \i Bragdon, 118 S. Ct. at 2207.\i0 \par

\par

----------End Footnotes----------

\par\par

The majority next presented several justifications for its decision, observing that several current agency and lower court interpretations support the Bragdon holding. The Court first addressed interpretations of the Rehabilitation Act and the Fair Housing Act, statutes from which Congress drew the ADA's definition of disability. The majority maintained that the ADA was enacted with this background of agency and case law in mind and that Congress therefore intended for the ADA definition to be interpreted in keeping with agency and lower court interpretations of these statutes. Quoting extensively \'5B*756\'5D from a 1988 opinion issued by the Office of Legal Counsel of the Department of Justice, n41 which maintained that the Rehabilitation Act should protect symptomatic and asymptomatic HIV-infected individuals from discrimination, the majority reasoned that Congress intended to give this position its active endorsement. n42 The Court further noted that \'22every \'5Blower\'5D court which addressed the issue \'5Bof HIV infection as a handicap\'5D before the ADA was enacted ... concluded that asymptomatic HIV infection satisfied the Rehabilitation Act's definition of a handicap.\'22 n43\par

\par

----------Footnotes----------

\par\par

n41. See Application of Section 504 of the Rehabilitation Act to HIV-Infected Individuals, 12. Op. Off. Legal Counsel 209 (1988) \'5Bhereinafter Application of Section 504\'5D. \par\par

n42. See \i Bragdon, 118 S. Ct. at 2207-08.\i0 \par\par

n43. \i Id. at 2208.\i0 \par

\par

----------End Footnotes----------

\par\par

Justice Kennedy maintained that agency interpretations of the ADA, though not as thorough, also supported the majority opinion. He noted that the Justice Department, after adopting a Rehabilitation Act regulation verbatim, added \'22'HIV infection (symptomatic and asymptomatic)' to the list of disorders constituting a physical impairment.\'22 n44 The decision also cited an opinion of the EEOC n45 that had concluded that \'22an individual who has HIV infection (including asymptomatic HIV infection) is an individual with a disability.\'22 n46\par

\par

----------Footnotes----------

\par\par

n44. \i Id. at 2209.\i0 Note that the regulation accepts HIV infection only as a \'22physical impairment,\'22 which is just one part of the ADA \'22disability\'22 definition. It does not establish the other requirements for a finding of disability - that HIV substantially limits a major life activity. \par\par

n45. The Equal Employment Opportunity Commission is an agency authorized to administer parts of the ADA as it applies to employment. See \i 42 U.S.C. 12111 \i0 -17 (1994). \par\par

n46. \i Bragdon, 118 S. Ct. at 2209\i0 (citing EEOC Interpretive Manual 902 .4(c)(1), Definition of the Term \'22Disability,\'22 at 902-21 (March 1995)). \ par

\par

----------End Footnotes----------

- \par\par

Finally, the Court turned to Dr. Bragdon's contention that, even if HIV infe ction is a disability under the ADA, the mandate not to discriminate might be q ualified by what is referred to as the \'22direct threat\'22 provision of the A DA. This ADA provision states that \par\par

\par

\par

nothing in this subchapter shall require an entity to permit an individual to participate in or benefit from the goods, services, facilities, privileges, adv antages and accommodations of such entity where such individual poses a direct threat to the health or safety of others. n47\par

\par

\'5B*757\'5D To find a \'22direct threat,\'22 there must be \'22a significan t risk to the health or safety of others.\'22 n48 In School Board of Nassau Cou nty v. Arline, n49 the Court established that this risk assessment must be done from the standpoint of the person refusing the treatment or accommodation and must be based on medical or other objective evidence. n50 The Bragdon opinion f urther ruled that the assessment should not defer to individual judgments, even those of health care professionals such as Dr. Bragdon. n51 Although the major ity agreed with the Court of Appeals that Dr. Bragdon did not present any objec tive, medical evidence showing that it would be safer to treat respondent Abbot t in a hospital, it remanded on this issue because of a concern that the Court of Appeals may have placed mistaken reliance on the 1993 CDC Dentistry Guidelin es and the 1991 American Dental Association Policy on HIV. n52 The Court expres sed its opinion that the CDC Guidelines were meant only to recommend universal precautions as to the best way to combat the risk of HIV transmission; they do not assess the level of risk and should not be considered definitive on the pre sent issue. Moreover, the Court warned that the American Dental Association is not a public health authority and its policy might address only the ethical obl igations of dentists to treat individuals; it does not indicate the statistical likelihood of HIV transmission. The majority remanded this \'22direct threat\' 22 issue to the Court of Appeals, instructing them not to rely so heavily on th e two reports but to focus instead on the testimony of health experts. n53\par

\par

----------Footnotes----------

- \par\par

n47. \i 42 U.S.C. 12182\i0 (b)(3) (1994). \par\par

n48. \i Bragdon, 118 S. Ct. at 2210\i0 (citing \i School Board of Nassau Co unty v. Arline, 480 U.S. 273, 287 and n.16 (1987)\i0 and \i 42 U.S.C. 12182\i0 (b)(3) (1994)) (\'22Because few, if any, activities in life are risk free, Arl ine and the ADA do not ask whether a risk exists, but whether it is significant .\'22). \i 42 U.S.C. 12182\i0 (b)(3) also defines \'22direct threat\'22 as a \' 22significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services.\'22 Id. \par\par

n49. \i 480 U.S. 273 (1987).\i0 \par\par
n50. See \i Bragdon, 118 S. Ct. at 2210\i0 (citing \i Arline, 480 U.S. at 2
88).\i0 \par\par
n51. See id. \par\par
n52. See id. at 2211. \par\par
n53. See id. at 2211-13. The Court remanded because it did not have briefs a
nd arguments directed to the entire record of the case and believed it did not
have enough evidence of this expert testimony. The Court, however, did consider
briefly petitioner's main points: (1) that the use of high-speed drills and su
rface cooling with water creates a risk of airborne HIV transmission and (2) th
at CDC had identified seven dental workers with possible occupational transmiss
ion of HIV. The Court expressed its opinion that the evidence of these two clai
ms may not be established well enough to carry Petitioner's claim that treatmen
t would present a \'22direct threat\'22 to the health and safety of others. See
id. at 2212. \par
\par
----------End Footnotes----------
- \par\par
\'5B*758\'5D Justice Stevens wrote a brief concurrence, joined by Justice
Breyer, stating that he agreed with the majority that HIV falls within the ADA
definition of disability, but that he would prefer an outright affirmance on th
e direct threat issue. n54 Justice Ginsburg also wrote a brief concurrence stat
ing that she believed that \'22no rational legislator ... would require nondisc
rimination once symptoms become visible but permit discrimination when the dise
ase, though present, is not yet visible.\'22 n55\par
\par
----------Footnotes----------
- \par\par
n54. See id. at 2213 (Stevens, J., concurring). \par\par
n55. Id. at 2213-14 (Ginsburg, J., concurring). \par
\par
----------End Footnotes----------
- \par\par
Chief Justice Rehnquist, joined by Justices Scalia, Thomas, and O'Connor, n5
6 concurred in the judgment in part and dissented in part. The Chief Justice be
gan his opinion by finding fault with the Court's failure to make an individual
ized inquiry as to whether HIV substantially limited respondent's decision not
to reproduce. n57 The ADA could not be clearer, he reasoned, on the requirement
that the disability determination must be made \'22with respect to an individu
al.\'22 n58\par
\par
----------Footnotes----------
- \par\par
n56. Justice O'Connor joined Chief Justice Rehnquist's opinion as to Part II
only (the direct threat issue) but wrote her own dissent concerning whether HI
V should be considered an ADA disability. See id. at 2217-18. \par\par
n57. See id. at 2214-15. (Rehnquist, C.J., concurring in the judgment in par
t and dissenting in part). \par\par
n58. Id. at 2214 (quoting \i 42 U.S.C. 12102\i0 (1994)). Chief Justice Rehn
quist also pointed out that this individualized test would have been very hard
to satisfy in the present case. When respondent Abbott was asked whether her HI
V infection had in any way impaired her ability to carry out any of her life fu
nctions, she had answered \'22No.\'22 See id. at 2215. \par
\par

----------End Footnotes----------
- \par\par
Chief Justice Rehnquist also dissented from the finding that reproduction co
nstitutes a \'22major life activity.\'22 He pointed to the same Rehabilitation
Act regulations as did the majority - regulations which contain a representativ
e list of several major life activities: \'22functions such as caring for one's
self, performing manual tasks, walking, seeing, hearing, speaking, breathing,
learning, and working.\'22 n59 Agreeing with the majority that this list \'22is
illustrative, not exhaustive,\'22 he nevertheless criticized the majority for
failing to demonstrate why reproduction should be considered a major life activ
ity in the same sense as the listed functions. n60 The dissenters disagreed \'5
B*759\'5D with the majority's definition of \'22major\'22 as being \'22centra
l to the life process itself.\'22 n61 The Chief Justice pointed out that all th
e other activities that have been interpreted to be \'22major life activities\
'22 under the ADA are repetitively performed and essential to the day-to-day ex
istence of an individual. n62 Reproduction is of a different nature altogether.
n63\par
\par
----------Footnotes----------
- \par\par
n59. 45 C.F.R. 84.3(j)(2)(ii) (1998), cited in \i Bragdon, 118 S. Ct. at 221
5.\i0 \par\par
n60. \i Bragdon, 118 S. Ct. at 2215\i0 (Rehnquist, C.J., concurring in the
judgment in part and dissenting in part). \par\par
n61. \i Id. at 2215\i0 (quoting opinion of Kennedy, J. at 2205-06). \par\p
ar
n62. \i Id. at 2215.\i0 \par\par
n63. See infra note 81 and accompanying text. \par
\par
----------End Footnotes----------
- \par\par
Moreover, the Chief Justice explained that the inclusion of physiological di
sorders affecting the reproductive system n64 in the regulations' definition of
\'22physical impairment\'22 does not necessarily indicate that reproduction is
a major life activity. He pointed out that there are numerous disorders of the
reproductive system that are so painful that they limit a woman's ability to w
alk and work. n65 His opinion determined that those with HIV infection are stil
l physically able to engage in sexual intercourse, give birth to a child, and p
erform the manual tasks necessary to rear a child. The dissenters therefore con
cluded that the respondent failed to demonstrate that any of her major life act
ivities were substantially limited by her HIV infection. n66\par
\par
----------Footnotes----------
- \par\par
n64. See id. (Rehnquist, C.J., concurring in the judgment in part and dissen
ting in part) (citing 28 C.F.R. 36.104 (1998)). \par\par
n65. See id. \par\par
n66. See \i id. at 2215-16.\i0 \par
\par
----------End Footnotes----------
- \par\par
With regard to the \'22direct threat\'22 issue, the Chief Justice concurred
with the decision to vacate the Court of Appeal's judgment, but his decision so
ught to further elucidate what he saw as the Court's \'22cryptic direction to t

he lower court.\'22 n67 Pointing to the statutory \'22direct threat\'22 definit
ion, n68 he, like the majority, suggested that the Court of Appeals should read
dress whether treating the infected patient would pose \'22a significant risk t
o the health or safety of others.\'22 n69 His opinion disagreed, however, with
the majority's direction to give special weight and authority to the views of p
ublic health authorities and pointed out that Arline n70 expressly declined to
distinguish between the respect that should be given to \'22official\'22 medica
l \'5B*760\'5D judgment and to \'22private\'22 medical judgment, such as th
at of Dr. Bragdon. n71 The Chief Justice's opinion gave the lower court some gu
idance as to how he believed they should rule on the issue. His opinion stated
that \'22it is clear\'22 that the evidence that petitioner Bragdon offered sho
uld be \'22more than enough evidence to avoid summary judgment on the 'direct t
hreat' question.\'22 n72 In fact, he expressed the opinion that, given the seve
rity of risk involved with contracting HIV (for instance, near certain death),
it is likely that petitioner Bragdon will be able to prevail on the \'22direct
threat\'22 claim. n73\par
\par
----------Footnotes----------
\par\par
n67. \i Id. at 2216.\i0 \par\par
n68. See supra note 47 and accompanying text. \par\par
n69. \i Bragdon, 118 S. Ct. at 2216\i0 (Rehnquist, C.J., concurring in the
judgment in part and dissenting in part) (citing \i 42 U.S.C. 12182\i0 (b)(3) (
1994)). \par\par
n70. \i 480 U.S. 273 (1987).\i0 \par\par
n71. See \i Bragdon, 118 S. Ct. at 2216-17\i0 (Rehnquist, C.J., concurring
in the judgment in part and dissenting in part). \par\par
n72. \i Id. at 2217.\i0 The evidence Chief Justice Rehnquist referred to wa
s (1) the Centers for Disease Control and Prevention's study identifying seven
instances of possible transmission of HIV from patients to dental workers and (
2) forty-two documented incidents of occupational transmission of HIV to health
care workers other than dental professionals. See \i id. at 2217.\i0 \par\par

n73. See id. \par
\par
----------End Footnotes----------
\par\par
Justice O'Connor's brief opinion, concurring in part and dissenting in part,
agreed with the Chief Justice that (1) the claim of disability should be evalu
ated on an individualized basis and (2) that respondent had not proven that her
asymptomatic HIV status substantially limited one or more of her major life ac
tivities. Justice O'Connor argued that since reproduction is not a major life a
ctivity, there is \'22no need to address whether other aspects of ... family re
lationships not raised in this case could constitute major life activities; nor
is there reason to consider whether HIV status would impose a substantial limi
tation on one's ability to reproduce if reproduction were a major life activity
.\'22 n74\par
\par
----------Footnotes----------
\par\par
n74. \i Id. at 2217-18.\i0 (O'Connor, J., concurring in the judgment in par
t and dissenting in part). \par
\par
----------End Footnotes----------

- \par\par
The Court's ruling in Bragdon suffers from two principal defects. First, its interpretation expands the coverage of the ADA far beyond the plain meaning an d intended scope of the statute. Second, by basing its decision on the \'22majo r life activity\'22 of reproduction, the Court creates a new category of indivi duals whom it will consider disabled - a category that does not adequately prot ect those with HIV but instead is likely to be applied in both an over-inclusiv e and under-inclusive manner. \par\par

When Congress enacted the ADA, it acted against a \'5B*761\'5D backgroun d where regulations had defined the term \'22major life activities\'22 to inclu de activities such as \'22caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.\'22 n75 In choosi ng to employ the term \'22major life activity,\'22 Congress implicitly adopted this interpretation of the term without seeking to amend it in any manner. n76 At the time of its consideration of the ADA, Congress was aware of the devastat ing impact HIV infection could have on a person's life. n77 In fact, the legisl ative history indicates that Congress heard testimony from the Presidential Com mission on HIV, which recommended that Congress draft the ADA so that \'22all p ersons with symptomatic or asymptomatic HIV infection should be clearly include d as persons with disabilities ....\'22 n78 Yet Congress apparently rejected th is recommendation. The fact that HIV infection is nowhere mentioned in this bil l may indicate that Congress felt that the established definition of \'22major life activities\'22 would be sufficient to offer protection \'5B*762\'5D fo r those individuals with HIV infection that Congress intended to fall within th e ADA's reach - those for whom established \'22major life activities\'22 are af fected by their HIV infection. n79\par

\par

----------Footnotes----------

- \par\par

n75. 29 C.F.R. 1630.2(i) (1998). This was how the regulations promulgated un der the Rehabilitation Act of 1976 defined \'22major life activities.\'22 When Congress enacted the ADA, rather than providing an illustrative list of disabil ities that would be covered by the ADA (a task that would unavoidably have turn ed to political considerations and interest groups' arguments), it chose to use a \'22multi-pronged definition that would sufficiently narrow the class of pro tected beneficiaries without leaving some disabilities off a magic list.\'22 Er ica Worth Harris, Controlled Impairments Under the Americans with Disabilities Act: A Search for the Meaning of \'22Disability,\'22 \i 73 Wash. L. Rev. 575, 5 81 (1998).\i0 In constructing this multi-pronged definition, Congress chose to use terms employed by the Rehabilitation Act, terms that had been refined thro ugh a series of agency regulations and court decisions interpreting this Act. \par\par

n76. Although this list only purports to be illustrative and not exhaustive, there is a definite thread among the listed activities, a thread that cannot b e said to suggest the inclusion of reproduction as a major life activity. See i nfra pp. 112-14. The majority ignores the absence of activities such as reprodu ction in these regulations and instead relies definitively on an opinion prepar ed by the Office of Legal Counsel of the Department of Justice, an opinion stat ing that \'22we believe that it is reasonable to conclude that the life activit y of procreation ... is substantially limited for an asymptomatic HIV-infected individual.\'22 Application of Section 504, supra note 41, at 209, 216, quoted in \i Bragdon, 118 S. Ct. at 2207.\i0 Congressional reliance on this informal opinion letter would seem misplaced, however, in light of the fact that Congres s rejected - by virtue of refusal to include HIV as a specific disability under

the ADA - a recommendation by the Presidential Commission on HIV to include \'
22all persons with symptomatic or asymptomatic HIV infection ... as persons wit
h disabilities.\'22 Brief for Petitioner at 26 n.18, \i Bragdon v. Abbott, 118
S. Ct. 2196 (1998)\i0 (quoting S. Rep. No. 101-116, at 19 (1989)). See also in
fra note 77 and accompanying text. \par\par

n77. HIV was identified as the cause of AIDS by 1983. See F. Barre-Sinoussi
et al., Isolation of a T-lymphotropic Retrovirus from a Patient at Risk for Acq
uired Immune Deficiency Syndrome (AIDS), 220 Sci. 868 (1983); R.C. Gallo et al.
, Frequent Detection and Isolation of Cytopathic Retroviruses (HTLV-III) from P
atients with AIDS and at Risk for AIDS, 224 Sci. 500 (1984); J.A. Levy et al. I
solation of Lymphocytopathic Retroviruses from San Francisco Patients with AIDS
, 225 Sci. 840 (1984). \par\par

n78. S. Rep. No. 101-116, at 19 (1989). \par\par

n79. There is no evidence that Congress intended for HIV infection to be exe
mpt from the analysis that all other impairments are subject to: that a physica
l impairment must satisfy the definition of disability to trigger the ADA's pro
tection. Congress must have realized that the ADA might fairly be interpreted n
ot to cover asymptomatic HIV infection, and thus its failure to include any ref
erence to HIV infection or to reproduction as a major life activity can reasona
bly be said, as the petitioner argues, to indicate that Congress could not reac
h a consensus on the issue. The petitioner stated that \par\par

\par
\par
HIV infection is nowhere mentioned in the legislation passed after extensive d
ebate. So visible was this issue that it is unreasonable to attribute the omiss
ion to a drafting error. The more likely explanation is that the ADA would not
have passed if it contained a special provision that all asymptomatic persons w
ith HIV are disabled.\par
\par
Petitioner's Brief at 26 n.18, Bragdon (No. 97-156). The respondent, however,
argues that this omission does not indicate an intention to exclude asymptomati
c HIV infection from the coverage of the ADA. Respondent reasons that Congress'
s extensive discussion of HIV infection indicates that Congress realized that t
he statute would cover this impairment. Respondent stated that \par\par

\par
\par
there was an extended debate about an amendment to exempt food-handling employ
ees who were diagnosed with an infectious or contagious disease such as HIV. Th
e amendment was defeated, but the debate makes clear that the legislators unani
mously understood that the definition of disability covered all persons with HI
V, not just those with symptoms.\par
\par
Respondent Abbott's Brief at 34 n.43, Bragdon (No. 97-156). \par\par

The fact that there was discussion about specifically excluding from coverag
e food-handling employees with HIV does not indicate, as the respondent's brief
argues, that \'22the legislators unanimously understood\'22 that the statute w
ould cover those with asymptomatic and symptomatic HIV infection. Rather, it ma
y indicate instead that the legislators realized that the statute could potenti
ally be interpreted to cover some individuals with HIV infection (those who wer
e substantially limited in performing \'22major life activities\'22 such as wal
king, seeing, hearing, etc.) and they wished to limit the statute's protective
reach to exclude those who would be handling food. \par
\par
- - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - -

- \par\par
As Chief Justice Rehnquist stated and as several Circuit Courts have recogni
zed, including reproduction in the definition of \'22major life activity\'22 di
sregards the fact that all the activities mentioned in the regulations n80 are
\'22activities \'5Bthat\'5D are repetitively performed and essential in the day
-to-day existence of a normally functioning individual.\'22 n81 A failure to
\'5B*763\'5D care for one's self, perform manual tasks, walk, see, hear, spea
k, breathe, learn, or work n82 clearly indicates that the individual must be di
sabled in some manner. Failure to reproduce, however, is not an activity perfor
med by the majority of the population at any one time. Furthermore, plenty of p
erfectly healthy, well-functioning people choose not to reproduce. n83 Neverthe
less, in an effort to find a way to fit asymptomatic HIV infection into the ADA
definition, the Bragdon majority disregards the thread among these activities
and instead adopts a new meaning of \'22major.\'22 Justice Kennedy states that
\'22the plain meaning of ... 'major' denotes comparative importance.\'22 Follow
ing this definition, the Court holds that \'22reproduction and the sexual dynam
ics surrounding it are central to the life process itself,\'22 and thus are cle
arly of comparative importance. n84\par
\par
----------Footnotes----------
- \par\par
n80. The regulations contain an illustrative list of \'22major life activiti
es.\'22 See supra note 75 and accompanying text. \par\par
n81. \i Bragdon, 118 S. Ct. at 2215\i0 (Rehnquist, C.J., concurring in the
judgment in part and dissenting in part). See also \i Krauel v. Iowa Methodist
Med. Ctr., 95 F.3d 674, 677\i0 (8\'5Bsu'th'\'5D Cir. 1996); \i Zatarain v. WDS
U-Television, Inc., 881 F. Supp. 240, 243 (E.D. La. 1995)\i0 (stating that unl
ike other activities on the regulatory list, which people engage in every day,
a person is not \'22called upon to reproduce throughout the day, every day\'22
and also asserting that \'22treating reproduction as a major life activity unde
r the ADA would be a conscious expansion of the law ... beyond the province of
this Court\'22), aff'd, \i 79 F.3d 1143\i0 (5\'5Bsu'th'\'5D Cir. 1996)(no publ
ished opinion). \par\par
n82. These activities are drawn from an illustrative list contained in regul
ations promulgated under the Rehabilitation Act. See supra note 75 and accompan
ying text. \par\par
n83. The Brief for the Petitioner points out that many people undergo volunt
ary sterilization and queries whether these people will be considered disabled.
\'22A person who intentionally blinds himself is just as disabled as one who w
as accidentally blinded. So why would a person who was voluntarily sterilized n
ot be disabled?\'22 Petitioner's Brief at 36, Bragdon (No. 97-156). This statem
ent underscores the fact that society as a whole does not consider inability to
reproduce as a disability. Society accepts that many would choose to voluntari
ly sterilize themselves, but considers those who voluntarily blind themselves t
o be mentally unstable. This is because when an individual blinds himself, he d
isables himself from participating in a major life activity, but those who choo
se to sterilize themselves are simply making a choice not to engage in reproduc
tion. If reproduction were a major life activity, many people would be choosing
to disable themselves each year through sterilization procedures, and society
would be condoning it. Certainly this is not the case. Rather, it is quite clea
r that society does not consider reproduction a major life activity. Nor does
it consider failure to reproduce to be a disability. \par\par
n84. \i Bragdon, 118 S. Ct. at 2205.\i0 \par
\par

----------End Footnotes----------
\par\par
Reproduction deviates from the thread of regulatory and other established \'22major life activities\'22 in a second respect. An individual's inability to participate in these major life activities is the cause of discrimination in all other instances. The goal of the ADA is to prevent these inabilities from keeping the individuals out of mainstream American life. n85 In the case of an \'5B*764\'5D HIV-positive individual, it is not her inability (or limitation) in reproduction that is the basis for discrimination. The reason that an HIV-positive individual experiences discrimination is because she has a deadly and infectious disease which may present a direct threat to the health and safety of others in some circumstances. By establishing reproduction as a major life activity, the Court departs from a pattern that defines all other \'22major life activities.\'22 Reproduction is the only major life activity that leads to discrimination unrelated to the inability to engage in the specified major life activity. Most people do not know that the individual is limited in her ability to reproduce and the cause of their discrimination stems from other sources. Thus, the Court expands the definition of \'22major life activity\'22 in yet another manner in an effort to extend the statute's reach to those with asymptomatic HIV infection.\par
\par
----------Footnotes----------
\par\par
n85. The ADA provides a list of privately owned public accommodations subject to Title III protection, including: hotels, restaurants, bars, other establishments serving food and drink, motion picture houses, stadiums, lecture halls, other places of public gathering, bakeries, grocery stores, clothing stores, other sales establishments, laundromats, gas stations, travel services, shoe repair services, other service establishments, terminals, other stations used for public transportation, museums, libraries, parks, other places of recreation, schools, senior citizen centers, gymnasiums, golf courses, and other places of exercise and recreation. See \i 42 U.S.C. 12181\i0 (7) (1994). It is difficult to imagine how those with reproductive disabilities would need the ADA's protection to be able to go to such places in the mainstream of American life. It seems unlikely that Congress intended to protect those whose reproductive disorders do not lead to discrimination which would keep them out of museums, places of recreation, etc. See Petitioner's Brief at 29-30, Bragdon (No. 97-156). \par
\par
----------End Footnotes----------
\par\par
In addition to extending the statute's reach by establishing a new definition for \'22major life activity,\'22 the Bragdon Court establishes a new interpretation of the term \'22substantially limits.\'22 Rather than requiring the limitation to be physical in nature, the Court finds that the limitation may be based on moral and social pressures. An HIV-infected individual does not have significant trouble becoming pregnant, nor has pregnancy been shown to accelerate disease progression in an HIV-positive mother. n86 A woman is not physically limited in her ability to engage in sexual intercourse, to give birth to a child, and to perform the manual tasks necessary to rear a child to maturity; n87 it is, rather, a moral choice which inhibits the \'5B*765\'5D HIV-positive mother from reproducing. n88 Because there is a risk of passing a deadly disease on to her child, she voluntarily decides not to engage in reproduction. HIV, however, does not foreclose a woman from engaging in the activity of reproduction. In fact, with proper prenatal care and antiretroviral treatment, the risk of p

assing HIV on to the child drops to eight percent n89 - a risk much smaller tha
n that many women face concerning passing on genetic defects to their child, so
me of which are as deadly as HIV. n90\par
\par
----------Footnotes----------
- \par\par
n86. See Petitioner's Brief at 5, Bragdon (No. 97-156) (citing Rachana Kumar
et al., Impact of Pregnancy on Maternal AIDS, 42 J. Repro. Med. 429, 433 (1997
) (\'22Pregnancy does not appear to accelerate \'5BAIDS\'5D disease progression
, except in women with symptomatic infection or low CD4 counts.\'22); F.D. John
stone, HIV and Pregnancy, 103 Brit. J. Obstetrics & Gynaecology 1184, 1185 (199
6) (stating that \'22the survival time of patients with AIDS was not affected b
y pregnancy in a small study\'22)). \par\par
n87. See \i Bragdon, 118 S. Ct. at 2215\i0 (Rehnquist, C.J., concurring in
the judgment in part and dissenting in part). The majority shows a willingness
to extend the ADA's scope far beyond protecting those with physical limitations
; it even suggests that financial limitations weigh toward applying ADA protect
ion. The majority states that \'22the decision to reproduce carries economic an
d legal consequences as well. There are added costs for antiretroviral therapy,
supplemental insurance, and long-term health care for the child who must be ex
amined and, tragic to think, treated for the infection.\'22 \i Id. at 2206.\i0
Note that even the majority refers to engaging in reproduction as a decision,
acknowledging that choice is involved here, as it is not with other major life
activities. See infra note 88. \par\par
n88. The CDC has clearly taken the stand that HIV positive women can and sho
uld have a choice concerning reproduction. It has instructed doctors counseling
HIV positive women to give only \'22nondirective\'22 counseling. Pregnancy is
thus a choice for HIV infected women, just as it is for any other woman. See U.
S. Public Health Service Recommendations for Human Immunodeficiency Virus Couns
eling and Voluntary Testing for Pregnant Women, MMWR Morbidity and Mortality Wk
ly. Rep., July 7, 1995, at 10. Other authors also criticize efforts to discoura
ge HIV-positive women from bearing children. See, e.g., Taunya Lovell Banks, Th
e Americans With Disabilities Act and the Reproductive Rights of HIV Infected W
omen, 3 Tex. J. Women & L. 57, 69-70 (1994) (\'22Although a few women are disab
led in ways that limit their reproductive choices, the choices of most disabled
women are restricted for nonmedical reasons. These 'women encounter substantia
l legal, medical, and familial resistance to their choice of motherhood.' ... T
his reaction demonstrates the public view that a disability of either the mothe
r or her potential offspring forecloses the possibility of procreation.\'22) (f
ootnote omitted). \par\par
n89. See supra note 39. \par\par
n90. See discussion infra pp. 118-19. \par
\par
----------End Footnotes----------
- \par\par
Moreover, by focusing on how HIV can potentially influence reproduction, rat
her than on how it actually influences reproduction in light of mitigating meas
ures, the Supreme Court condones a trend which seeks to further expand the \'22
substantially limits\'22 definition. In 1997, the Equal Employment Opportunity
Commission (EEOC) issued guidelines to the Code of Federal Regulations that sug
gest that the degree of \'22substantial limitation\'22 under the ADA should be
assessed without reference to possible mitigating measures. n91 Adopting the EE
OC's interpretation would drastically expand the \'22substantially limits\'22 d
efinition by offering ADA protection to individuals with controlled impairments

even if they do not experience a substantial limitation in any major life acti
vity. For example, an individual who is legally blind but whose vision is \'5B*
766\'5D correctable (a \'22mitigating measure\'22) would have a disability. n
92 By declining to invalidate the EEOC's position, n93 the Supreme Court tolera
tes this expansion of the \'22substantially limits\'22 definition. Thus, in add
ition to its outright efforts to expand the definition of disability, the Bragd
on Court permits the EEOC's far-reaching interpretation to stand.\par
\par
----------Footnotes----------
\par\par
n91. The EEOC guidelines in the appendix to the Code of Federal Regulations
provide that \'22the determination of whether an individual is substantially li
mited in a major life activity must be made on a case-by-case basis, without re
gard to mitigating measures such as medicines, or assistive or prosthetic devic
es.\'22 29 C.F.R. app. 1630.2(j) (1998). \par\par
n92. See Harris, supra note 75, at 580. Harris envisions several circumstanc
es where the ADA would protect individuals who do not experience a substantial
limitation in any major life activity. She points out that \par\par
\par
\par
an individual who can see perfectly with corrective lenses, but is legally bli
nd without those lenses, has a disability. Similarly, an individual with hypert
ension who controls his conditions with oral medication has a disability becaus
e the hypertension could cause a stroke or death if unmedicated. According to t
he \'5BEEOC\'5D guideline, such individuals have disabilities even if they do n
ot experience, and have never experienced, any limitation from their condition.
\par
\par
Id. (footnotes omitted). \par\par
n93. Justice Kennedy did acknowledge that HIV's effect on reproduction could
be lessened, but declined the opportunity to rule on the EEOC's position, stat
ing that \'22we need not resolve this dispute \'5Bwhether mitigating measures s
hould be considered in evaluating whether HIV substantially limits reproduction
\'5D in order to decide this case.... It cannot be said as a matter of law that
an eight percent risk \'5Bthe risk when antiretroviral therapy is considered\'
5D does not represent a substantial limitation on reproduction.\'22 \i Bragdon,
118 S. Ct. at 2206.\i0 \par
\par
----------End Footnotes----------
\par\par
Finally, the Bragdon decision expands the reach of the ADA by dismissing the
need to make an individualized inquiry as to whether HIV \'22substantially lim
its ... major life activities ....\'22 n94 The Court did not inquire whether Ms
. Abbott would engage in the activity of reproduction in the absence of HIV in
fection. In fact, when she was asked \'22whether her HIV infection had in any w
ay impaired her ability to carry out any of her life functions, respondent answ
ered 'No.'\'22 n95 Chief Justice Rehnquist points out that Ms. Abbott \'22studi
ously avoided\'22 asserting that reproduction is a major life activity for her
and expressly argued that \'22the major life activity inquiry should not turn o
n a particularized assessment of the circumstances of this or any other case.\'
22 n96 The Court apparently adopted Ms. Abbott's novel approach towards interpr
eting the ADA and found - without \'5B*767\'5D conducting an individualized
inquiry - that HIV infection substantially limits an individual's major life a
ctivity of reproduction. n97 This approach clearly opens up the protection of t

he ADA to new applications and has already been recognized and applied by lower courts as a new and valid approach for interpreting the ADA. n98 Thus, the Bra gdon decision further augments the reach of the ADA's protection by sending a m essage to other courts that the statute does not mandate an individualized inqu iry as to whether the \'22major life activity\'22 at stake is \'22substantially limited.\'22 n99\par
\par
----------Footnotes----------
\par\par
n94. \i Id. at 2214\i0 (Rehnquist, C.J., concurring in the judgment in part and dissenting in part) (quoting 12102(2)(A) (1994)). Chief Justice Rehnquist argued that \par\par
\par
\par
the Act could not be clearer on this point: Section 12102(2) states explicitly that the disability determination must be made 'with respect to an individual. ' Were this not sufficiently clear, the Act goes on to provide that the 'major life activities' allegedly limited by an impairment must be those 'of such indi vidual.'\par
\par
Id. \par\par
n95. \i Id. at 2215\i0 (emphasis added). \par\par
n96. Id. \par\par
n97. See \i id. at 2206.\i0 \par\par
n98. In \i Colwell v. Suffolk County Police Dep't, 158 F.3d 635 (2d Cir. 199 8),\i0 petition for cert. filed, \i 67 U.S.L.W. 3484\i0 (U.S. Jan. 13, 1999) (No. 98-1164), the Court of Appeals for the Second Circuit indicated its belief that the Bragdon opinion partially discharged the requirement of an individual ized inquiry under the ADA: \par\par
\par
\par
We do not think that such major life activities as seeing, hearing, or walking are major life activities only to the extent that they are shown to matter to a particular ADA plaintiff. Rather, they are treated by the EEOC regulations an d by our precedents as major life activities per se. \par
\par
\i Id. at 642\i0 (quoting \i Reeves v. Johnson Controls World Services, Inc., 140 F.3d 144, 151-52 (2d. Cir. 1998)).\i0 Further, the Colwell Court stated t hat \'22the Supreme Court adopted this approach in Bragdon when it determined that reproduction is a major life activity without considering whether reproduc tion was an important part of the respondent's life.\'22 Id. (citing \i Bragdon , 118 S. Ct. at 2204-05).\i0 \par\par
n99. Cf. \i 42 U.S.C. 12102\i0 (1994) (requiring that the disability determ ination be made with respect to the individual) and supra note 94. \par
\par
----------End Footnotes----------
\par\par
The goal of the Bragdon Court is certainly commendable. HIV infection is a d evastating problem in this country and Congress should take action to assure th at individuals with HIV have access to proper medical and dental care. n100 How ever, the Bragdon decision may fall short of assuring this protection. Because the Court confines its discussion to the effect HIV infection has on a woman's ability to reproduce, it may be logically inferred that the decision should onl y extend to those who would otherwise be able to reproduce - women of child-bea

ring age. n101 If the Court's goal was to protect all HIV-infected individuals from discrimination, the ADA protection offered by the Bragdon decision is under-inclusive. Children, \'5B*768\'5D homosexual men, and women past child-bearing age are unlikely or unable to reproduce regardless of their HIV status, so the fact that they have HIV infection is not substantially limiting their participation in the activity of reproduction. The Bragdon decision expands the role of the ADA, but its holding does not clearly illustrate that all individuals with HIV infection should be considered disabled. n102 The scope of the ADA would have to be expanded even further to bring all HIV-infected individuals within its reach. Rather than having the Court over-extend the ADA in such a fashion as to disable it and open it up to many novel claims, n103 it would be far better for Congress to pass legislation which clearly prohibits discrimination against those with HIV infection.\par

\par

----------Footnotes----------

\par\par

n100. Routine health care is significantly more important to an individual with a debilitated immune system. See Michael Glick, Intraoral Manifestations Associated with HIV Disease, in Dental Management of Patients with HIV 153, 154-57 (Michael Glick ed., 1994). \par\par

n101. Although the decision does not make an individualized inquiry as to whether respondent Abbott is limited in reproduction, it does rely on evidence that a woman's ability to reproduce is limited by HIV infection. The Court stated that \'22for the statistical and other reasons we have cited, of course, the limitations on reproduction may be insurmountable here.\'22 \i Bragdon, 118 S. Ct. at 2206.\i0 \par\par

n102. The Court declined to address whether having HIV is a per se disability. See \i id. at 2207.\i0 Justice Kennedy's opinion, however, indicated that the majority of the Court might have liked to extend ADA protection to all HIV-infected individuals. He stated that, \'22given the pervasive, and invariably fatal, course of the disease, its effect on major life activities of many sorts might have been relevant to our inquiry.\'22 \i Id. at 2204-05.\i0 It seems unlikely, however, that the reasoning that the Court adopts, based on the major life activity of reproduction, will be interpreted to establish such an all-encompassing rule. \par\par

n103. See discussion infra pp. 118-19. \par

\par

----------End Footnotes----------

\par\par

The Bragdon decision also cripples the statute by opening it up to over-inclusive interpretations. By defining reproduction to be a \'22major life activity,\'22 the Court adopts a standard that may extend coverage to many individuals who are not clearly disabled. The Bragdon decision raises questions about whether all individuals who have difficulty reproducing are disabled under the ADA. n104 Should the ADA protect even those whose limitations arise in the natural course of life? In the aftermath of the Bragdon decision, a Minnesota woman has already brought suit that her early menopause entitles her to ADA disability protection. n105 Although the District Court for the District of Minnesota refused to consider her limitation in reproduction as a limitation of a major life activity, n106 this case illustrates how \'5B*769\'5D the Bragdon decision has opened up the ADA to many disputable and novel claims based on its finding that reproduction is a major life activity.\par

\par

----------Footnotes----------

- \par\par
n104. See, e.g., Katie Cook Morgan, Should Infertility Be a Covered Disabili
ty Under the ADA?: A Question for Congress, Not the Courts, \i 65 U. Cin. L. Re
v. 963 (1997).\i0 This article notes that pre-Bragdon courts were split on the
issue of whether infertility was covered by the ADA. See \i id. at 969.\i0 Th
e Court's holding that reproduction is a major life activity is likely to tip t
he balance toward protection of infertility as an ADA disability. \par\par
n105. See \i McGraw v. Sears, Roebuck & Co., 21 F. Supp. 2d 1017, 1019-21 (D
. Minn. 1998).\i0 \par\par
n106. The district court held that although Bragdon \par\par
\par
\par
found an inability to have children to be a cognizable ADA disability in an AI
DS case.... the Court does not read Bragdon to suggest that every woman in, dur
ing, or after menopause suffers an ADA disability because her ability to have c
hildren is impaired. The Court takes judicial notice of menopause as an entirel
y normal consequence of human aging. As such, it is clearly distinguishable fro
m early loss or impairment of childbearing resulting from a communicable viral
illness.\par
\par
Id. \par
\par
----------End Footnotes----------
- \par\par
Furthermore, the applicability of the Bragdon decision to genetic defects wi
ll become an increasingly important question as knowledge in the field of human
genetics rapidly grows. Researchers are currently pursuing an international co
llaborative effort to map the entire human genome. n107 With this research come
s discoveries of many genes which are linked to various diseases. There are gen
es linked to color blindness, colon cancer, Huntington's disease, Downs Syndrom
e, and other conditions. Accordingly, it is becoming increasingly possible for
an individual to determine what dangers he or she has of passing on various di
seases to his or her child. If an HIV-infected individual is considered disable
d because she has an eight percent chance n108 of passing on HIV to her child,
would an individual who has a greater likelihood of having a child with a deadl
y genetic disease also be considered disabled? n109 What if the parent will nev
er get the disease but only has the possibility of passing it on to his or her
children (as occurs with a recessive gene)? Some genetic diseases, such as Hunt
ington's disease, are as equally devastating and deadly to the body as HIV infe
ction. Huntington's disease often appears in early adulthood and inevitably cau
ses death after an extended period of dementia and loss of muscle control. n110
A woman with a Huntington's disease gene has a fifty percent chance of passing
a deadly gene on to her child. Does this mean that an \'5B*770\'5D individ
ual with Huntington's disease is clearly disabled, or should we interpret Justi
ce Kennedy's discussion regarding the detrimental effect of HIV on the body's i
mmune system even during the course of the asymptomatic phase n111 to mean that
a disease must be already at work in the body in order for it to constitute a
disability? If the Court intends to distinguish HIV infection from genetic abno
rmalities on this basis, the scope of ADA coverage could thus depend on whether
scientific knowledge of a disease has reached a point where scientists know th
e mechanics of the disease's progression. n112\par
\par
----------Footnotes----------
- \par\par

n107. See, e.g., Paul Jacobs, The Race to Crack the Gene Code, L. A. Times, Oct. 29, 1998, at A1, available in \i 1998 WL 18888238.\i0 \par\par

n108. See supra note 39. \par\par

n109. Current debate indicates that it is likely that ADA coverage will be expanded in this direction. The EEOC has issued a policy statement validating the proposition that genetic discrimination falls under the term disability as defined in the ADA. See EEOC Compliance Manual 902.4(c)(2), Definition of the Term \'22Disability,\'22 at 902-45 (March 1995). See also Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, \i 29 Hous. L. Rev. 23, 33 (1992);\i0 Lynda M. Fox & Sherman G. Finesilver, Genetics and the Workplace: ADA Applicability to Genetic Information, Colo. Law., April 1997, at 75, 76. \par\par

n110. See Brian R. Gin, Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act, \i 97 Colum. L. Rev. 1406, 1406 (1997).\i0 \par\par

n111. See \i Bragdon, 118 S. Ct. at 2203-04.\i0 \par\par

n112. Under this theory, if a disease is already operating within the mother's body, then it leads to ADA disability coverage. If, however, it is just a genetic defect that may be passed on to future children, but will not affect the mother's health, it is outside the scope of the ADA. \par

\par

----------End Footnotes----------\par\par

The Bragdon decision leaves many such questions unanswered. By establishing reproduction as a new \'22major life activity,\'22 broadly construing the term \'22substantially limits,\'22 and dismissing the need to make an individualized inquiry, the Court greatly expands the ADA's definition of disability. The Court's first attempt to clarify this definition drastically departs from the traditional interpretation of this statute and creates great uncertainty by opening up the ADA to many novel claims. Further, its interpretation most likely does not adequately protect those with HIV from discrimination. Rather than actively expanding the reach of this statute, the Court would have done far better to encourage Congress to pass specific legislation protecting those with HIV. \par\par

\pard

\qc Summer, 1998\par
\par
\pard
\qc 11 Harv. J. Law & Tec 571\par
\par
\pard
LENGTH: 10824 words \par\par\pard
ARTICLE: DNA: FIVE DISTINGUISHING FEATURES FOR POLICY ANALYSIS \par\par\pard

Ronald M. Green* and A. Mathew Thomas** \par\par\pard

----------Footnotes----------\par\par

\par

* Ph.D., Director, Ethics Institute at Dartmouth College, Hanover, New Hampshi
re. Former Director of the National Human Genome Research Institute's Office of
Genome Ethics.\par
\par
** J.D., Harvard Law School, Class of 2000. Former Deputy Director of the Nati
onal Human Genome Research Institute's Office of Genome Ethics.\par
\par
----------End Footnotes----------
- \par\par\pard
SUMMARY: ... The influx of genetic science into biomedicine and research raises
the question of whether predictive or diagnostic information derived from the
molecular analysis of DNA merit distinctive legal consideration or policy treat
ment. ... Those who favor a ban on genetic testing for insurance and employment
generally point to the following factors: the need for fairness in risk distri
bution; the availability of insurance; the danger of discrimination, abuse, and
stigmatization of individuals with genetic diseases and their relatives; conce
rn over confidentiality of genetic information; the desire to protect an indivi
dual's right not to know his or her genetic profile; the preservation of indivi
dual autonomy regarding genetic information; and the absence of absolute reliab
ility, accuracy, and predictability based on genetic testing for sound actuaria
l risk classification. ... A similar concern of external group harm relates to
the increasing interest in behavioral genetic disorders. ... These concerns ar
e likely to increase as genetic research is used to stratify levels of risk wit
hin populations. ... Risk classification schemes also neglect to account for t
he possibility of disease prevention through the early identification and treat
ment of a genetic disorder. ... Should legislation against genetic discriminati
on extend beyond DNA analysis to these other sources of genetic information, su
ch as family histories? Some authors have advocated this position. ... \par\
par\pard
TEXT: \par\par
\'5B*571\'5D I. INTRODUCTION \par\par
The influx of genetic science into biomedicine and research raises the quest
ion of whether predictive or diagnostic information derived from the molecular
analysis of DNA merit distinctive legal consideration or policy treatment. The
question arises in research, clinical care, and health policy settings. In res
earch settings, investigators and Institutional Review Boards (\'22IRBs\'22) mu
st consider whether tissue samples containing DNA should be treated differently
from other specimens that are not subject to molecular DNA analysis. n1 In cli
nical care settings, physicians or genetic counselors must consider whether the
use of DNA-based information carries wider obligations than the use of ordinar
y confidential medical information. n2 In health policy settings, insurers, leg
islators, and other regulators must consider whether information derived direct
ly from the analysis of DNA should be treated differently from other medical in
formation currently used in making decisions about insurance or employment. n3\
par
\par
----------Footnotes----------
- \par\par
n1 See Joan Stephenson, Pathologists Enter Debate on Consent for Genetic Res
earch on Stored Tissue, \i 275 JAMA 503, 503-04 (1996).\i0 \par\par
n2 See Lori B. Andrews, Legal Aspects of Genetic Information, 64 YALE J. BIO
LOGY & MED. 29, 33-36 (1991). \par\par
n3 See Peter S. Harper, Genetic Testing and Insurance, 26 J. ROYAL C. PHYSIC
IANS LONDON 184 (1992).\par

\par
----------End Footnotes----------
\par\par
We argue that, in these and other contexts, DNA is different. We base this judgment on a series of quantitative and qualitative considerations. In some respects, genetic information derived from the analysis of DNA differs from other medical information only by a matter of degree. Much biomedical research and clinical care threatens subjects' or patients' privacy; but information derived from DNA can do \'5B*572\'5D so to a significantly greater extent. DNA-derived information also poses novel risks not previously encountered in other biomedical contexts. One example is the possibility of harm to distant persons, some not yet even born, that can result from certain kinds of DNA research. \par\par

We recognize that it is hard to sustain a claim of total novelty about the use of genetic information in biomedical settings. Critics of our position may point to existing biomedical areas that have features similar to those exhibited by work with DNA. What we wish to show is that in both its quantitative and qualitative respects, DNA is different enough from materials or information dealt with in previous biomedical endeavors to warrant special considerations in research, clinical, and health policy settings. We acknowledge that some aspects of genetic singularity have been explored by other scholars; however, our goal is to provide a comprehensive conceptual overview of the genetic terrain and outline the relevant issues for consideration. \par\par

II. FIVE DISTINGUISHING FEATURES \par\par

Taken together, five aspects of DNA contribute to our belief that predictive or diagnostic information derived from the molecular analysis of DNA is different. Three derive from the intrinsic nature of DNA -- DNA's informational nature, longevity, and role as an identifier -- and two reflect the wide array of people and interests that can be affected by DNA's utilization in research, clinical care, or insurance and employment contexts -- familial risks and community impacts. \par\par

A. Informational Risks \par\par

The risks associated with the information-rich nature of DNA have long been apparent in the area of genetics. While most of the risks in traditional biomedicine arise from direct physical interventions in people's bodies, whether through invasive surgical procedures or the administration of experimental drugs, this is not usually the case in genetics, where the principal risks are related to the information revealed about subjects' genetic inheritance. Among these risks are anxiety, distress, and other psychological harms to subjects who learn that they carry genes that may predispose them to serious medical problems. n4 These risks are magnified when effective therapeutic interventions are not yet available for the condition and the subject is forced to live with \'5B*573\'5D the prospect of unavoidable illness. Such individuals comprise a growing class that has been called the \'22asymptomatic ill.\'22 n5 Other risks are incidental and include: inadvertent disclosure of painful facts about family relationships (such as non-paternity n6); stigmatization associated with having a genetic abnormality; and intra-familial discord. Although the likelihood of some of these harms is small, their occurrence can be devastating for individuals. n7 As Francis Collins, Director of the National Human Genome Research Institute of the National Institutes of Health (\'22NIH\'22) has suggested, powerful new genetic knowledge may prove to be \'22toxic information.\'22 n8\par
\par
----------Footnotes----------
\par\par

n4 See Charles Siebert, The DNA We've Been Dealt, N.Y. TIMES MAG., Sept. 17, 1995, at 50. \par\par

n5 See Dorothy Nelkin, Diagnosis: The Social Implications of Biological Tests, in EMERGING ISSUES IN BIOMEDICAL POLICY: AN ANNUAL REVIEW, VOLUME I: SETTING ALLOCATION PRIORITIES; GENETIC AND REPRODUCTIVE TECHNOLOGIES 215 (Robert H. Blank & Andrea L. Bonnicksen eds., 1992). \par\par

n6 See Dorothy C. Wertz, Ethical and Legal Implications of the New Genetics: Issues for Discussion, 35 SOC. SCI. & MED. 495, 499 (1992). \par\par

n7 See Nancy E. Kass, Participation in Pedigree Studies and the Risk of Impeded Access to Health Insurance, IRB: REV. HUMAN SUBJECTS RES., Sept.-Oct. 1993, at 7, 9. \par\par

n8 See Videotape: The Human Genome Project (National Human Genome Research Institute, National Institutes of Health, 1996) (discussion by Francis Collins).
\par
\par
----------End Footnotes----------
\par\par

There are also economic risks of discrimination in employment, medical insurance, and life insurance, at least until prohibited by law. n9 While at least seven states currently have laws prohibiting genetic discrimination in employment n10 or medical insurance, n11 most states leave open the possibility that employers or insurers may request a general medical release and thereby obtain genetic test results that are included in a medical report. Similarly, individuals claiming discrimination have the burden of proving that they have been discriminated against on the basis of genetic information.\par
\par
----------Footnotes----------
\par\par

n9 See E. Virginia Lapham et al., Genetic Discrimination: Perspectives of Consumers, 274 SCIENCE 621 (1996). \par\par

n10 See IOWA CODE ANN. {\f0\'A7} 729.6 (West 1996); N.H. REV. STAT. ANN. {\f0\'A7} 141-H:3 (1995); N.J. STAT. ANN. {\f0\'A7}{\f0\'A7} 10:5-5, -12, -43 to -49, 17B:30-12 (West 1996) (comprehensive anti-discrimination statue that includes provisions for employment, housing, banking, privacy, health, life, and disability insurance); N.Y. EXEC. LAW {\f0\'A7} 296(1), (19) (McKinney 1993); OR. REV. STAT. {\f0\'A7} 659.036 (1995); R.I. GEN. LAWS {\f0\'A7} 28-6.7-1 (1995); WIS. STAT. ANN. {\f0\'A7} 111.372 (West 1996). \par\par

n11 See Kathy L. Hudson et al., Genetic Discrimination and Health Insurance: An Urgent Need for Reform, 270 SCIENCE 391 (1995).\par
\par
----------End Footnotes----------
\par\par

Federal guidance on genetic discrimination in employment contexts has primarily come from the U.S. Equal Employment Opportunity Commission (\'22EEOC\'22). In its 1995 compliance manual, n12 the EEOC \'5B*574\'5D suggested that discrimination for dominant genetic disorders would be covered by the American with Disabilities Act. However, there is some concern about whether this ruling would cover carriers of recessive or X-linked disorders. n13\par
\par
----------Footnotes----------
\par\par

n12 EEOC, 2 EEOC COMPLIANCE MANUAL {\f0\'A7} 902, Order 915.002, 902-45 (1995). \par\par

n13 See Karen H. Rothenberg, Breast Cancer, The Genetic \'22Quick Fix,\'22 a

nd the Jewish Community, 7 HEALTH MATRIX 97, 112 (1997).\par
\par
----------End Footnotes----------
\par\par
A wrinkle in federal attempts to regulate genetic discrimination in insuranc
e contexts stems from the fact that self-funded plans account for one-third of
the non-elderly insured and are expected to increase significantly. n14 Self-fu
nded plans fall under an exemption of the federal Employee Retirement Income Se
curity Act of 1974 n15 (\'22ERISA\'22) and are immune from state regulation. Th
is problem suggests that national legislative efforts may offer the best opport
unity to bypass ERISA exemptions, as well as to provide unified and consistent
policy. At least eight U.S. Senators and Representatives have already introduce
d bills addressing genetic discrimination in insurance and employment. n16\par

\par
----------Footnotes----------
\par\par
n14 See Hudson et al., supra note 11, at 391. \par\par
n15 Pub. L. No. 93-406, 88 Stat. 829 (codified as amended in scattered secti
ons of 5, 18, 26, and 29 U.S.C.). \par\par
n16 See Genetic Fairness Act of 1996, S. 1600, 104th Cong. (proposed by Sens
. Feinstein and Mack); Genetic Privacy and Nondiscrimination Act of 1996, S. 18
98, 104th Cong. (proposed by Sen. Domenici); Genetic Privacy and Nondiscriminat
ion Act of 1996 S. 1416, 104th Cong. (1995) (proposed by Sens. Hatfield and Ma
ck); H.R. 3477, 104th Cong. (1996) (amendment to the Fair Labor Standards Act o
f 1938 that would restrict employers in obtaining, disclosing, and using geneti
c information, proposed by Rep. Joseph Kennedy); Genetic Privacy and Nondiscrim
ination Act of 1995, H.R. 2690, 104th Cong. (proposed by Rep. Stearns).\par
\par
----------End Footnotes----------
\par\par
The most significant step in combating genetic discrimination to date occurr
ed in 1996 with the passage of the Health Insurance Portability and Accountabil
ity Act n17 (\'22HIPAA\'22). HIPAA bars group insurance plans from using most g
enetic information as a preexisting condition and bans the use of genetic infor
mation as a qualification for entrance into the plan. n18 HIPPA does make an ex
ception for genetic information that is clearly linked to a medical diagnosis;
n19 however, a healthy person who tests positive for a genetic mutation would n
ot fall within this category. n20 As significant as HIPAA may become in regulat
ing the discriminatory use of genetic information, it does not provide an absol
ute bar on discrimination. Insurers can still use test \'5B*575\'5D results t
o increase rates, set lifetime caps, or exclude coverage for particular conditi
ons. n21 Moreover, in seeking to curb genetic discrimination, HIPAA overlooks o
ther potential interests, such as the privacy concerns of insurees. Insurers ca
n demand genetic testing or test results and can divulge test results without a
uthorization. n22\par
\par
----------Footnotes----------
\par\par
n17 See Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified in scattered se
ctions of 18, 26, 29, and 42 U.S.C.A.). \par\par
n18 See \i 26 U.S.C.A. {\f0\'A7}{\f0\'A7} 9801\i0 -9806 (West. Supp. 1998).
\par\par
n19 See {\f0\'A7}{\f0\'A7} 9801(a)(1) & (b)(1)(B). \par\par

n20 See {\f0\'A7} 9801(a)(1) (permitting exclusion only if \'22medical advic
e, diagnosis, care, or treatment was recommended or received\'22 for the geneti
c condition). \par\par
n21 See Rothenberg, supra note 13, at 112. \par\par
n22 See id.\par
\par
----------End Footnotes----------
- \par\par
Those who favor a ban on genetic testing for insurance and employment genera
lly point to the following factors: the need for fairness in risk distribution;
the availability of insurance; the danger of discrimination, abuse, and stigma
tization of individuals with genetic diseases and their relatives; concern over
confidentiality of genetic information; the desire to protect an individual's
right not to know his or her genetic profile; the preservation of individual au
tonomy regarding genetic information; and the absence of absolute reliability,
accuracy, and predictability based on genetic testing for sound actuarial risk
classification. n23\par
\par
----------Footnotes----------
- \par\par
n23 See Eric Mills Holmes, Solving the Insurance/Genetic Fair/Unfair Discrim
ination Dilemma in Light of the Human Genome Project, \i 85 KY.L.J. 503\i0 (Sp
ring 1996-97).\par
\par
----------End Footnotes----------
- \par\par
By contrast, those who support the use of DNA tests in insurance and employm
ent practices emphasize the need for equitable, not equal, distribution of risk
; the precedent set by the current use of family histories in insurance; the ne
ed to improve the efficiency of actuarial underwriting vis a vis genetic testin
g; the fears of adverse selection if individuals with known serious health risk
s disproportionally take advantage of insurance opportunities, thus bankrupting
the industry; n24 the applicant's good faith duty to disclose; and the unlikel
ihood that underwriting based on genetic tests will deprive people of insurance
. n25\par
\par
----------Footnotes----------
- \par\par
n24 See Robert Pokorski, Genetic Screening and the Insurance Industry, 64 YA
LE J. OF BIOLOGY & MED. 53 (1991); Robert Pokorski, Insurance Underwriting in t
he Genetic Era, 60 AM. J. HUMAN GENETICS 205 (1997). \par\par
n25 See Holmes, supra note 23, at 555.\par
\par
----------End Footnotes----------
- \par\par
These risks were apparent from the earliest years of genetic science. The ga
thering of family pedigree data has always had the potential for revealing sens
itive, private information about one's lineage. Insurers and employers have alr
eady used knowledge that diseases run in families to label, stigmatize, and dis
criminate. n26 However, the developing capacity for molecular analysis raises t
hese risks to a new level. For one thing, this capacity makes possible unpreced
ented access to information on the basis of minute amounts of tissue collected
from individuals with \'5B*576\'5D or without their full, informed consent.
As medical geneticist Peter Harper has noted, the fact that DNA samples can be

used for analysis, no matter from where in the body they are collected or what the individual's age or clinical state, makes these samples a far more invasiv e source of information than any kind of previously collected tissue or family history. n27\par
\par
----------Footnotes----------
\par\par
n26 See Kass, supra note 7, at 9. \par\par
n27 Harper, supra note 3, at 184.\par
\par
----------End Footnotes----------
\par\par
The growing ability of molecular analysis to provide predictive and diagnost ic assessments about specific individuals also places the risks associated with a genetic diagnosis in a qualitatively different realm. The highly specific as sessment of individual vulnerability resulting from mutational analysis is dis tinctive because it singles out the individual's genetic risk based on the sure presence of a genetic lesion. This is quite different from prior risk assessme nt based on pedigree analysis since the analysis of the DNA from a single indiv idual can uncover existing medical conditions or the risks of future disease fo r that person (as opposed to an average based on members of a family or other d emographic group). n28\par
\par
----------Footnotes----------
\par\par
n28 See Charles M. Culver, The Concept of Genetic Malady, in MORALITY AND TH E NEW GENETICS 156 (Bernard Gert et al. eds., 1996).\par
\par
----------End Footnotes----------
\par\par
It remains true, of course, that we are far more than the sum of our genes. We must be careful not to succumb to \'22genetic determinism\'22 or \'22genetic essentialism,\'22 n29 which claims that genetic analyses provide complete know ledge of an individual's life prospects. Genetic research is also making it inc reasingly clear that environmental conditions can influence the expression of e ven highly penetrant genes. Nevertheless, genetic information can be relevant t o understanding an individual's vulnerabilities and possibilities. As the Human Genome Project moves forward, the informational importance of DNA will greatly increase. Analysis of an individual's DNA will provide unprecedented access to very private information about that person, some of which may be unknown to th e DNA donor.\par
\par
----------Footnotes----------
\par\par
n29 The term \'22genetic essentialism\'22 has been introduced by Dorothy Nel kin and Susan Lindlee to describe the position that reduces the self to a molec ular entity, equating human beings with their genes. See generally DOROTHY NELK IN & SUSAN LINDLEE, THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON 41-49 (1995). \par
\par
----------End Footnotes----------
\par\par
\'5B*577\'5D B. The Longevity of DNA \par\par
A second relatively distinctive aspect of DNA with important legal implicati

ons is its longevity, whether as information or biochemical substance. This lon
gevity creates the possibility of long-term and even transgenerational harms fo
r persons. \par\par

Long-term informational risks derive from the creation of libraries of store
d DNA, transformed cell lines, or databases of genetic information. In some cas
es, these preserved remains from past or current genetic studies may outlive th
e individuals who donated them and prove to be a threat to their descendants. T
his renders problematic the standard requirement of research that subjects shou
ld be free to withdraw at any time. Once a sequence of DNA has been characteriz
ed and placed in a computer database open to the public, there is no simple way
the donor or donor's descendants can put an end to their exposure to harm. \p
ar\par

The problem is amplified by the exponential growth in our genetic knowledge.
Unlike most medical data, which reveals results generated at fixed time points
, DNA databases have the capacity to generate new information over time as fut
ure genetic tests are developed. Soon we may be able to identify the genetic ba
sis for many more disorders, predispositions, and genetic traits. We will also
have greater understanding of the genetic factors underlying many complex, poly
genic disorders and behavioral conditions or traits not now seen to have geneti
c causes. The association of the APOE gene allele with increased risk of Alzhei
mer's disease is an example of genetic factors contributing to, but not directl
y causing, disease conditions. n30 Recent research into the genetic bases of ma
le sexual orientation illustrates the growing reach of behavioral genetics. n31
As a result, even if we allow for non-transmission of certain genes and for di
fferent phenotypical expression of some genes in individuals, the risk remains
that DNA donated today may expose the progeny of the donors to new and unimagin
ed forms of stigmatization and discrimination. George Annas has analogized DNA
to an individual's \'22'future diary' written in a code \'5B*578\'5D we hav
e not yet broken.\'22 n32 The longevity of DNA information means that to some e
xtent it is also the diary of an individual's descendants.\par
\par
----------Footnotes----------
\par\par

n30 See Ann M. Saunders et al., Association of Apolipoprotein E Allele Epsil
on 4 with Late-onset Familial and Sporadic Alzheimer's Disease, 43 NEUROLOGY 14
67 (1993). \par\par

n31 See Stella Hu et al., Linkage Between Sexual Orientation and Chromosome
Xq28 in Males but Not in Females, 11 NATURE GENETICS 249 (1995). \par\par

n32 George Annas, Privacy Rules for DNA Databanks, \i 270 JAMA 2346, 2346 (1
993).\i0 \par
\par
----------End Footnotes----------
\par\par

Over thirty states already authorize the banking of DNA data in DNA \'22data
banks\'22 or \'22libraries.\'22 n33 In favor of DNA libraries, one might argue
that DNA samples are a highly efficient means of identification. However, the
capacity for DNA to generate personal information about specific individuals, s
uch as disease possibilities, goes beyond identification and suggests a much gr
eater threat to individual autonomy. At least one article has suggested that th
e banking of genetic materials by government agencies may violate the privacy p
rovisions of the Fourth Amendment. n34 Legal controversy over proposals by the
Department of Defense for enduring DNA databases of military personnel exemplif
ies the growing problem in this area. n35\par
\par

----------Footnotes----------

- \par\par

n33 See ALA. CODE {\f0\'A7} 36-18-20 to -31 (Supp. 1991); ARIZ. REV. STAT. A NN. {\f0\'A7} 31-281 (West Supp. 1997); ARK. CODE ANN. {\f0\'A7} 12-12-1102 to -1116 (Michie Supp. 1997); CAL. PENAL CODE {\f0\'A7} 290.2 (West Supp. 1998); C OLO. REV. STAT. {\f0\'A7} 17-2-201(5)(g)(I) (Supp. 1996); CONN. GEN. STAT. ANN. {\f0\'A7} 54-102g (West Supp. 1998); DEL. CODE ANN. tit. 29, {\f0\'A7} 4713 (1 997); FLA. STAT. ANN. {\f0\'A7} 943.325 (West 1996 & Supp. 1998); GA. CODE ANN. {\f0\'A7} 24-4-60 (1995); IDAHO CODE {\f0\'A7} 19-5501 to -5518 (1997); 730 IL L. COMP. STAT. ANN. 5/5-4-3 (West 1996); IND. CODE {\f0\'A7} 20-12-34.5-3 (1993); IOWA CODE ANN. {\f0\'A7} 13.10 (West 1995); KY. REV. STAT. ANN. {\f0\'A7} 17 .175 (Michie 1996); LA. REV. STAT. ANN. {\f0\'A7} 15:601 to -620 (West Supp. 19 98); ME. REV. STAT. ANN. tit. 25, {\f0\'A7} 1572 (West. Supp. 1997); MASS. GEN. LAWS ANN. ch. 22E, {\f0\'A7} 2 (West Supp. 1998); MINN. STAT. {\f0\'A7} 609.34 61 (1994); MO. ANN. STAT. {\f0\'A7} 650.055 (West Supp. 1998); NEB. REV. STAT. {\f0\'A7} 29-4104 (Supp. 1997); NEV. REV. STAT. ANN. {\f0\'A7} 179A.075 (Michi e 1989); N.H. REV. STAT. ANN. {\f0\'A7} 632-A:22 (Supp. 1997); N.J. STAT. ANN. {\f0\'A7} 53:1-20.21 (West Supp. 1998); N.C. GEN. STAT. {\f0\'A7} 15A-266.6 (Su pp. 1997); OHIO REV. CODE ANN. {\f0\'A7} 109.573 (Banks-Baldwin Supp. 1998); OK LA. STAT. ANN. tit. 74, {\f0\'A7} 150.27a (West. Supp. 1998); 35 PA. CONS. STAT . ANN. {\f0\'A7} 7651.303 (West Supp. 1998); S.D. CODIFIED LAWS {\f0\'A7} 23-5- 14 (Michie Supp. 1997); TEX. GOV'T CODE ANN. {\f0\'A7} 411.142 (West Supp. 1998); VA. CODE ANN. {\f0\'A7} 19.2-310.2 (Michie Supp. 1997); WASH. REV. CODE ANN. {\f0\'A7} 43.43.754 (West Supp. 1997); WYO. STAT. ANN. {\f0\'A7} 7-19-402 (Mic hie 1997). \par\par

n34 See E. Donald Shapiro & Michelle L. Weinberg, DNA Databanking: The Dange rous Erosion of Privacy, \i 38 CLEV. ST. L. REV. 455 (1990).\i0 \par\par

n35 See Bradley Graham, Two Marines Face Court-Martial Over DNA Test: Case E nters National Debate on the Use of Genetic Data, WASH. POST, Apr. 12, 1996, at A1.\par

\par

----------End Footnotes----------

- \par\par

We believe that when genetic information becomes irretrievably public, as in computerized databases of large stretches of DNA, efforts should be made to re duce the likelihood that this information can be traced back to identifiable in dividuals without their consent. As we will see, however, such efforts are comp licated by a third feature of DNA that poses a challenge to investigators: the fact that DNA carries so much information that anonymization may be difficult o r impossible. \par\par

\'5B*579\'5D C. DNA as an Identifier \par\par

The information-rich nature of DNA means that even anonymous or anonymized D NA sequences can identify the individuals who contributed them. Stored DNA or g enetic information collected in research can be compared with DNA collected fro m individuals for other purposes, or even with distinctive phenotypical charact eristics whose genetic basis is understood, and identifying matches can be made . As our knowledge of genotype-phenotype correlations grows, the preferred form of identification may soon be a numerically expressed DNA pattern of every ind ividual, banked along with that individual's DNA profile in a national DNA comp uterized data bank. n36\par

\par

----------Footnotes----------

- \par\par

n36 See Gary T. Marx, DNA Fingerprints May One Day Be Our National ID Card,

WALL ST. J., Apr. 20, 1989, at A14 (suggesting the possibility of a numerically expressed DNA pattern).\par
\par
----------End Footnotes----------
\par\par
DNA's potential for identification also has paradoxical implications for genetic research: in some cases, collecting samples from identifiable subjects for new studies may be preferable to using anonymous DNA. Ordinarily, the use of anonymous tissue samples has not involved significant risks for human subjects no matter how sensitive the genetic test. Existing federal regulations permit the routine employment of these samples in research without the consent of the original donors. n37 But DNA is not just tissue. Distribution of anonymous samples to other investigators or publication of the information they contain may at some future time lead back to the donor or the donors' offspring, who never consented to such widespread exposure of intimate facts about themselves. Thus, it is preferable to use DNA from individuals who are apprised of this risk and knowingly consent to it, as opposed to using existing anonymous samples or libraries. New donors are in a position to learn of the risks and decide whether they wish to participate. Donors of anonymous DNA cannot make such a decision but nevertheless remain vulnerable to subsequent exposure and harm.\par
\par
----------Footnotes----------
\par\par
n37 See 45 C.F.R. {\f0\'A7} 46.101(b)(4) (1998).\par
\par
----------End Footnotes----------
\par\par
Once this special aspect of both DNA and genetic research is recognized, other steps can be taken to reduce the risks. In large-scale sequencing studies, for example, efforts can be made to use DNA from multiple donors to form \'22patchwork\'22 sequences, reducing the likelihood that any one individual's genome is disclosed. Double-blind collection strategies and lottery-like selection of DNA from multiple donors can be used to prevent individuals from accessing their own DNA. This can further protect donors' anonymity by reducing their ability to \'5B*580\'5D intentionally or unintentionally reveal the location of their DNA once it has been used by research. An advisory issued by the NIH's National Human Genome Research Institute required steps like these in federally funded genomic sequencing research. n38\par
\par
----------Footnotes----------
\par\par
n38 See NATIONAL HUMAN GENOME RESEARCH INSTITUTE, NCHGR-DOE GUIDANCE ON HUMAN SUBJECTS ISSUES IN LARGE-SCALE DNA SEQUENCING (1996), available at <http://www.nhgri.nih.gov/Grant_info/Funding/Statements/RFA/human_subjects.html >.\par
\par
----------End Footnotes----------
\par\par
The uniqueness of these three risks of DNA -- its informational density, longevity, and ability to reveal the identity of the donor -- is underscored by the announcement by Scottish researchers that they have been able to clone a sheep using the nucleus from a donor sheep's somatic cell. n39 Although the scenarios here border on science fiction, it is no longer technically inconceivable to imagine someone's preserved somatic cell lines being used to reconstitute a genetic replicate of that individual. The possibility that one's genetic \'22twin

\'22 might be brought into being long after one's death dramatically illustrate
s the observation that DNA can be used at any time in the future, with or witho
ut one's consent, to reveal intimate, identifying facts about an individual.\pa
r
\par
----------Footnotes----------
\par\par
n39 See I. Wilmut et al., Viable OffspringDerived from Fetal and Adult Mamma
lian Cells, 385 NATURE 810 (1997).\par
\par
----------End Footnotes----------
\par\par
D. Familial Risks \par\par
Legal and policy considerations in medicine have traditionally revolved arou
nd the individual subject or patient, n40 ranging from issues of how a study or
intervention will affect an individual to whether the individual will have the
opportunity to provide voluntary and informed consent. The impact of genetic m
edicine, however, is complicated by the fact that genes may be shared among mem
bers of families, ethnic or racial communities, and other groups with a distinc
tive genetic inheritance. As one writer observes, \'22By definition, human gene
tics pertains to relatedness, rather than separateness.\'22 n41 This not only c
reates special risks for individuals but also widens the circle of people who a
re exposed to risk and who must be considered as involved in the research or cl
inical context.\par
\par
----------Footnotes----------
\par\par
n40 See generally Louis J. Elsas II, A Clinical Approach to Legal and Ethica
l Problems in Human Genetics, \i 39 EMORY L.J. 811 (1990).\i0 \par\par
n41 Michelle A. Mullen, The New Human Genetics: Ethical Issues and Implicati
ons for Public Policy, 96 KAN. MED. 55, 56 (1995).\par
\par
----------End Footnotes----------
\par\par
The possibility of risk to other family members is the most familiar express
ion of this aspect of DNA. Genetic studies on particular individuals routinely
implicate other family members and expose \'5B*581\'5D them -- sometimes wi
thout their consent -- to physical, psychological, and social harms. The abilit
y to test for a mutation leading to Huntington's Disease has produced instances
where one monozygotic twin wished to be tested for the presence of a mutation
while the other did not. n42 Moral theorists suggest that either choice can be
rational. n43 Yet testing one twin almost invariably alerts the other to his ge
netic status. This creates a dilemma for the clinician or researcher who faces
such competing claims.\par
\par
----------Footnotes----------
\par\par
n42 See Audrey Heimler & Andrea Zanko, Huntington Disease: A Case Study Desc
ribing the Complexities and Nuances of Predictive Testing of Monozygotic Twins,
4 J. GENETIC COUNSELING 125; see also 5 J. GENETIC COUNSELING 47-50 (letter an
d replies to Heimler & Zanko, supra). \par\par
n43 See Culver, supra note 28, at 97-122.\par
\par
----------End Footnotes----------

- \par\par
Another facet of this problem appears when the patient or subject refuses to disclose information of vital importance to other family members. One would think that a woman whose child is diagnosed with Fragile X Syndrome, an inherited disorder that can lead to severe mental retardation, especially in male children, would feel an obligation to share this information with her sisters who might wish to use it in their reproductive decision-making. Similarly, a married person would seem to be morally obligated to share relevant genetic information with a spouse whose life may be profoundly affected as a result of a condition that may be passed on to the couple's children. \par\par
In both situations, however, fear, family conflicts, or tensions sometimes prevent people from acting on their moral obligation. n44 The President's Commission for the Study of Ethical Problems in Medicine has recommended that disclosure of a patient's confidential medical information to others should be made only if four conditions are met: one, reasonable attempts to elicit voluntary disclosure are unsuccessful; two, there is a high probability of very serious harm; three, there is reason to believe disclosure will prevent the harm; and, four, disclosure is limited to the information necessary for diagnosis or treatment of another person. n45 However, it is not yet clear for legal purposes that \'5B*582\'5D shared or imposed genetic risks come within this framework of analysis. n46\par
\par
----------Footnotes----------
- \par\par
n44 See ALICE WEXLER, MAPPING FATE: A MEMOIR OF FAMILY, RISK, AND GENETIC RESEARCH 12-13 (1995). The halting and ultimately unsuccessful efforts made by Alice Wexler's grandmother to inform Alice's father of the genetic risks associated with his impending marriage to Alice's mother illustrates the difficulties that many families experience in this area. \par\par
n45 THE PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS 44 (1983). \par\par
n46 See Lori B. Andrews, The Genetic Information Superhighway: Rules of the Road for Contacting Relatives and Recontacting Former Patients, in HUMAN DNA: LAW AND POLICY 133, 133 (Bartha Maria Knoppers et al. eds., 1996); Marshall B. Kapp, Ethical and Legal Implications of Advances in Genetic Testing Technology, 1994 LEGAL MED. 305, 311.\par
\par
----------End Footnotes----------
- \par\par
In some instances, the problem is not a patient's or subject's limited disclosure of jointly relevant information, but the need for other reluctant family members to participate in research or clinical care. This is especially true in linkage studies, where the cooperation of many individuals is needed to identify genetic loci for disorders. By refusing to cooperate, one or more family members can effectively exercise a veto over work of benefit to their relatives. Conversely, some individuals may experience pressure bordering on coercion from relatives eager to have all family members participate in a study. n47 This problem becomes particularly acute in psychiatric genetics whenever some members of a family suffer from a compromised capacity to consent. n48 Whether coerced or not, participation in linkage studies may also inflict information on some family members for which they are unprepared. n49 Additional harms can result from publishing data from family studies when the family is unique enough to make identification of its members possible. n50\par

\par
----------Footnotes----------
\par\par
n47 See Lisa S. Parker & Charles W. Lidz, Familial Coercion to Participate in Genetic Family Studies: Is There Cause for IRB Intervention?, IRB: REV. HUMAN SUBJECTS RES., Jan.-Apr. 1994, at 6. \par\par
n48 See David Shore et al., Legal and Ethical Issues in Psychiatric Genetic Research, 48 AM. J. MED. GENETICS 17 (1993). \par\par
n49 See Peter S. Harper, Research Samples from Families with Genetic Disease: A Proposed Code of Conduct, 306 BRIT. MED. J. 1391 (1993). \par\par
n50 See Madison Powers, Publication-Related Risks to Privacy: Ethical Implications of Pedigree Studies, IRB: REV. HUMAN SUBJECT RES., Jul.-Aug., 1993, at 7.\par
\par
----------End Footnotes----------
\par\par
Another side of this problem appears when parents request testing of their children for adult-onset disorders, such as Huntington's disease, or for asymptomatic carrier status for disorders like cystic fibrosis or X-linked Severe Combined Immune Deficiency. These requests can expose the child to potential psychosocial harms with little corresponding benefit for the child. They can also deprive the child of autonomy as an adult to request or refuse such testing. n51 For those reasons, several medical professional organizations have taken strong positions against acceding to such requests. n52 Those who defend such \'5B*583\'5D testing point to parental decision making rights regarding their children as well as tangible parental needs for purposes of future reproductive decision making or financial planning. n53 Here we see a clear and unresolved instance of possible familial conflict over access to genetic information. Parents exert their claims while genetic professionals potentially feel compelled to enter as fiduciaries on the child's behalf. n54\par
\par
----------Footnotes----------
\par\par
n51 See Dena S. Davis, Genetic Dilemmas and the Child's Right to an Open Future, \i 28 RUTGERS L.J. 549, 549-92 (1997)\i0 \par\par
n52 See AMA Council on Ethical and Judicial Affairs, Testing Children for Genetic Status, CODE OF MEDICAL ETHICS REPORTS, July 1995, at 47-57; ASHG/ACMG Boards of Directors, Points To Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents, 57 AM. J. HUMAN GENETICS 1233-41 (1995). \par\par
n53 See Mary Z. Pelias, Duty to Disclose in Medical Genetics: A Legal Perspective, 39 AM. J. OF HUMAN GENETICS 347, 349 (1991); Mary Z. Pelias and Susan H. Blanton, Genetic Testing in Children and Adolescents: Parental Authority, the Rights of Children, and Duties of Geneticists, 3 U. CHI. L. SCH. ROUNDTABLE 525-43 (1996). \par\par
n54 The requirement of \'22minimal harm\'22 that generally applies to all non-therapeutic research on children makes this conflict even more pressing and acute for genetic researchers. See 45 C.F.R. {\f0\'A7} 46.404 (1997).\par
\par
----------End Footnotes----------
\par\par
A special familial problem of DNA-derived information access arises when an individual from whom that information has been gathered has died. Other family members may need access to the deceased's genetic test results for their own me

dical decision making. Since the deceased are not protected by federal human su
bjects regulations, no apparent legal obstacles exist for research organization
s to share this information. Nevertheless, the deceased may have had strong vie
ws about the disposition of her or his genetic information. Distribution of thi
s information to relatives who request it may also inflict harms on other survi
ving family members. n55\par
\par
----------Footnotes----------
- \par\par
n55 See Ronald M. Green & A. Mathew Thomas, Whose Gene Is It: A Case Discuss
ion About Familial Conflict over Genetic Testing for Breast Cancer, 6 J. GENETI
C COUNSELING 245 (1997).\par
\par
----------End Footnotes----------
- \par\par
The potential for familial conflicts and harms involving the collection of D
NA calls into question the individual autonomy model that has dominated legal t
hinking in this area. n56 According to this model, the clinician or researcher
has a primary obligation to an individual's welfare. Apart from exceptional cir
cumstances, some stipulated by law, n57 the patient or subject must give consen
t and retains his or her confidentiality rights, even when disclosing informati
on gathered during treatment or research is needed to prevent harm to innocent
third parties.\par
\par
----------Footnotes----------
- \par\par
n56 See Sonia M. Suter, Whose Genes Are These Anyway? Familial Conflicts ove
r Access to Genetic Information, \i 91 MICH. L. REV. 1854 (1993).\i0 \par\par

n57 JAMES C. BECK. CONFIDENTIALITY VERSUS THE DUTY TO PROTECT: FORESEEABLE H
ARM IN THE PRACTICE OF PSYCHIATRY (1990).\par
\par
----------End Footnotes----------
- \par\par
In the broader context of treatment decisions where families share the econo
mic and emotional (as opposed to medical) impact of decision \'5B*584\'5D m
aking, some scholars have called for replacing the patient-autonomy model with
a family-centered model of decision making. n58 Whenever family members signifi
cantly disagree about the appropriate course of care for one of their members,
this model resorts to family conferences with decision-making authority.\par
\par
----------Footnotes----------
- \par\par
n58 See Jeffrey Blustein, The Family in Medical Decision-making, 23 HASTINGS
CENTER REP. 6 (1993); James Hardwig, What About The Family? 20 HASTINGS CENTER
REP. 5 (1990); Mark G. Kuczewski, Reconceiving the Family: The Process of Cons
ent in Medical Decisionmaking, 26 HASTINGS CENTER REP. 30 (1996); James L. Nels
on, Taking Families Seriously, 22 HASTINGS CENTER REP. 6 (1992).\par
\par
----------End Footnotes----------
- \par\par
A similar approach may seem suitable to genetic decision making, where the f
amily, rather than individual members, is often regarded as the \'22patient.\'2
2 However, we should be wary about such a fundamental change in our social para

digms. The traditional model appropriately privileges the relationship between the individual clinician or researcher and the patient/subject. Among other things, this model sustains trust, the vital element in patients' or subjects' willingness to enter the medical system. Enhanced communication alone resolves many family conflicts. Genetic counselors, in particular, are aware of the fact that conflicts over genetic information often reveal deeper processes of familial tension. Resolving the tension usually requires patience and understanding rather than externally imposed decisions. n59\par
\par
----------Footnotes----------
\par\par
n59 See PATRICIA T. KELLY, DEALING WITH DILEMMA: A MANUAL FOR GENETIC COUNSELORS 99 (1977).\par
\par
----------End Footnotes----------
\par\par
E. Community Impacts \par\par
A fifth distinctive aspect of DNA-derived information is that it is potentially shared by members of larger ethnic, racial, or other communities beyond the individual or family. Sickle-cell anemia is associated with persons of African descent, Tay-Sachs disease with persons of Ashkenazi Jewish heritage, and Mediterranean Fever with Armenians. n60 The history of eugenic abuses provides a frightening illustration of how easily group stigmatization can result from the misuse of such genetic information. n61 Increases in knowledge from DNA-derived information intensify the potential for these abuses and possibly \'5B*585\'5D create new forms of stigmatization or discrimination. Serious harms for members of communities occurs if genetic information is utilized to reinforce prejudice against existing classes of people (so-called \'22demic\'22 discrimination) n62 and/or to create new classes of genetic \'22untouchables.\'22\par
\par
----------Footnotes----------
\par\par
n60 See TROY DUSTER, BACKDOOR TO EUGENICS 160-62 (1990). \par\par
n61 See Daniel J. Kevles, Out Of Eugenics: The Historical Politics of the Human Genome, in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 3 (Daniel J. Kevles & LeRoy Hood eds., 1992); Kenneth L. Garver & Bettylee Garver, Eugenics: Past, Present, and the Future, 49 AM. J. HUMAN GENETICS 1109 (1991); Kenneth L. Garver & Bettylee Garver, The Human Genome Project and Eugenic Concerns, 54 AM. J. HUMAN GENETICS 148 (1994). \par\par
n62 See Eric T. Juengst, The Perils of Genetic Genealogy, 10 CENTER VIEWS 1 (1996).\par
\par
----------End Footnotes----------
\par\par
Controversy surrounding the Human Genome Diversity Project highlights the fear that genetic medicine may intensify group prejudice. n63 This proposal to collect, preserve, and analyze genetic samples from people world-wide has raised genuine concerns that established genomic markers will become the defining factor in determining who belongs to a particular social group. If this occurs, these markers may serve to exclude individuals who lack defining markers or guarantee pariah status for others who possess them.\par
\par
----------Footnotes----------
\par\par

n63 See id.\par
\par
----------End Footnotes----------
\par\par
A similar concern of external group harm relates to the increasing interest in behavioral genetic disorders. Information regarding the genetic bases of particular conditions may reinforce stigmatizing stereotypes. While the information may be of medical importance, it might be used to support a genetic \'22determinism\'22 that overlooks environmental contributions. This concern has informed discussions of the research concerning the genetics of alcoholism within the Native American community. n64 The concern has contrasted with the generally positive support for genetic research expressed by members of the National Alliance for the Mentally Ill. n65 Would the identification of genes linked to culturally or socially undesirable traits lead to prenatal \'22de-selection\'22 if couples are pressured to screen and abort fetuses with these markers? This fear has been raised in the debate surrounding the so-called \'22gay\'22 gene. n66\par
\par
----------Footnotes----------
\par\par
n64 See INDIAN HEALTH SERVICES, DRAFT IHS GUIDELINES ABOUT THE COLLECTION AND USE OF RESEARCH SPECIMENS 1-8 (1996). \par\par
n65 See Laura L. Hall, Severe Mental Illness, Genetics, and People, Presentation at the Institute of Medicine Discussion on Behavioral Genetics (July 17, 1996). \par\par
n66 See DEAN HAMER & PETER COPELAND, THE SCIENCE OF DESIRE: THE SEARCH FOR THE GAY GENE AND THE BIOLOGY OF BEHAVIOR (1994).\par
\par
----------End Footnotes----------
\par\par
Genetic research may also be used to generate new classes of \'22untouchables.\'22 For example, recent breast cancer research in the Ashkenazic Jewish community suggests that a BRCA mutation potentially predisposing one to breast and ovarian cancer exists in over two percent of this population. n67 Since a majority of carriers have a \'5B*586\'5D mutation detectable by standard molecular techniques, it is possible to identify women with the mutation. n68 While researchers are only beginning to understand the long term benefits of this discovery, the immediate repercussions might be externally or internally imposed discrimination against women of Ashkenazic heritage. External discrimination may result from mandatory screening of Jewish females. n69 Those found to have the mutation, or even untested but suspected members of the group, might be denied employment or insurance because of apprehensions about their health status. Internal group stigmatization might occur from within Hasidic Jewish communities towards women found to have the mutation. Current screening initiatives in this population for Tay-Sachs disease and other recessive disorders base their success on voluntary compliance with the effort to prevent marriage between carriers. Since most marital matches in this community are pre-arranged, prevention efforts have been implemented with great success and with relatively little inconvenience for the couples involved. n70 However, in this same community women found to carry the dominant BRCA mutation might be relegated to a class of unsuitable marital partners. Worries about this possibility led U.S. Jewish leaders of the Dor Yeshorim program, which offers screening for recessive disorders to members of the Jewish community, to refuse to test for the BRCA mutations. n71 Concerns have also prompted requests for the National Human Genome Research Insti

tute to develop guidelines for genetic research in this population. These conce
rns are likely to increase as genetic research is used to stratify levels of ri
sk within populations.\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n67 See C. Oddoux et al., The Carrier Frequency of the BRCA2 6174delT Mutati
on Among Ashkenazi Jewish Individuals Is Approximately 1%, 14 NATURE GENETICS 1
88 (1996); Jeff P. Struewing et al., The Carrier Frequency of the BRCA1 185dela
g Mutation Is Approximately 1 Percent in Ashkenazi Jewish Individuals, NATURE G
ENETICS 198 (1995); Jeff P. Struewing et al., The Risk of Cancer Associated wit
h Specific Mutations of BRCA1 and BRCA2 Among Ashkenazi Jews, \i 336 N. ENG. J.
MED. 1401 (1997).\i0 \par\par
n68 See AMERICAN COLLEGE OF MEDICAL GENETICS, STATEMENT ON POPULATION SCREEN
ING FOR BRCA-1 MUTATION IN ASHKENAZI JEWISH WOMEN (1996). \par\par
n69 See Rothenberg, supra note 13, at 103. \par\par
n70 See Etty Broide et al., Screening for Carriers of Tay-Sachs Disease in t
he Ultraorthodox Ashkenazi Jewish Community in Israel, 47 AM. J. MED. GENETICS
213 (1993). \par\par
n71 See Personal Conversation with Rabbi Joseph Ekstein, Director of the Dor
Yeshorim Program, in Brooklyn, N.Y. (February 3, 1997).\par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - - -
- \par\par
Unfortunately neither federal regulations nor the common law adequately addr
ess community concerns. For example, federal guidelines explicitly prohibit con
sideration of the \'22possible long-range effects of applying knowledge gained
in the research\'22 n72 among the risks of research. Our long-standing legal fo
cus on individual autonomy as \'5B*587\'5D the basis of the physician-patie
nt and researcher-subject relationships creates a further obstacle to consideri
ng the impact of genetic research on communities. Within such a paradigm, commu
nity values such as loyalty, integrity, and solidarity, are often missed or dis
counted. n73\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par
n72 45 C.F.R. {\f0\'A7} 46.111 (1997). \par\par
n73 See Thomas H. Murray, Individualism and Community: The Contested Terrain
of Autonomy, 24 HASTINGS CENTER REP. 32-33 (1994).\par
\par
- - - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - - -
- \par\par
Finally, genetic concerns frustrate analogical comparisons to other areas of
medical law or policy. The rationale of preventing the spread of disease that
underlies policy in AIDS or communicable disease contexts seems unwarranted for
predictive genetic testing since issues such as the controllability of the spr
ead of the disease, treatability, or certainty of transmission may differ from
the infectious disease context. n74 Thus, while solutions may not involve a ful
l-scale abandonment of individual autonomy, the challenges of community-oriente
d thinking that genetics introduces into the framework of traditional legal con
siderations will prove especially challenging.\par
\par
- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - -
- \par\par

n74 See, e.g., Kenneth E. Labowitz, Beyond Tarasoff: AIDS and the Obligation to Breach Confidentiality, \i 9 ST. LOUIS U. PUB. L. REV. 495, 512 (1990).\i0 \par
\par
----------End Footnotes----------
\par\par
III. POLICY IMPLICATIONS \par\par
The preceding five features, when taken together, justify regarding DNA-derived information as different from other types of medical information. The issue of stored tissue samples provides an illustration of this difference. Pathologists are uncomfortable with new limitations on the use of tissue samples in research or other contexts. n75 They suggest the use of tissues gathered during medical care or surgery has resulted in important medical advances. They point to the problems of securing extensive consent from patients for the future disposition of tissue samples.\par
\par
----------Footnotes----------
\par\par
n75 See, e.g., Wayne W. Grody, Molecular Pathology, Informed Consent, and the Paraffin Block, 4 DIAGNOSTIC MOLECULAR PATHOLOGY 155 (1995).\par
\par
----------End Footnotes----------
\par\par
These reservations are reasonable where researchers gather tissue not subject to molecular analysis. However, as the DNA analysis of tissue increasingly becomes the norm, no guarantee exists that future studies will not invite significant harms for an expanding circle of people genetically related to the individual donor. As we have indicated, not even the anonymization of information derived from DNA analysis can guarantee full protection from these harms. This does not mean that individuals cannot or should not donate tissue that will be subject to molecular genetic analysis. However, it does place greater weight on the requirement of full and informed consent concerning the risks involved. \'5B *588\'5D It may also require thinking about the legitimate legal and ethical claims of family and community members to involvement in these decisions. \par
\par
The uniqueness of DNA also has implications for the creation of DNA databases used for identification purposes by government agencies, such as the military. The Pentagon, for example, suggests that it would primarily use DNA samples for identifying the remains of personnel killed in the line of duty. While dental records and fingerprints already allow for some identification, the Pentagon claims that DNA databases provide a superior means of identification. Critics of the policy question the adequacy of privacy safeguards and the potential for abuse of DNA information. \par\par
The government's past track record with social security numbers provides genuine cause for concern. The original Social Security Act n76 claimed that social security numbers would be used primarily for the distribution of benefits. Today, computer systems are capable of linking our social security numbers with almost every aspect of our life. From law school admissions to legal infractions, the government has collected a \'22pedigree\'22 of our life activities. n77 As the private sector becomes involved here, one must wonder what has become of the original Congressional guarantees of confidentiality and privacy. n78\par
\par
----------Footnotes----------

- \par\par
n76 Social Security Act, ch. 531, {\f0\'A7} 205, 49 Stat. 624 (1935) (curren
t version at \i 42 U.S.C.A. {\f0\'A7} 405\i0 (West Supp. 1998). \par\par
n77 See OFFICE OF TECHNOLOGICAL ASSESSMENT, 101ST CONG., GENETIC WITNESS: FO
RENSIC USES OF DNA TESTS 115 (1990). \par\par
n78 See Social Security Act {\f0\'A7} 205.\par
\par
----------End Footnotes----------
- \par\par
In light of the five features described above, significant safeguards should
be enacted to ensure clear limitations on the use of such DNA registries. The
military has made some progress in revising its policy by reducing the time the
samples would be held from seventy-five to fifty years, by allowing soldiers t
o have their samples destroyed upon request after departure, and by requiring c
onsent for military uses other than remains identification. However, the new po
licy still requires soldiers to submit to DNA sampling and permits DNA material
to be turned over without consent when subpoenaed during the investigation or
prosecution of a felony. This latter fact is especially troubling given that th
e Federal Bureau of Investigation has already started a national criminal DNA r
egistry. n79\par
\par
----------Footnotes----------
- \par\par
n79 The FBI already uses a computerized database to chart the frequency of c
ertain genes in the U.S. population. See Rick Weiss, DNA Takes the Stand, 135 S
CI. NEWS 74 (1989).\par
\par
----------End Footnotes----------
- \par\par
Similarly, once samples are collected, it remains an open question whether a
ny legal precedents would bar the military from converting the \'5B*589\'5D
DNA samples to commercially profitable uses. Norman-Bloodsaw v. Lawrence Berke
ley Laboratory, n80 in which the Ninth Circuit held that a state- and federall
y-operated employer can be held liable under both the U.S. and California Const
itutions for unauthorized testing of its employees' genetic material (even when
provided as part of a general physical examination), provides some support for
the argument that the military could not profit from its DNA samples absent au
thorization. Further, in one of most notable cases on patenting human cell line
s, Moore v. Regents of the University of California, n81 the California Supreme
Court ruled that Moore, the patient plaintiff, stated a cause of action for br
each of fiduciary duty and lack of informed consent where his physician failed
to disclose his commercial research interest in Moore's cells before conducting
a medical procedure. However, the Moore court also held that even where there
was a lack of informed consent, the plaintiff failed to state a cause of action
for conversion because he had no property interests in his cells after doctors
removed them from his body. n82 Thus, absent the institution of additional saf
eguards, it is possible that courts will choose to follow Moore's second holdin
g, allowing the deference traditionally accorded to the military in the area of
constitutional rights n83 to trump Norman-Bloodsaw's authorization requirement
.\par
\par
----------Footnotes----------
- \par\par
n80 \i 135 F.3d 1260 (9th Cir. 1998).\i0 \par\par

n81 \i 793 P.2d 479, 485-86 (Cal. 1990).\i0 \par\par
n82 \i Id. at 487-97.\i0 \par\par
n83 See, e.g., \i Goldman v. Weinberger, 475 U.S. 503 (1986)\i0 (deferring to military regulation that prevented Orthodox Jew from wearing yarmulke while in uniform); \i Rostker v. Goldberg, 453 U.S. 57 (1981)\i0 (denying Fifth Amendment due process and equal protection challenge to selective service policy requiring only men to register for the draft).\par
\par
----------End Footnotes----------
\par\par
The area of genetic testing for employment or insurance provides a final example of the importance of the policy implications of these five aspects of DNA-derived information. Those seeking to craft legal protections against discrimination in these areas, especially in the area of insurance, have frequently encountered a definitional problem. If we prohibit discrimination on the basis of genetic information, what counts as \'22genetic\'22? Many common disorders have a genetic basis. Is the gathering of a standard medical history from an applicant for life insurance therefore to be ruled out of bounds? Should the use of family histories, which also can be broadly construed as conveying genetic information, be banned? \par\par
An appreciation of the five features offered above suggests that an initial distinction should be made between medical tests that reveal \'5B*590\'5D existing health problems, and DNA molecular analysis that only predict disease susceptibility without establishing severity or age of onset. n84 These latter types of genetic testing are not simply \'22an extension of diagnostic tests that describe people's current condition.\'22 n85 DNA-based risk classification schemes overlook environmental factors that affect a person's health. n86 As one commentator notes, \'22in our excitement we forget that there's still the nurture part of the equation. It hasn't gone away just because we have the opportunity to understand the nature part more quantitatively.\'22 n87 Risk classification schemes also neglect to account for the possibility of disease prevention through the early identification and treatment of a genetic disorder. Similarly, though there is little evidence to support such a claim at the present time, one cannot completely dismiss the scientific promise of standard cures for genetic disorders through genetic therapy.\par
\par
----------Footnotes----------
\par\par
n84 See Susan O'Hara, Comment, The Use of Genetic Testing in the Health Insurance Industry: The Creation of a \'22Biologic Underclass,\'22 \i 22 SW. U. L. REV. 1211 (1993);\i0 Richard Saltus, Genetic Clairvoyance, BOSTON GLOBE, Jan. 8, 1995, Magazine at 14, 26. \par\par
n85 Genetic Testing; Protecting the Rights of the Insured, STAR TRIB., Feb. 14, 1995, at 12A. \par\par
n86 See id. \par\par
n87 Siebert, supra note 4, at 94; see also Jane E. Brody, Good Habits Outweigh Genes as Key to a Healthy Old Age, N.Y. TIMES, Feb. 28, 1996, at C9.\par
\par
----------End Footnotes----------
\par\par
Should legislation against genetic discrimination extend beyond DNA analysis to these other sources of genetic information, such as family histories? Some authors have advocated this position. n88 This question requires careful study in terms of its feasibility in the context of existing underwriting practices.

However, we suggest that an appreciation of these five features of DNA explains why, at a minimum, information derived directly from molecular analysis of DNA should be singled out for special protection by legislation. Because of the pr odigious amount of information that molecular DNA-analysis can provide, not jus t about the individuals tested, but about their relatives and others with whom they share similar genetic material, there is good reason for placing special e mphasis on tests involving direct analysis of DNA. By prohibiting discriminatio n based on testing of this sort, we can call a halt to an ethically invasive pr ocedure with virtually unlimited risks for many people outside the testing cont ext before this procedure becomes established and made the basis of intense com mercial competition.\par

\par

----------Footnotes----------

- \par\par

n88 See Hudson et al., supra note 11, at 393.\par

\par

----------End Footnotes----------

- \par\par

\'5B*591\'5D Admittedly, drawing a line between molecularly-derived DNA an d other forms of \'22genetic\'22 information creates some anomalies. n89 An ind ividual's relatives may be just as imperiled by disclosure of a full family his tory to an insurance company as by her submitting to a buccal swab for DNA anal ysis. Nevertheless, the five features we have signaled, taken together, justify drawing one bright line distinction at least at the point where molecular DNA analysis begins. No medical examination of a patient and no family history per mits the degree of identification of genetic susceptibilities in the individual , kin, and descendants that is made possible by the direct analysis of DNA. Wit hout prejudging the value of a broader definition of genetics in this context, qualitative and quantitative considerations thus combine to recommend placing t his kind of testing in a class by itself.\par

\par

----------Footnotes----------

- \par\par

n89 See Joseph S. Alper & Jonathan R. Beckwith, Distinguishing Genetic from Nongenetic Medical Tests: Some Implications for Antidiscrimination Legislation, 4 SCI. & ENGINEERING ETHICS 141 (1998).\par

\par

----------End Footnotes----------

- \par\par

IV. CONCLUSION \par\par

Until just a few years ago, genetics was primarily a medical specialty focus ing on rare inherited single-gene disorders that affected only a small number o f people. Today, as tests for hundreds of genetic markers are identified that i ndicate inheritance, predisposition, or susceptibility to not only purely genet ic diseases, but also to complex disorders suspected of having a genetic compon ent, n90 all of us are potentially involved in genetic medicine.\par

\par

----------Footnotes----------

- \par\par

n90 See NEIL A. HOLTZMAN, PROCEED WITH CAUTION: PREDICTING GENETIC RISKS IN THE RECOMBINANT DNA ERA 303 (1989).\par

\par

----------End Footnotes----------

- \par\par

In the future we can expect that an increasing number of research protocols and clinical procedures will involves genetics. Investigators, IRBs, and patien ts themselves must all become increasingly sophisticated about the special risk s associated with genetic medicine. The beginning of this effort is an understa nding of the distinctive informational nature of DNA and the fact that, in some ways, it is a shared possession of families and communities. With this widened perception of risks, we can anticipate and reduce the harms of genetic researc h and genetic medicine. \pard
\sect \sectd \sbknone
\page \fl \f0 \fs20 \li000\ri000 \pard

\qc Hofstra Law Review\par
\par
\pard
\qc Winter, 1998\par
\par
\pard
\qc 27 Hofstra L. Rev. 411\par
\par
\pard
LENGTH: 33697 words \par\par\pard
NOTE: THE CASSANDRA COMPLEX: AN EMPLOYER'S DILEMMA IN THE GENETIC WORKPLACE \p ar\par\pard
Joanne Seltzer*\par
\pard
* The Author wishes to thank Professor Janet L. Dolgin and Michael Marks Cohe n, Esq. for their generous guidance, the staff of the Hofstra Law Review for th eir tireless editing, and her family for their unending support and patience. T his Note is dedicated to my husband, Gary Seltzer, without whose understanding, adaptability, and encouragement, this Note, and for that matter, law school wo uld have remained a dream deferred. \par\par\pard
SUMMARY: ... Advances in genetic research could potentially enable the employe r to \'22predict the future\'22 by providing him with information regarding the genetic make-up of current and prospective employees. ... Iowa, North Carolin a, New Hampshire, New York, Rhode Island, Texas, and Wisconsin have enacted sta tutes that ban genetic testing and genetic discrimination in the workplace, and , in some cases, ban the sale and interpretation of genetic information to the employer by a third party. ... Confronted with the ethical and legal dilemmas of the genetic workplace with little or no legislative or administrative guidan ce, the employer of the new millennium will be left with few options for avoidi ng legal consequences, whether the employer chooses to use the new-found geneti c information or not. ... Additionally, gene reading, except in cases of single gene disease, is an incomplete measurement, which does not take into account t he possibility of avoiding disease through environmental or personal health fac tors. ... Employers concerned with the worker's safety and health could use ge netic testing and screening to provide information about threats posed to emplo yees and applicants by existing workplace conditions. ... The final choice reg arding assumption of risk should remain with the employee or the applicant, unl ess co-workers or third parties will also share the risk. ... \par\par\pard

The next time Apollo \'22caught at love,\'22 he sought to get love back by prom ising to teach Cassandra the art of prophecy. He kept his promise, but Cassandr a still refused to be his lover. Divine gifts, once given, cannot be withdrawn, so Apollo's revenge was that she could keep her gift of prophecy but that no o

ne would believe her. n1\par
\par
----------Footnotes----------
-n1. ARIANNA HUFFINGTON, THE GODS OF GREECE 50 (1993).\par
\par
----------End Footnotes----------
- \par\par\pard
TEXT: \'5B*412\'5D \par\par
I. Introduction \par\par
Like the conflicted Cassandra, an employer in the new millennium will face a baffling legal predicament. Advances in genetic research could potentially enable the employer to \'22predict the future\'22 by providing him with information regarding the genetic make-up of current and prospective employees. Equipped with this crystal ball, the employer might be able to foresee the possibility that certain employees will incur costly and debilitating diseases or that they will fall victim to substance addiction, mental illness, or criminal propensities. But, as in the myth of Cassandra, without clear guidance on the legal and ethical use of this gift, the gift will prove to be virtually useless. Under the statutory restrictions imposed by the Rehabilitation Act of 1973 n2 and its successor, the Americans with Disabilities Act of 1990 (\'22ADA\'22), n3 an employer will not be able to use this information to make employment decisions without risking liability for employment discrimination.\par
\par
----------Footnotes----------
- \par\par
n2. \i 29 U.S.C. 701\i0 -96 (1994). \par\par
n3. \i 42 U.S.C. 12101\i0 -213 (1994). \par
\par
----------End Footnotes----------
- \par\par
However, closing one's eyes to this information will be equally problematic. Under the common law doctrines of negligent hiring, negligent retention, and negligent entrustment, an employer may be held responsible to third parties for the damage or injuries caused by an employee's illness or dangerous propensity that the employer could have anticipated and prevented. The employer of the next millennium, therefore, will face the prospect of liability for failing to act on the genetic information he is statutorily preempted from accessing. \par\par
Part I of this Note gives an overview of past experiments with genetic predisposition and determinism, including the quest for the \'22perfect person\'22 embodied by the \'22Eugenic Movement\'22 of the late \'5B*413\'5D nineteenth and early twentieth centuries, and the quest for the \'22perfect worker\'22 undertaken by American employers since the 1940s. Part II examines the origins, goals, organization, and progress of the Human Genome Project, including the ethical and legal considerations raised by its findings. Part III of this Note reviews existing state and federal legislation and administrative regulations to examine their sufficiency in providing guidelines for the use of genetic information in the workplace. Using existing anti-discriminatory statutes, regulations, and judicial decisions, Part IV of the Note analyzes the \'22Cassandra Complex,\'22 an employer's liability for either using or ignoring available genetic information. Finally, Part V presents recommendations to the employer on preparing for the advent of the genetic workplace. \par\par
II. Historical Background \par\par
A. The Eugenic Movement: The Quest for the \'22Perfect Person\'22\par

\par
The quest for the perfect person found its political expression in the Eugenic Movement, which swept across the United States in the late nineteenth and earl y twentieth centuries. Developed as a theory in 1883, \'22eugenics\'22 is descr ibed as the science of improving the human race by the careful selection of pa rents. n4 French scientist Sir Francis Galton, a cousin of Charles Darwin, n5 e xpounded the first theories of modern eugenics in the late 1800s. n6 Creating t he term eugenics from the Greek root meaning \'22well born,\'22 Galton maintain ed that \'22afflictions \'5Bsuch\'5D as mental retardation, mental illness and criminality were incurable hereditary defects, and that measures preventing rep roduction by those with such undesirable characteristics would eliminate many s ocial problems.\'22 n7 By the turn of the century, Galton's ideas on individual heredity had been expanded by his colleagues to include the concept that each \'5B*414\'5D individual's germ cells were \'22\'22part of a continuous stre am of germplasm which has been in existence ever since the appearance of life o n the globe, and which is destined to continue in existence as long as life rem ains on the globe.'\'22 n8 In this expansive context, the concern of geneticist s shifted from the individual's genetic traits to the \'22pools\'22 of traits s pecific to race, nationality, or economic position. n9 In the early part of the twentieth century, Galton's theories took root and flourished in a number of c ountries including the United States, England, and Germany. n10\par
\par
----------Footnotes----------
\par\par
n4. See Eric M. Jaegers, Note, Modern Judicial Treatment of Procreative Righ ts of Developmentally Disabled Persons: Equal Rights to Procreation and Sterili zation, 31 U. Louisville J. Fam. L. 947, 950 (1993); see also George P. Smith, II, Genetics, Eugenics, and Public Policy, \i 1985 S. Ill. U. L.J. 435, 437 (19 85)\i0 (defining \'22eugenics\'22 as an \'22approach designed to give \'22the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had'\'22) (quoting Commen t, Eugenic Artificial Insemination: A Cure for Mediocrity?, \i 94 Harv. L. Rev. 1850, 1852 (1981)).\i0 \par\par
n5. See Robert N. Proctor, Genomics and Eugenics: How Fair Is the Comparison ?, in Gene Mapping: Using Law and Ethics as Guides 57, 59 (George J. Annas & Sh erman Elias eds., 1992). \par\par
n6. See Jaegers, supra note 4, at 950. \par\par
n7. Id. \par\par
n8. Robert J. Cynkar, Buck v. Bell: \'22Felt Necessities\'22 v. Fundamental Values?, \i 81 Colum. L. Rev. 1418, 1422 (1981)\i0 (quoting Paul Popenoe & Ros well Hill Johnson, Applied Eugenics 25 (1918)). \par\par
n9. See \i id. at 1421.\i0 \par\par
n10. See Daniel J. Kevles, Eugenics and the Human Genome Project: Is the Pas t Prologue?, in Justice and the Human Genome Project 14, 15 (Timothy F. Murphy & Marc A. Lappe eds., 1994). Spurred by their American counterparts, German sci entists, funded by the Nazi government, conducted substantial research into gen etics. See Proctor, supra note 5, at 59-61. Racial hygiene, the care for germin al health, was pronounced a primary medical responsibility. See id. In Germany, as in the United States, eugenic policies were first implemented by forced ste rilizations. See id. \par
\par
----------End Footnotes----------
\par\par
In the United States, the political unrest and economic change of the 1870s

and 1880s, as well as the xenophobic sentiment that followed World War I, produ
ced fertile ground for the growth of the Eugenic Movement in early 1900s. n11 E
ugenicists, supported by \'22scientific\'22 evidence that intelligence and pers
onality traits were genetically inheritable, n12 maintained that society could
actively improve itself by discouraging the reproductive capacity of its undesi
rable members and by encouraging reproduction of the desirable ones. n13 Indivi
duals considered unfit because of criminal backgrounds, low intelligence, or ab
use of alcohol or drugs were targeted for negative eugenics - the effort \'22to
eradicate the socially inadequate germplasm from the American stock.\'22 n14 U
ltimately, the \'22unfit\'22 label expanded to include individuals with physica
l deformities, diseases such as epilepsy, syphilis, tuberculosis, or leprosy, a
nd people of poor economic means. n15\par
\par
----------Footnotes----------
\par\par
n11. See Cynkar, supra note 8, at 1423. \par\par
n12. As their scientific basis, eugenicists used the work of Gregor Mendel,
who developed genetic ratios through his experiments with crossbreeding peas. S
ee id. at 1421. At a time when knowledge of genetics was in its infancy, eugeni
cists used these ratios to support their theories of the inheritability of indi
vidual characteristics and psychological traits. See id. \par\par
n13. See Jaegers, supra note 4, at 950; see also Jana Leslie-Miller, From Be
ll to Bell: Responsible Reproduction in the Twentieth Century, 8 Md. J. Contemp
. Legal Issues 123, 124 (1997) (commenting that the science of eugenics \'22jus
tified discrimination on the basis of race, class, and sex\'22). \par\par
n14. Cynkar, supra note 8, at 1428. \par\par
n15. See James E. Bowman, Genetics and African Americans, \i 27 Seton Hall L
. Rev. 919, 922 (1997).\i0 Immigrants from \'22undesirable racial stocks,\'22
such as the early twentieth century waves of Eastern Europeans, were also targe
ted for negative eugenic policies. See Proctor, supra note 5, at 61. The testim
onies of prominent eugenicists were influential in the enactment of the Immigra
tion Restriction Act of 1924, which effectively reduced the flow of immigrants
to the United States by 95 percent. See id. \par
\par
----------End Footnotes----------
\par\par
\'5B*415\'5D The negative eugenic policies demanded that those with inferi
or germplasm be rendered incapable of producing offspring to ensure that their
deleterious genes would not have an opportunity to further \'22infect\'22 socie
ty. n16 To implement these policies, eugenicists proposed the establishment of
a nationwide plan of mandatory, long-term care in custodial institutions for th
e genetically unfit. The advent in the 1890s of the salpingectomy and the vasec
tomy, relatively simple procedures to prevent reproduction, allowed eugenicists
to advocate sterilization as a \'22more humane\'22 method of accomplishing the
eugenic goals. n17\par
\par
----------Footnotes----------
\par\par
n16. See Cynkar, supra note 8, at 1428-30. \par\par
n17. See id. at 1429. Positive eugenics, or the promotion of the reproductio
n of the \'22fit,\'22 offered financial incentives for the increased reproducti
on of \'22fitter families.\'22 See Proctor, supra note 5, at 60. The manifestat
ions of positive eugenics were significantly more benign than those of negative
eugenics. The American Eugenic Society, established in 1923, mounted eugenic e

xhibits at state fairs, proudly exhibiting \'22superior\'22 individuals in thei
r \'22human stock\'22 pavilion. The winners of the Fitter Family competitions,
in the three categories of small, medium and large, were awarded medals declari
ng them \'22Grade A Individuals.\'22 Although the criteria for selection are un
clear, all of the hopeful competitors were required to take an intelligence quo
tient (\'22IQ\'22) test and the Wassermann test for syphilis. See Kevles, supra
note 10, at 17. The choice instrument for measuring intelligence in these gene
tic competitions was the Binet-Simon intelligence test, whose validity was seri
ously in question by 1919. See Mary L. Dudziak, Oliver Wendell Holmes as a Euge
nic Reformer: Rhetoric in the Writing of Constitutional Law, \i 71 Iowa L. Rev.
833, 851 n.125 (1986).\i0 \par
\par
----------End Footnotes----------
- \par\par
The Eugenic Movement found legislative expression in the enactment of state
sterilization laws. Starting with Indiana in 1907, thirty states passed compuls
ory sterilization laws by 1940, resulting in approximately 50,000 procedures by
the end of World War II. n18 Sterilization laws were upheld by the Supreme Cou
rt in 1927 in the landmark \'5B*416\'5D case of Buck v. Bell, n19 the Court
's first consideration of the constitutionality of state sterilization statutes
. The reluctant plaintiff was Carrie Buck, a seventeen-year-old girl from Appal
achia \'22who had a funny drawl and who perpetrated the sin of having a child o
ut of wedlock.\'22 n20 The Supreme Court upheld the Virginia sterilization law
as a valid exercise of state police power. n21 The distinguishing feature of th
e case was Justice Holmes' positive endorsement of eugenic theories, according
more weight to the rights of society as a whole than to Buck's individual procr
eative rights under the Fourteenth Amendment. n22 Justice Holmes concluded: \'2
2It is better for all the world, if instead of waiting to execute degenerate of
fspring for crime, or to let them starve for their imbecility, society can prev
ent those who are manifestly unfit from continuing their kind.... Three generat
ions of imbeciles are enough.\'22 n23\par
\par
----------Footnotes----------
- \par\par
n18. See Proctor, supra note 5, at 61. In 1910, the Attorney General from Ca
lifornia, U.S. Webb, explained that the targets of the \'22sterilization progra
m\'22 in his state were \'22\'22most of the insane, epileptic, imbecile, idioti
c, sexual perverts; many of the confirmed inebriates, prostitutes, tramps and c
riminals, as well as the habitual paupers found in our country poor-asylums.\'
22 Leslie-Miller, supra note 13, at 130-31. He also declared that many children
in orphan homes belong to the class known as degenerates. See id. at 131. Forc
ed sterilization as a condition for release from mental institutions was justif
ied by the president of the Medical Association of the State of Alabama who arg
ued that \'22\'22it \'5Bwas\'5D not humane to allow the insane to propagate his
species to the injury of himself and the public.\'22 Id. at 130. Unfortunatel
y, due to the lack of knowledge regarding mental illness, the residents of ment
al institutions included recovering alcoholics, people with mild cases of epil
epsy, and those with low IQ scores, who, in today's context, would hardly be cl
assified as insane. See id. While American states were busy legislating sterili
zation laws, Nazi Germany enacted its own version in 1933, the Law for the Prot
ection of Genetically Diseased Offspring, resulting in approximately 350,000 fo
rced sterilizations by the end of the Nazi regime. See Proctor, supra note 5, a
t 61. \par\par
n19. \i 274 U.S. 200 (1927).\i0 \par\par

n20. Leslie-Miller, supra note 13, at 128. Buck was committed to the State C olony for Epileptics and Feebleminded in Lynchburg, Virginia by her guardian, M rs. Dobbs, who, upon discovering that Buck was pregnant, determined that the in stitution would be best able to handle her \'22unmanageable and promiscuous\'22 behavior. See Cynkar, supra note 8, at 1437; see also Dudziak, supra note 17, at 848 (finding that the State of Virginia sought to prevent \'22propagation\'2 2 by people it felt \'22mentally defective and socially inadequate\'22). Buck, like her mother who was institutionalized in the same colony, was classified as hereditarily feebleminded and was determined to have passed on her genetic dis order to her illegitimate offspring. The lower court found that Buck was the \' 22\'22probable potential parent of socially inadequate offspring,\'22 and that she could be \'22\'22sterilized without detriment to her general health.\'22 Leslie-Miller, supra note 13, at 128. This conclusory statement was based on ev idence such as Buck's low score on the Binet-Simon intelligence test, her pregn ancy, and hearsay from institution staff members. See id. Subsequent history pr oved that both Buck and her mother were of average intelligence, and that her d aughter was a second grade honor roll student before dying at the age of eight. See Jaegers, supra note 4, at 957. \par\par

n21. See \i Buck, 274 U.S. at 200.\i0 \par\par

n22. See Leslie-Miller, supra note 13, at 129. \par\par

n23. \i Buck, 274 U.S. at 207.\i0 Justice Holmes, a social Darwinist at hea rt, was a believer in the possibility for science to breed a better race of hum an beings. This belief, in conjunction with his view that state legislatures an d Congress should be left free to conduct social experimentation, combined to c reate his strong rhetoric in Buck v. Bell. See Dudziak, supra note 17, at 856. In his short opinion, Justice Holmes saw fit to cite only one case and saw no n eed to carefully ponder the constitutional arguments. See id. at 858. He subseq uently declared that the Buck decision was \'22\'22one decision that I wrote \' 5Bthat\'5D gave me pleasure.\'22 Id. at 859; see also Cynkar, supra note 8, at 1443-45 (discussing Justice Holmes' opinion in Buck v. Bell). \par

\par

----------End Footnotes----------

\par\par

Beginning in the 1930s, there was a gradual decline of support for eugenic t heories. n24 Increased scientific understanding of mental retardation disproved the theoretical foundations of eugenics by proposing that the majority of ment al illness is not inheritable. n25 Secondly, the outcome of the Nazi eugenic mo vement--the atrocities promoted by Adolf Hit \'5B*417\'5D ler--chilled Ameri can enthusiasm for eugenic theories. n26 Finally, procreative autonomy began to emerge as a fundamental right. n27 Although not explicitly overruling Buck v. Bell, the Supreme Court in 1941 articulated its opposition to involuntary steri lization in Skinner v. Oklahoma, n28 declaring that the state's unequal applic ation of sterilization in the criminal context was a constitutional violation a nd holding that procreation is a fundamental right. n29\par

\par

----------Footnotes----------

\par\par

n24. See Jaegers, supra note 4, at 954. \par\par

n25. See id. at 955. \par\par

n26. See id. \par\par

n27. See id. at 957. \par\par

n28. \i 316 U.S. 535 (1942).\i0 This Supreme Court case challenged the cons titutionality of Oklahoma's Habitual Criminal Sterilization Act requiring compu lsory sterilization of individuals convicted of two or more felonies involving

\'22moral turpitude.\'22 See \i id. at 536.\i0 Disputing the contention that c
riminal tendencies are heritable, the Court concluded that the statute violated
\'22the most elementary notions of due process.\'22 \i Id. at 545.\i0 \par\p
ar
n29. See \i id. at 541.\i0 \par
\par
----------End Footnotes----------
- \par\par
B. Eugenics in the United States Workplace: The Quest for the \'22Perfect Wo
rker\'22\par
\par
The quest for the perfect person, dismissed by American society in the 1940s,
found new expression in the quest for the perfect worker in the decades followi
ng World War II. Technological advancements in the post-war industrial explosio
n, especially the introduction of many new chemicals in the workplace reignited
the interest in eugenics. However, this time the interest centered on identify
ing workers whose genetic makeup would be best suited to withstand increased ex
posure to industrial toxins. \par\par
After World War II, several large employers established medical screening pr
ograms to identify employees whose genetic makeup might render them \'22hyper-s
usceptible\'22 to workplace toxins. These early industrial eugenic experiments
would prove to be as misguided as the social eugenic policies of prior decades.
Under the guise of extending workplace protection, these policies openly discr
iminated against workers with little valid scientific support and with even les
s consideration for the potential detrimental impact upon the lives of the indi
viduals tested. n30\par
\par
----------Footnotes----------
- \par\par
n30. Genetic testing in industry takes two forms: genetic screening and gene
tic monitoring, or cytogenetics. See Office of Tech. Assessment, U.S. Congress,
Genetic Monitoring and Screening in the Workplace 1 (1990) \'5Bhereinafter Gen
etic Monitoring and Screening\'5D. Genetic monitoring involves periodic exams o
f current employees to evaluate modifications in their genetic material, such a
s chromosomal damage or molecular mutation, which occur in the course of their
employment. See id. Genetic monitoring targets the entire active workforce and
its focus is the identification of environmental workplace risks that can be r
educed through the implementation of prevention programs. See id. at 2. Genetic
screening, on the other hand, involves efforts to test applicants or employees
for certain inherited characteristics that might render them susceptible to wo
rkplace substances. See id. at 3. The target of genetic screening is the indivi
dual and its purpose is, according to the Office of Technology Assessment (\'22
OTA\'22), to improve employee productivity, to lower workers' compensation cost
s through healthier employees, and to improve employers' health care cost-conta
inment efforts. See id. As a means to achieve these industrial goals, the OTA s
uggested that \'22this could be done through exclusion (i.e., not hiring those
with deleterious genes because of the potential drain on health insurance).\'22
Id. The OTA was created by the Technology Assessment Act of 1972. See Technolo
gy Assessment Act of 1972, Pub. L. No. 92-484, 86 Stat. 797 (codified as amende
d at \i 2 U.S.C. 471\i0 -81 (1994). Its purpose is to serve Congress by giving
objective analyses of major policy issues related to technical and scientific c
hange. See Office of the Fed. Register, Nat'l Archives and Records Admin., The
United States Government Manual 61 (1995). \par
\par

----------End Footnotes----------
\par\par
\'5B*418\'5D Discriminatory treatment of workers on the basis of the results of sickle cell screening and enzyme testing illustrates both the dangers inherent in stereotyping workers without valid medical or scientific justification and the potential liability for employers in either accessing or ignoring the results of genetic tests. An examination of the ethical and legal problems that arose with these exclusionary policies serves as a preview of the potential problems that may face an employer when genetic testing becomes readily available. \par\par
1. Sickle Cell Screening\par
\par
As early eugenicists postulated, many genetic traits are prevalent in specific races and nationalities, making genetic exclusionary policies particularly stigmatizing to certain segments of society. n31 Sickle cell anemia is an inherited blood disorder in which red blood cells become sickled, or crescent shaped, causing physical symptoms of varying severity. n32 The disease manifests itself in homozygous individuals, those who have inherited the sickle cell gene from both parents. n33 Heterozygous individuals, those who have inherited one normal hemoglobin gene and one sickle cell gene, test positive for the disease trait but effectively have no adverse physical manifestations. n34 The sickle cell trait is concentrated in people of African ancestry and, to a lesser degree, those of Middle Eastern or Mediterranean ancestry. n35\par
\par
----------Footnotes----------
\par\par
n31. See supra note 15 and accompanying text. \par\par
n32. See Mark A. Rothstein, Employee Selection Based on Susceptibility to Occupational Illness, \i 81 Mich. L. Rev. 1379, 1385 (1983).\i0 \par\par
n33. See id. \par\par
n34. See id. \par\par
n35. See Katherine Brokaw, Genetic Screening in the Workplace and Employers' Liability, \i 23 Colum. J.L. & Soc. Probs. 317, 323-24 (1990)\i0 (stating that one of the most significant problems with workplace screening is that many genetic traits, like sickle cell, correspond to ethnicity). \par
\par
----------End Footnotes----------
\par\par
Interest in screening for sickle cell anemia increased after the deaths of four black Army recruits while training at moderately high \'5B*419\'5D altitudes at Fort Bliss, Texas. n36 With little scientific corroboration, the Air Force Academy imposed an entrance ban on carriers of the sickle cell gene, regardless of whether they showed evidence of the disease. n37 In addition, the Department of Defense initiated a policy of excluding sickle cell carriers from aviation and flight crew training. n38 Following the Air Force's lead, Congress passed the National Sickle Cell Anemia Control Act of 1972, n39 which appropriated federal funds for voluntary testing programs to detect the sickle cell gene in the black population. n40 The government, like the armed forces, ignored the critical difference between the sickle cell trait carried by healthy heterozygous individuals and the sickle cell disease, thereby perpetuating the stigmatization of over two million blacks. n41\par
\par
----------Footnotes----------
\par\par

n36. See Proctor, supra note 5, at 72. \par\par
n37. See id. \par\par
n38. See id. \par\par
n39. Pub. L. No. 92-294, 86 Stat. 136 (1972). \par\par
n40. See Bowman, supra note 15, at 920. \par\par
n41. See id. \par
\par
----------End Footnotes----------
\par\par
Industry soon reacted to the government's concern, suspecting that healthy carriers of the sickle cell gene might prove more vulnerable, or hyper-susceptible, to hemolytic agents such as amino and nitro compounds, benzene, cadmium, carbon monoxide, and cyanide. n42 In a three month study of genetics in the workplace, the New York Times reported that Du Pont de Nemours & Co. (\'22Du Pont\'22) had routinely given pre-employment blood tests to black applicants to identify carriers of the sickle cell gene. n43 Dr. Charles F. Reinhardt, Director of Du Pont's Haskell Lab for Toxicology and Industrial Medicine, told the Times that the tests were started in 1972 at the request of a group of black employees. n44 Dr. Bruce W. Karrh, the Medical Director for Du Pont, maintained that no job placement decisions had been made on the basis of the tests. n45\par
\par
----------Footnotes----------
\par\par
n42. See Brokaw, supra note 35, at 323. \par\par
n43. See Richard Severo, Screening of Blacks by Du Pont Sharpens Debate on Gene Tests, N.Y. Times, Feb. 4, 1980, at A1. \par\par
n44. See id. \par\par
n45. See id. \par
\par
----------End Footnotes----------
\par\par
Subsequently, in the 1981 congressional hearings investigating the existence of genetic screening in the workplace, Dr. Karrh testified that the testing program had been publicly misconstrued. n46 He reaffirmed that the screening of black employees and applicants was purely for \'5B*420\'5D their information and benefit and that no decisions had been made regarding placement or promotion as a result of the tests. n47 These reassuring statements contradicted prior admissions by Dr. Reinhardt in the New York Times article that \'22the tests would definitely influence the employment process.\'22 n48 Both Dr. Karrh and Dr. Reinhardt were unable to testify as to how many blacks applicant had been screened since the program had been initiated in 1972 or how many instances of sickle cell had been found. n49 Both maintained that no systematized data had been derived from the tests. n50 After numerous interviews with company officials, the New York Times concluded that \'22it remains difficult to determine precisely what is happening with genetic screening at Du Pont.\'22 n51\par
\par
----------Footnotes----------
\par\par
n46. See Genetic Screening and the Handling of High-Risk Groups in the Workplace: Hearings Before the Subcomm. on Investigations and Oversight of the House Comm. on Science and Tech., 97th Cong. 261 (1981) \'5Bhereinafter High-Risk Groups\'5D. \par\par
n47. See id. \par\par
n48. Severo, supra note 43, at A1. \par\par

n49. See id. \par\par
n50. See id. \par\par
n51. Id. \par
\par
----------End Footnotes----------
- \par\par
The Du Pont officials did seem to agree on one fact. Despite their concern f
or the health of their employees, no thought had been given to genetic testing
of white workers of Mediterranean ancestry susceptible to inheritable blood dis
eases. n52 To explain this inconsistency, Dr. Karrh stated in congressional hea
rings that the tests were limited to blacks because \'22the original request ca
me from them.\'22 n53 However, he confirmed that many of Du Pont's sites contin
ued testing black applicants, and that determination of who was black and would
therefore be tested was done \'22by appearance.\'22 n54 Moreover, even though
the tests were ostensibly conducted for the employee's personal use, Dr. Karrh
said that employee's medical records were retained in the company medical files
, accessible on a \'22need-to-know\'22 basis. n55 Also at the 1981 hearings, Dr
. Barton Childs, a professor at the Johns Hopkins Medical School, testified th
at he could see no reason for the Du Pont screening program, but affirmed that
this screening effectively stigmatized healthy individuals and exposed them to
discrimination in employment and in health insurance. n56\par
\par
----------Footnotes----------
- \par\par
n52. See id. \par\par
n53. High-Risk Groups, supra note 46, at 282. \par\par
n54. Id. \par\par
n55. See id. at 283-84. \par\par
n56. See id. \par
\par
----------End Footnotes----------
- \par\par
2. Enzyme Testing\par
\par
In addition to screening black applicants for the sickle cell trait, Du Pont t
ested applicants for two enzyme deficiencies prevalent in specific \'5B*421\'
5D races and nationalities: Glucose-6-phosphate dehydrogenase (\'22G-6-PD\'22
) deficiency and Serum alpha subscript 1-antitrypsin (\'22SAT\'22) deficiency.
n57 G-6-PD deficiency is a biochemical genetic condition involving red blood ce
lls, n58 which occurs homozygously in males and is found primarily in blacks fr
om Central Africa, Mediterraneans, Asians, East Indians, Filipinos, and Oceania
ns. n59 A deficiency of the enzyme interferes with the oxidation of glucose and
was believed to endanger individuals exposed to industrial amino and nitro com
pounds. n60 However, no information or studies exist to back up the proposition
that deficient individuals exhibit a heightened medical risk from exposure to
industrial chemicals. n61\par
\par
----------Footnotes----------
- \par\par
n57. See id. at 284. \par\par
n58. See Rothstein, supra note 32, at 1386. \par\par
n59. See id. at 1390. \par\par
n60. See id. at 1385. \par\par
n61. See id. at 1386. \par

\par
----------End Footnotes----------
- \par\par
SAT deficiency, occurring most frequently among people of northern European ancestry, n62 is responsible for a predisposition to alveolar destruction leadi ng to chronic pulmonary disease. n63 Smoking and exposure to dusty environments exacerbate the condition. n64 As with the other genetic conditions, there is a significant difference in outcome between homozygous and heterozygous individu als, with only ten percent of SAT deficient heterozygotes ultimately developin g the disease. n65\par
\par
----------Footnotes----------
- \par\par
n62. See id. at 1390-91. \par\par
n63. See id. at 1387. \par\par
n64. See id. \par\par
n65. See id. \par
\par
----------End Footnotes----------
- \par\par
Dr. Karrh testified in the congressional hearings that Du Pont tested for th e two enzyme deficiencies on a limited basis to determine if the tests would be of value in protecting the health of susceptible employees. n66 He concluded t hat the tests were generally found not to be useful in an occupational setting. n67 In his testimony, Dr. Karrh stated that he could not answer the question a s to whether employees and applicants were notified prior to testing, n68 and h e affirmed that there were no counseling or educational programs available for those workers found to test positive for the deficiencies. n69\par
\par
----------Footnotes----------
- \par\par
n66. See High-Risk Groups, supra note 46, at 266. \par\par
n67. See id. \par\par
n68. See id. at 284. \par\par
n69. See id. at 285. \par
\par
----------End Footnotes----------
- \par\par
Dr. Karrh nevertheless admitted that the results of tests for G-6-PD deficie ncy had been used to reassign four employees from positions that \'5B*422\'5D had potential exposure to amino compounds. n70 He reassured the congressmen th at upon discovery of this practice, the plant physician was advised that tests should not be used as the sole criteria for placement decisions. n71 As with si ckle cell testing, the results of the enzyme deficiency tests were filed with t he medical records of the employee. n72 Dr. Karrh did not elaborate as to the p lanned use for these findings nor what workplace decisions they would engender. n73 Commenting on Du Pont's screening policies, Dr. Jonathan King, molecular b iologist at the Massachusetts Institute of Technology, maintained that:\par
\par
----------Footnotes----------
- \par\par
n70. See id. \par\par
n71. See id. \par\par
n72. See id. at 283-84. \par\par

n73. See id. at 283-87. \par
\par
----------End Footnotes----------
\par\par
\par
\par
\'22This policy of Du Pont's is very clearly a eugenic policy .... Du Pont's p
osition is scientific racism. They say they are not bigots because all this is
based on science. But the fact is that people are not going to get sick because
they are hypersusceptible, they are going to get sick because they are being p
oisoned.\'22 n74\par
\par
The New York Times investigative study uncovered another company that had been
testing thousands of workers to determine if \'22defective\'22 genes were maki
ng them more vulnerable to substances in the workplace. n75 Ironically, in this
report, the employer, the Dow Chemical Company (\'22Dow\'22), was equally cens
ured, but in this case for its failure to act on the basis of the test results.
n76 Under the guidance of Medical Director Jack Killian, Dow began conducting
genetic monitoring on its workers to detect change in chromosomal structure due
to exposure to workplace substances. n77 By the mid-1970s, Dr. Killian became
convinced that workers who exhibited consistently high rates of broken chromoso
mes should be notified and transferred away from the chemicals that might be th
e cause of their chromosomal mutations. n78 According to Dr. Killian, when he a
nd his colleagues determined that the chromosomal breakage centered on workers
exposed to benzene and epichlorohydrin, Dow officials grew distant, hostile, an
d defensive about the findings. n79 Dr. Killian eventually left Dow, along with
the key \'5B*423\'5D people who contributed to the study. n80\par
\par
----------Footnotes----------
\par\par
n74. Severo, supra note 43, at A1. \par\par
n75. See Richard Severo, Disputes Arise over Dow Studies on Genetic Damage i
n Workers, N.Y. Times, Feb. 5, 1980, at A1. \par\par
n76. See id. \par\par
n77. See id. \par\par
n78. See id. \par\par
n79. See id. \par\par
n80. See id. Dr. Dante Picciano, the geneticist who worked under Dr. Killian
, had a similar problem in convincing Dow Chemical Company (\'22Dow\'22) offici
als that the genetic results were significant enough to necessitate corporate a
ction. See id. He, like Dr. Killian, eventually left Dow. See id. \par
\par
----------End Footnotes----------
\par\par
Dow, like Du Pont, maintained that after more than a decade and a half of ge
netic screening involving thousands of workers, it had no exact figure for how
many workers were screened, what the tests concluded, or how the company might
use genetic monitoring in the future. n81 Dow's explanation for its failure to
act on Dr. Killian's data was that his results were difficult to evaluate and
that it would be irresponsible to alarm workers by citing findings that might p
rove to be inaccurate. n82 The Dow experiment, although initially established f
or outwardly beneficial reasons such as the protection of industrial workers, w
as eventually condemned because of the company's failure to act on the results
of the test.\par

\par
----------Footnotes----------
\par\par
n81. See Richard Severo, Genetic Tests by Industry Raise Questions on Rights of Workers, N.Y. Times, Feb. 3, 1980, at A1. \par\par
n82. See id. \par
\par
----------End Footnotes----------
\par\par
The two corporations, Dow and Du Pont serve as early examples of employers confronted with the Cassandra Complex. Lacking clear legal and ethical guidance, they were both censured, one for acting and one for failing to act on the results of predictive employee testing. n83\par
\par
----------Footnotes----------
\par\par
n83. Not all exclusionary practices were based on medical testing. Some were enacted simply on the basis of a worker's sex and misconceptions as to its limitations. These practices, like the broad exclusions of healthy heterozygous individuals, were based on groundless generalizations of a group's physical limitations. In January 1980, 13 female employees of the American Cyanamid Company (\'22American\'22), along with their labor union, brought a sexual discrimination suit against the company under Title VII of the Civil Rights Act of 1964. See High-Risk Groups, supra note 46, at 172. The plaintiffs maintained that American fostered a policy barring all women except those whose infertility was medically documented from certain jobs involving exposure to lead. See id. Five of the women had undergone voluntary sterilization in order to keep their positions. See id. A year prior to the suit, the Occupational Safety and Health Administration (\'22OSHA\'22) had charged American with a violation of OSHA's regulatory standards and had fined the company $10,000 for its sex-based exclusionary policies. See \i Oil, Chem. & Atomic Workers Int'l. Union v. American Cyanamid Co., 741 F.2d 444, 450 n.1 (D.C. Cir. 1984).\i0 OSHA settled the suit. See id. OSHA's Lead Standard rejected the absolute exclusion of fertile women, requiring instead that testing and transfers apply equally to men and women planning to parent children. See High-Risk Groups, supra note 46, at 188-89. The issue of gender-biased policies was addressed by the Supreme Court in the landmark case of \i International Union v. Johnson Controls, Inc., 499 U.S. 187 (1991).\i0 The action was brought by women workers who had chosen to be sterilized to avoid losing their jobs. See \i id. at 192.\i0 Johnson Controls' policy, like American's, excluded women from the battery manufacturing process where the primary ingredient was lead. See \i id. at 206.\i0 In holding the policy violative of women's rights under Title VII, the Court concluded that decisions regarding the welfare of future children should be left to parents rather than to employers. See id. Addressing the potential liability of the employer from suits by the offspring of exposed workers, the Court explained: \'22If, under general tort principles, Title VII bans sex-specific fetal-protection policies, the employer fully informs the woman of the risk, and the employer has not acted negligently, the basis for holding an employer liable seems remote at best.\'22 \i Id. at 208.\i0 \par
\par
----------End Footnotes----------
\par\par
\'5B*424\'5D \par\par
C. Congressional Interest in Genetic Monitoring and Screening\par

\par
The newspaper reports exposing industrial experiments with genetic monitoring and screening finally reached the ears of Congress. Alarmed by the rising contr oversy, Congress commissioned the Office of Technology Assessment (\'22OTA\'22) to conduct a survey on genetic monitoring and screening in the workplace. n84 The national survey targeted the 500 largest United States industries (Fortune 500), the fifty largest utility companies, and thirty-three major unions. n85 M uch to the government's surprise, the 1982 survey documented that six companies were actually conducting genetic monitoring and screening, and that fifty-five companies indicated they would \'22possibly\'22 use genetic tests within the n ext five year period. n86 Albert Gore, Chairman of the Subcommittee on Investig ations and Oversight of the Committee on Science and Technology (\'22Subcommitt ee\'22), commented that \'22instead of putting a controversy to rest, the OTA s tudy gives further evidence of the need to examine in much more detail the deve lopment of cytogenetic screening as well as its ramifications.\'22 n87\par
\par
----------Footnotes----------
\par\par
n84. See Genetic Monitoring and Screening, supra note 30, at 18. \par\par

n85. See id. \par\par
n86. See id. at 21-22; see also Genetic Screening of Workers: Hearing Before the Subcomm. on Investigations and Oversight of the House Comm. on Science and Tech., 97th Cong. 2 (1982) \'5Bhereinafter Genetic Screening of Workers\'5D (f inding that \'22a handful of companies are currently using these methods and a more appreciable number intend to implement these practices in the next 5 years \'22). \par\par
n87. \i Genetic Screening of Workers, supra \i0 note 86, at 2. \par
\par
----------End Footnotes----------
\par\par
On the same day that the New York Times released the results of the OTA's co ntroversial survey, n88 Representative Gore convened a hearing before the Subco mmittee to discuss the survey findings and their ethical and legal implications for industry. n89 After analyzing the results of the survey, the Subcommittee heard various experts voice their concerns over the developing trend of genetic screening and monitoring in the workplace. Dr. Gretchen Kolsrud of the OTA tes tified in part that the problems were arising due to the rapid development of g enetic technologies. n90 She stated that \'22we have no ethical guidelines to t ell us how or whether to use these capabilities because we have not had to face the questions that are being posed by the potential of these new technolo \'5 B*425\'5D gies ever before.\'22 n91 Dr. Kenneth B. Miller, Medical Director f or the Workers' Institute for Safety and Health, stated that accepted guideline s for medical screening stressed \'22the need for a demonstrated benefit to th e individual with little potential for harm.\'22 n92 He added that in order for early intervention and treatment to be effective, there must be both \'22a cle ar definition of what the disease state is and \'5Bknowledge of\'5D the natural progression of the disease.\'22 n93 Dr. Miller concluded that in the case of g enetic screening, where there is no known disease and no predictable progressio n from chromosomal differences to disease, the potential harm to the individual might outweigh the hypothetical benefit. n94 Dr. Miller predicted that, by lab eling individuals as \'22hyper-susceptible,\'22 employers could shift the respo nsibility for workplace safety to the genetics of the worker. This shift would deflect \'22the attention that might be paid to the employer's inability or unw

illingness to make the workplace safe for all those who trust that their health will be protected on the job.\'22 n95 Mark Rothstein, Professor at the College of Law, West Virginia University and an expert on the ethical ramifications of genetic screening, also testified before the subcommittee. n96 He anticipated that with the advent of genetic screening, the potential workforce would become divided into two groups. He explained that \'22one group would contain super h ealthy, disease-resistant persons; a second group would contain able-bodied per sons who are unemployable because of an atypical hereditary trait or a chromoso mal anomaly that places them in a category of statistically higher risk of occu pational illness.\'22 n97 Representative Gore observed that genetic surveillanc e was \'22akin to a black art and that it is really very tentative and prematur e. Nevertheless, companies are rushing headlong into this technique, or apparen tly many of them are ready to move quickly into this area.\'22 n98\par
\par
----------Footnotes----------
\par\par
n88. See Richard Severo, 59 Top U.S. Companies Plan Genetic Screening, N.Y. Times, June 23, 1982, at A12. \par\par
n89. See \i Genetic Screening of Workers, supra \i0 note 86, at 1-2. \par\p ar
n90. See id. at 44. \par\par
n91. Id. at 45. \par\par
n92. Id. at 50. \par\par
n93. Id. \par\par
n94. See id. \par\par
n95. Id. at 51. \par\par
n96. See id. at 97. \par\par
n97. Id. at 98-99. \par\par
n98. Id. at 44. \par
\par
----------End Footnotes----------
\par\par
In 1989, the OTA conducted a second survey, designed to remove ambiguities t hat might have been present in the initial survey and to provide trend data fo r the seven years that elapsed since the 1982 survey. n99 Of the 330 Fortune co mpanies responding to the 1989 survey, \'5B*426\'5D twelve health officers reported that their companies were currently conducting genetic monitoring or s creening, as compared with six reporting such use in 1982. n100 Substantiating the New York Times reports, the survey found that twenty-seven percent of healt h officers in the 1989 survey reported \'22the existence of medical criteria th at affected employment eligibility of job applicants. These included back ailme nts or problems, pregnancy, sensitivity to materials used in production, and re spiratory conditions.\'22 n101 Ultimately, with an almost audible sigh of relie f, the OTA concluded that the 1989 survey appeared to indicate that there was n o evidence of a sizeable increase in the number of companies using genetic scre ening or monitoring, and that fewer companies appeared to anticipate using it i n the future. n102\par
\par
----------Footnotes----------
\par\par
n99. See Office of Tech. Assessment, U.S. Congress, Medical Monitoring and S creening in the Workplace: Results of a Survey - Background Paper 3 (1991) \'5B hereinafter Medical Monitoring\'5D. \par\par
n100. See id. In the 1989 survey, 20 health officers stated that their compa

nies had conducted genetic screening or monitoring either currently or in the p
ast, whereas 18 officers reported such current or past use in the 1982 survey.
See id. \par\par
n101. Id. at 4. Of particular concern in the 1989 study was the question of
what pre-employment examinations would be considered acceptable. See id. at 4-7
. Most health and personnel officers responded affirmatively to the use of exam
inations to identify employees who were: physically unfit for employment; curre
ntly using drugs; at increased risk to workplace hazards or emotionally or psyc
hologically unstable. See id. The use of testing to identify high insurance ris
ks was found to be acceptable by a smaller proportion of health and personnel o
fficers. See id. Almost universally, corporate personnel officers thought perio
dic medical testing of employees in workplace settings where there were known h
ealth risks was appropriate. See id. In voicing their concerns for future genet
ic testing in the workplace, the respondents reported cost-effectiveness, relia
bility, and legality as primary considerations. See id. Over half of the health
officers responding to the survey agreed with the idea that genetic testing re
presented a potential threat to the rights of the employee. See id. Interesting
ly, those companies reporting current genetic testing were most likely to agree
with this idea. See id. The growing concern of employers over the rising cost
of health insurance featured prominently in their responses. See id. More than
a third of the respondents answered that an applicant's health insurance risk w
as assessed when considering his or her candidacy for a position with the compa
ny. \par\par
n102. See Genetic Monitoring and Screening, supra note 30, at 21-22. \par
\par
----------End Footnotes----------
\par\par
In the same year that the second survey was conducted, the United States gov
ernment publicly launched the Human Genome Project, the largest, most ambitious
experiment in human genetics to have ever been conducted. \par\par
III. The Human Genome Project \par\par
A. Origins\par
\par
As ethical debates raged on Capitol Hill, the seed for the ambitious Human Gen
ome Project was planted in the arid soil of Santa Cruz, New Mexico. In May 1985
, Robert Sinsheimer, who was then the chancellor \'5B*427\'5D of the Univer
sity of California at Santa Cruz, gathered an assorted mix of deoxyribonucleic
acid (\'22DNA\'22) experts to discuss the feasibility of mapping and sequencing
the entire human genome. n103 In the same year, Charles DeLisi, who had propos
ed an independent Human Genome Initiative to the Department of Energy (\'22DOE\
'22), became the Director of the DOE's Office of Health and Environmental Resea
rch. n104 After a 1986 meeting in Santa Fe, New Mexico, DeLisi proposed that ce
rtain national laboratories should become the center of the United States', and
perhaps the world's, human genome efforts. n105 Funding for DeLisi's proposals
began in fiscal year 1987, commanding an initial budget of $4.2 million. n106\
par
\par
----------Footnotes----------
\par\par
n103. See James D. Watson, The Human Genome Project: Past, Present, and Futu
re, Sci., Apr. 6, 1990, at 44, 45. The human genome consists of approximately 5
0,000 to 100,000 genes found on 23 pairs of chromosomes, with one set inherited
from each parent. See U.S. Dep't of Health and Human Servs. & U.S. Dep't of En
ergy, Understanding our Genetic Inheritance: The Human Genome Project: The Firs

t Five Years FY 1991-1995, at 9 (1990) \'5Bhereinafter The First Five Years\'5D
. Each chromosome contains a long molecule of DNA, whose two ribbon-like strand
s wrap around each other, forming a twisted ladder. The rungs of the ladder con
tain a linear array of bases called A, T, G, and C. The order of the four bases
on the DNA strand determines the information content of a particular gene. See
id.; see also Denise K. Casey, What Can the New Gene Tests Tell Us?, Judges' J
., Summer 1997, at 14, 15 (stating the order of \'22As, Ts, Cs, and Gs - is dif
ferent for everyone, which is what makes each of us unique\'22). For all our di
fferences, human beings are about 99.9 percent identical in their genetic bluep
rints, with the remaining one tenth of one percent accounting for all our physi
cal and mental variations. See id. at 16. All DNA sequence changes, called muta
tions, are either inherited from our parents or acquired during our lifetime an
d are responsible for human disease and abnormalities. See id. \par\par

n104. See Robert Cook-Deegan, The Gene Wars: Science, Politics, and the Huma
n Genome 79-80 (1994). By proposing his initiative to the Department of Energy
(\'22DOE\'22), DeLisi brought the Human Genome Project to the public policy age
nda. See id. \par\par

n105. See Watson, supra note 103, at 45. The origins of the project are cred
ited to several other independent events, including a meeting of prominent gene
ticists in Alta, Utah in 1984 and an influential article written by Nobel Laure
ate Renatto Dulbecco, which was published in Science in 1986, urging that the h
uman genome be sequenced. See Charles R. Cantor, Orchestrating the Human Genome
Project, Sci., Apr. 6, 1990, at 49, 49. All of the roots came together for the
first time at a meeting in Cold Spring Harbor, New York in 1986, where the cur
rent model of the project reached full idealization. See id. \par\par

n106. See Office of Tech. Assessment, U.S. Congress, Mapping Our Genes - Gen
ome Projects: How Big, How Fast? 100 (1988) \'5Bhereinafter How Big, How Fast?\
'5D. The funds were for 10 different projects being conducted at Columbia and H
arvard Universities and three national laboratories. See id. \par
\par
----------End Footnotes----------
- \par\par

In addition to the DOE, several other governmental agencies and private inst
itutions had launched corresponding programs with ambitious goals and sizeable
budgets. The National Institutes of Health (\'22NIH\'22) held a meeting in Octo
ber 1986 to set policy for the NIH's 3000 projects (with a combined budget of $
294 million) involving genetic mapping and sequencing. n107 The National Scienc
e Foundation, the \'5B*428\'5D Howard Hughes Medical Institute, and the Nat
ional Research Council (\'22NRC\'22) also committed substantial funding to rese
arch related to mapping and sequencing the human genome. n108\par
\par
----------Footnotes----------
- \par\par

n107. See id. at 93-94. The National Institutes of Health (\'22NIH\'22) is a
branch of the Department of Health and Human Services committed to biomedical
research to improve human health. See id. at 93. Its projects involving genetic
mapping and sequencing commanded a combined budget of $294 million. See id. \
par\par

n108. See id. at 102-07. The National Science Foundation, commissioned to co
ntinue the federal government's role in sponsoring basic research, had spent, i
n 1987, an estimated $32.7 million in research related to genetic sequencing an
d mapping. See id. In 1987, the Howard Hughes Medical Institute, a privately en
dowed organization, had committed an estimated $40 million to genetic research,
and the National Research Council, a federal agency providing the government w

ith advice regarding scientific issues, had recommended $200 million per year f
or a three year research project on the genome. See id. \par
\par
----------End Footnotes----------
\par\par
In light of these potentially conflicting projects, the Board of Basic Biolo
gy, Commission on Life Sciences of the National Academy of Sciences held a meet
ing in August 1986 and decided to commission a special NRC committee to prepare
a report as to how the United States should proceed with the Human Genome Proj
ect. n109 The committee's report urged the United States government to begin a
unified Human Genome Project and to cooperate with other interested nations. n1
10 The committee proposed a fifteen-year project, with an estimated budget of $
200 million per year. n111 At the same time, the House Committee on Energy and
Commerce commissioned the OTA to prepare a report assessing the scientific and
medical validity of the genome projects. n112 The OTA's final report, published
in April 1988, sounded a cautionary note regarding the possible ethical and le
gal implications of the genome projects. n113 The OTA concluded that the questi
on of whether the United States should enter the genetic arena was moot, since
mapping and sequencing activities had been ongoing for a decade with no governm
ental prohibition. n114 The report recommended that the federal government beco
me involved in genome research in the public interest of \'22making resources a
vailable in ways that are consistent with the considerations of \'5B*429\'5D
beneficence, justice, and autonomy.\'22 n115 The OTA stressed that the govern
ment's involvement was needed to ensure centralized control of the evolving tec
hnological applications of the genome project so that ethical issues, such as
voluntary testing and the access of data, could be addressed, regulated, and co
ntrolled by federal legislation. n116 In considering the ethical implications o
f the genome initiative, the report warned that \'22these questions are complex
and are not likely to be resolved in the near future. It will therefore be nec
essary to ensure that some means for explicitly addressing ethical issues atten
ds scientific work.\'22 n117 The report concluded with the recommendation that
the mapping and sequencing efforts continue to evolve as a multi-agency effort,
but that Congress regulate the level of involvement and control accorded to th
e participants. n118\par
\par
----------Footnotes----------
\par\par
n109. See Watson, supra note 103, at 45. \par\par
n110. See id. For additional information on international genome initiatives
, see generally Office of Tech. Assessment, U.S. Congress, Biotechnology in a G
lobal Economy (1991) (describing the increasing international attention focused
on the commercial and scientific development of new biotechnology); No<um e>ll
e Lenoir, French, European, and International Legislation on Bioethics, \i 27 S
uffolk U. L. Rev. 1249 (1993);\i0 Dorothy C. Wertz, International Perspectives
on Ethics and Human Genetics, \i 27 Suffolk U. L. Rev. 1411 (1993);\i0 Charle
s F. DeJager, Note, The Development of Regulatory Standards for Gene Therapy in
the European Union, 18 Fordham Int'l L.J. 1303 (1995). \par\par
n111. See Watson, supra note 103, at 45. \par\par
n112. See id. \par\par
n113. See How Big, How Fast?, supra note 106, at 79. \par\par
n114. See id. at 80-81. \par\par
n115. Id. at 87. \par\par
n116. See id. \par\par
n117. Id. at 88. \par\par

n118. See id. at 110. \par
\par
----------End Footnotes----------
\par\par
Congress assessed the need for centralized governmental involvement in the genome initiatives as early as January 1987. n119 The Biotechnology Competitiveness Act of 1987 n120 addressed the need for a federal policy coordinating biotechnical efforts, particularly encouraging the cooperation and communication between the research community, government, and industry. n121 Responding to perceived ethical and safety concerns, the proponents of the bill recommended the establishment of a Biomedical Ethics Board, an independent entity in the executive branch which would include representatives from all of the federal agencies funding biotechnology-related regulation, research, or promotion. n122 The bill additionally proposed the establishment of the National Advisory Panel on the Human Genome, co-chaired by the NIH and DOE officials to recommend the best strategy for the genome project, including the evaluation of ethical considerations raised by genetic research and prod \'5B*430\'5D uct development. n123 To ensure the bill's passage, its proponents raised the specter of the potential for destructive or unethical uses of the new genetic information if governmental controls were not imposed, as well as the overriding need to \'22keep the U.S. biotechnology industry the best in the world.\'22 n124\par
\par
----------Footnotes----------
\par\par
n119. On January 7, 1987, Senator Claude Pepper introduced The National Center of Biotechnology Information Act, S. 1354, that would give the NIH's National Library of Medicine responsibility for developing new biotechnical communication tools and for serving as repository and center of distribution for molecular biology information. See 133 Cong. Rec. H350 (daily ed. Jan. 21, 1987) (statement of Sen. Pepper). The bill was amended and introduced jointly by Senators Chiles, Kennedy, Domenici, Leahy, Graham, and Wilson on December 18, 1987 as the Biotechnology Competitiveness Act of 1987, S. 1966. See 133 Cong. Rec. S18,399-400 (daily ed. Dec. 18, 1987). \par\par
n120. \'22A bill to amend the Public Health Service Act to improve information and research on biotechnology and the human genome, and for other purposes. ...\'22 133 Cong. Rec. S18,399 (daily ed. Dec. 18, 1987). \par\par
n121. See id. at S18,399 (statement of Sen. Chiles). \par\par
n122. See id. at S18,400. \par\par
n123. See id. \par\par
n124. Id. at S18,405. To underscore this latter goal, the proponents introduced articles reporting advances in biotechnology by the Japanese, which threatened to topple the United States as the leading biotechnological giant. See id. at S18,402-03. Expounding on Japan's commitment of funds to biotechnology, the article warned of Japan's capacity for dominating biotechnology in the same manner that it had previously dominated the electronic and automotive fields. See id. \par
\par
----------End Footnotes----------
\par\par
In fiscal year 1988, the DOE was awarded $12 million of its $15 million budget request to continue its genome effort. An additional $18 million was subsequently awarded to the National Institutes of General Medical Sciences (\'22NIGMS \'22), the NIH's genome research division. n125 With these appropriations, Congress sent a clear message that both the DOE and the NIH would be responsible fo

r the development of a united Human Genome Project. n126\par
\par
----------Footnotes----------
\par\par
n125. See Watson, supra note 103, at 45-46. \par\par
n126. In hearings before the Senate Committee on Labor and Human Resources i
n July 1996, Senator Domenici reflected on the origins of the collaboration bet
ween the NIH and the DOE in the Human Genome Project. He stated: \par\par
\par
\par
I can remember vividly 10 years ago that we got this \'5BGenome Project\'5D st
arted by creating, believe it or not, a competition between the Department of E
nergy and the NIH. The NIH was kind of worried about whether they should do \'5
Bthe Project\'5D, and I said, well, fine, if they will not, let us have the Dep
artment of Energy do it, since they had been doing a lot of genetic work becaus
e of Hiroshima and Nagasaki. And, believe it or not, the enthusiasm of the NIH
changed in a positive and exponential manner once I introduced the bill to give
the Genome Project to the Department of Energy. \par\par
\par
\par
Advances in Genetics Research and Technologies: Challenges for Public Policy,
104th Cong. 2 (1996) \'5Bhereinafter Advances in Genetics Research\'5D. \par
\par
----------End Footnotes----------
\par\par
B. Project Planning and Organization\par
\par
Faced with the reality of having to cooperate in order to obtain continued fed
eral funding for their genome initiatives, the DOE and the NIH signed a Memoran
dum of Understanding in 1988 and appointed a joint advisory group to outline th
e strategy of the unified Human Genome Project. In April of 1990, the joint adv
isory group of the NIH's National Center for Human Genome Research (\'22NCHGR\'
22) and DOE's Office of Health and Environmental Research (\'22OHER\'22) publis
hed a comprehensive plan outlining the mission and organization of the first fi
ve years of the Human Genome Project. n127\par
\par
----------Footnotes----------
\par\par
n127. See The First Five Years, supra note 103. Although the two agencies fo
und themselves united in the new partnership, their individual interests in the
Human Genome Project were quite different. See How Big, How Fast?, supra note
106, at 99. Dating back to the Manhattan Project of World War II, the Office of
Health and Environmental Research (\'22OHER\'22) began as a health division fo
cusing on protecting people from the effects of radiation and on developing use
s for radioactive materials in medicine and biomedical research. See id. The pr
imary mission of the OHER continued to be the study of the sources of radiation
, pollution, and environmental toxins and to determine their effects on the env
ironment. See id. In its initial research efforts through its three national la
boratories, the DOE planned to use the results of the Human Genome Project to m
onitor the inherited effects of low level exposure to radiation and other envir
onmental hazards. See The First Five Years, supra note 103, at 31. The NIH's lo
ng history of support for genetic research was an extension of its mission to i
mprove the health of Americans. See Cantor, supra note 105, at 50. In its invol
vement in the Human Genome Project, the NIH focused on refinements in human gen

ome mapping and sequencing to combat human diseases. See id. The union of the r
elative strengths of the two agencies, NIH's expertise in medical application a
nd DOE's expertise in environmental technology, was considered the perfect marr
iage for the birth of the Human Genome Project. See The First Five Years, supra
note 103, at 32-33. \par
\par
----------End Footnotes----------
\par\par
\'5B*431\'5D The 1990 joint NIH and DOE plan articulated the overall goal
of the Human Genome Project: \'22to acquire fundamental information needed to f
urther our basic scientific understanding of human genetics and of the role of
various genes in health and disease.\'22 n128 Two of the specific goals for the
period from 1990 to 1995 were: (1) the production of a variety of physical map
s of all human chromosomes and of those of selected model organisms and (2) the
determination of the completed sequence of human DNA and the DNA of the model
organisms. n129 The program was expected to take fifteen years to complete, wit
h an estimated expenditure of $3 billion. n130 To address ethical and legal iss
ues, the agencies proposed a NIH and DOE joint working group on Ethical, Legal,
and Social Implications (\'22ELSI\'22) to anticipate and address the implicati
ons for individuals and society of mapping and sequencing the human genome. n13
1 The ELSI group's initial emphasis was on the \'22privacy of genetic informati
on, safe and effective introduction of genetic information in the clinical sett
ing, fairness in the use of genetic in \'5B*432\'5D formation, and professio
nal and public education.\'22 n132 Three percent of the overall Human Genome pr
oject budget was made available for the activities of the ELSI. n133\par
\par
----------Footnotes----------
\par\par
n128. The First Five Years, supra note 103, at 5. \par\par
n129. See id. Genetic \'22mapping is the process of determining the position
and spacing of genes, or other genetic landmarks, on the chromosomes relative
to one another.\'22 The First Five Years, supra note 103, at 9. Physical maps g
ive precise distances in terms of DNA base pairs and give access to the DNA its
elf in pieces that can be readily handled in the laboratory. See James D. Watso
n, Genes and the Legacy of Psychiatric Illness, Decade of the Brain, Spring 199
1, at 3. Genetic sequencing, the more ambitious of the two goals, involves the
identification of all three billion DNA base pairs in a linear pattern. See Ali
stair T. Iles, The Human Genome Project: A Challenge to the Human Rights Framew
ork, 9 Harv. Hum. Rts. J. 27, 29-30 (1996). By comparing the DNA of healthy and
diseased people, sequencing provides the best hope for understanding the molec
ular alterations responsible for disease. See Watson, supra note 103, at 44. Be
cause of the high costs involved in the sequencing technologies, it was project
ed that the sequencing of the entire human genome would take in excess of fifte
en years. See The First Five Years, supra note 103, at 6. \par\par
n130. See The First Five Years, supra note 103, at 6-7. \par\par
n131. See id. at 66. \par\par
n132. Francis Collins & David Galas, A New Five-Year Plan for the U.S. Human
Genome Project, Sci., Oct. 1, 1993, at 43, 45. \par\par
n133. See The First Five Years, supra note 103, at 20. \par
\par
----------End Footnotes----------
\par\par
C. Project Progress\par
\par

By fiscal year 1990, the Human Genome Project had grown from a $17.2 million program to one commanding a budget of $59.5 million. n134 With the increase in funding came increased concern with the application of the discoveries rapidly being made by the initiative. In hearings before the House of Representatives o n March 19, 1991, Representative Michael Andrews of Texas (D-TX), quoting Georg e Bernard Shaw, stated that \'22\'22science is always wrong. It never solves a problem without creating 10 more.'\'22 n135 He expressed a concern that with ea sy access to a person's genetic profile, there would be a heightened potential for unfair denial of benefits and jobs. n136 He urged Congress to enact laws th at would prevent discrimination based on genetic profiles while maintaining tha t \'22the promise of the human genome project should be enough to move us forwa rd as fast as possible.\'22 n137\par

\par

----------Footnotes----------

\par\par

n134. See S. Rep. No. 101-516, at 146 (1990). \par\par

n135. 137 Cong. Rec. E992 (daily ed. Mar. 19, 1991) (quoting George Bernard Shaw). \par\par

n136. See id. \par\par

n137. Id. The Congressional Record for April 22, 1991 includes remarks by Dr . Francis Collins, the Director of NIH's National Human Genome Research Institu te (\'22NHGRI\'22), announcing the project's success in identifying and cloning the gene for cystic fibrosis. See 137 Cong. Rec. E1354-56 (daily ed. Apr. 22, 1991). Dr. Collins, speaking before the Congressional Biomedical Research Caucu s, urged continued support for the program and assured the Representatives that concerns with the ethical and legal dilemmas created by the findings of the pr oject were being addressed. See id. \par

\par

----------End Footnotes----------

\par\par

The progress of the Human Genome Project continued in relative obscurity thr ough the next six years, with modest increases in funding. n138 \'5B*433\'5D

The Human Genome Project was given a sizeable boost on May 21, 1997, when the Senate passed the Mack-Feinstein Amendment, doubling the investment in biomedi cal research at the NIH by 2002 and renewing Congress' interest in the project. n139 In his congressional testimony on September 30, 1997, Dr. Collins stated that although only two percent of the human genome had been sequenced, projects initiated in 1996 would generate between 50 and 100 million base pairs of huma n DNA sequence by 1998, leading to a total sequence of the genome by 2005. n140 Dr. Francis Collins, Director of the NIH's National Human Genome Research Inst itute (\'22NHGRI\'22), further testified that as a result of the Human Genome P roject, new disease genes were discovered almost weekly, with recent identifica tion of the sequences of genes involved in the onset of colon cancer, diabetes, breast cancer, and Alzheimer's disease. n141 He added that ELSI's major focus in 1997 was to ensure the responsible use of genetic information, since the rap id increase in the number of genetic tests available to the individual greatly increases the potential for misinterpretation and abuse. n142\par

\par

----------Footnotes----------

\par\par

n138. According to the Budget of the United States, the following estimated funding levels were authorized for the National Center for Human Genome Resear ch: 1991 - $108 million; 1992 - $110.5 million; 1993 - $110.4 million; 1994 - $ 134.5 million; 1995 - $152 million; and 1996 - $166.7 million. See Office of Ma

nagement & Budget, Budget of the United States Government, Fiscal Year 1996 app
. at 475 (1995); Office of Management & Budget, Budget of the United States Gov
ernment, Fiscal Year 1995 app. at 437 (1994); Office of Management & Budget, Bu
dget of the United States Government, Fiscal Year 1994 app. at 612 (1993); Offi
ce of Management & Budget, Budget of the United States Government, Fiscal Year
1993 app. at 503 (1992); Office of Management & Budget, Budget of the United St
ates Government, Fiscal Year 1992, at 649 (1991); Office of Management & Budget
, Budget of the United States Government, Fiscal Year 1991 app. at 709-10 (1990
). \par\par
n139. See 143 Cong. Rec. S4867 (daily ed. May 21, 1997) (statement of Sen. K
ennedy). \par\par
n140. See Hearings Before the Subcomm. on Health and the Env't of the House
Comm. on Commerce, 143d Cong. 11 (1997) (statement of Francis S. Collins, Direc
tor of NHGRI). \par\par
n141. See id. \par\par
n142. See id. \par
\par
----------End Footnotes----------
- \par\par
The achievements of the Human Genome Project, in conjunction with internatio
nal genome initiatives and with private biotechnology corporations, continue on
a daily basis. n143 The discoveries made by the initiatives have contributed t
o the identification of the genes associated with diseases such as Huntington's
disease, neurofibromatosis types 1 & 2, certain genetic types of breast and co
lon cancers, hypertension, diabetes, and Alzheimer's disease. n144 Progress in
identifying genetic markers affecting predisposition to common ailments such as
lower back injuries, allergies, and arthritis have been equally successful. n1
45 Based on these findings, dozens of new biotechnology companies have sought t
o develop genetic tests for disorders ranging from arthritis to obesity. n146 O
n September 14, 1997, biologists at the NHGRI isolated the first gene that may
affect social behavior in mammals, a discovery which prom \'5B*434\'5D ises t
o shed new light on disorders of human social behavior such as schizophrenia an
d autism. n147\par
\par
----------Footnotes----------
- \par\par
n143. See Postscript infra notes 361-81 and accompanying text. \par\par
n144. See Collins & Galas, supra note 132, at 46. \par\par
n145. See Francis S. Collins et al., Variations on a Theme: Cataloging Human
DNA Sequence Variations, 278 Sci. 1580, 1580 (1997); David Shenk, Biocapitalis
m: What Price the Genetic Revolution?, Harper's Magazine, Dec. 1997, at 37, 38.
\par\par
n146. See Casey, supra note 103, at 14. \par\par
n147. See Nicholas Wade, Gene Found in Mice Could Affect Study of Human Beha
vior Disorders, Arizona Republic, Sept. 14, 1997, at A20. \par
\par
----------End Footnotes----------
- \par\par
D. Progress in Ethical Considerations\par
\par
From the discovery of the recombinant DNA technique in November 1974, which la
unched the age of genetic engineering to the scientific planning conferences in
the 1980s, there seems to be little documentary evidence indicating that the s
cientists who proposed the Human Genome Project considered its ethical and lega

l implications. n148 The reluctance by the scientific community to evaluate eth
ical problems squarely shifted to Congress the contradictory tasks of anticipat
ing the societal repercussions caused by the access to genetic information and
of continuing to champion expanding genetic projects.\par
\par
----------Footnotes----------
\par\par
n148. See Charles Weiner, Anticipating the Consequences of Genetic Engineeri
ng: Past, Present, and Future, in Are Genes Us? 31, 31 (Carl F. Cranor ed., 199
4). Dr. Arthur Caplan, Director of the University of Pennsylvania's Center for
Bioethics, suggested that this scientific reluctance to address ethical issues
stems from an awareness by researchers that ethical concerns may stand in the w
ay of continued funding for biotechnical projects. See Shenk, supra note 145, a
t 39-42. \par
\par
----------End Footnotes----------
\par\par
Governmental concern for the ethical dilemmas associated with the Human Geno
me Project were voiced several years prior its launching. n149 On January 26, 1
987, the OTA sponsored a workshop entitled Issues of Collaboration for Human Ge
nome Projects n150 which convened in preparation for the OTA's final assessment
report recommending federal control over the project. One of the speakers, Dr.
Mark Lappe of the University of Illinois at Chicago College of Medicine, warne
d of the long-term ethical implications of mapping and sequencing the human gen
ome. n151 He urged that scientific professionals take immediate steps to insure
that the results of the project be used for the benefit of society and to safe
guard against the misuse of sensitive genetic data. n152 In re \'5B*435\'5D
viewing the eugenic experiments of the past, Dr. Lappe warned that, armed with
the results from the Human Genome Project, eugenicists would, for the first tim
e, be able to point to \'22hard\'22 genetic data to attain their desired ends.
n153 He concluded that \'22because of the intrinsic capacity of genomic informa
tion to be used to discriminate (both invidiously and acceptably) among members
of the population and to affect their entitlements, it is also highly desirabl
e that protections against significant abuse be in place before the project get
s underway.\'22 n154\par
\par
----------Footnotes----------
\par\par
n149. One of the earliest expression of concern came from Senator Edward Ken
nedy in his address at the Harvard Medical School in May 1975: \par\par
\par
\par
\'22When science develops techniques that have the potential to fundamentally
change society, society has the right to determine how the technique is to be
used, whether it should be developed in the first place, and if so, under what
constraints. A decision to pursue the kind of research discussed ... requires t
he informed consent of the society - which, after all - is called upon to fund
it.\'22 \par\par
\par
\par
Weiner, supra note 148, at 43. \par\par
n150. See Office of Tech. Assessment, U.S. Congress, Mapping Our Genes: Fede
ral Genome Projects: How Vast? How Fast? (1987) \'5Bhereinafter Mapping Our Gen
es\'5D (Transcript of Workshop: \'22Issues of Collaboration for Human Genome Pr

ojects\'22). \par\par
n151. See id. at 6. \par\par
n152. See id. at 21. \par\par
n153. See id. at 44. \par\par
n154. Id. at 60 (emphasis added). For a more thorough discussion of the ethi
cal challenges generated by the Human Genome Project, see Justice and the Human
Genome Project, supra note 10. \par
\par
----------End Footnotes----------
- \par\par
The joint report from the NIH and the DOE, which outlined the first five yea
rs of the Human Genome Project, gave considerable attention to the report of th
e working group, ELSI, and to the ethical, social, and legal issues awaiting th
e dawn of the genetic era. n155 The report stressed the need to protect individ
uals and society from the possible hazards resulting from the new methods for d
etecting and predicting hereditary illness. n156 The report underscored that \'
22the use of genetic information, for good or ill, has long been an issue in ou
r society. But the quantity and complexity of genetic information that should b
ecome available requires that special precautions be taken.\'22 n157 In analyzi
ng the potential discriminatory effects caused by the release of genetic inform
ation to employers and insurers, the report concluded that \'22the interim phas
e, before adequate treatment is available, is the one in which the most deleter
ious consequences can occur, such as discrimination against gene carriers, loss
of employment or insurance, stigmatization, untoward psychological reactions a
nd attention.\'22 n158 After outlining a plan for addressing these ethical dile
mmas, n159 the ELSI working group concluded that a critical ethical component f
or the first five years was informing the general public of the goals of the Hu
man Genome Project and soliciting from them their questions and concerns. n160\
par
\par
----------Footnotes----------
- \par\par
n155. See The First Five Years, supra note 103, at 65-71. \par\par
n156. See id. at 65. \par\par
n157. Id. \par\par
n158. Id. \par\par
n159. See id. at 66-69. \par\par
n160. See id. at 70. The relative anonymity of the Human Genome Project was
commented on by the Director of NHGRI, who stated: \par\par
\par
\par
\'22If you ask the average person what the Human Genome Project is and what it
will do, most people will say, Huh? But when the history of science is written
100 years from now, this will be seen as the greatest scientific project of th
e century, maybe of all time.\'22 \par\par
\par
\par
Mark Schoofs, How Genetics is Changing our Lives, Village Voice (New York, N.Y
.), Sept. 30, 1997, at 18. \par
\par
----------End Footnotes----------
- \par\par
\'5B*436\'5D Seven years after its initial report, ELSI produced a final r
eport in September 1997. n161 Although the report's findings centered on the ac

curacy and confidentiality of genetic test results in laboratories and medical offices, the report echoed the themes of its 1990 plan. Strongly advocating inf ormed consent wherever genetic specimens could be traced back to the subject, t he ELSI working group stressed that \'22under no circumstances should results w ith identifiers be provided to any outside parties, including employers, insure rs, or government agencies...\'5Bnor should any person\'5D be subjected to unfa ir discrimination by a third party on the basis of having had a genetic test or receiving an abnormal genetic test result.\'22 n162 In conceding that its prio r mandate for universal education was more difficult that initially anticipated , the task force stated that \'22identifying a genetic variant that has a much higher frequency in some ethnic groups than in others could have a stigmatizing effect on that group.\'22 n163 In April 1990, James D. Watson, co-discoverer o f the structure of DNA and Director of the NCHGR in the infancy of the Human Ge nome Project, warned:\par

\par

----------Footnotes----------

\par\par

n161. See Promoting Safe and Effective Genetic Testing in the United States: Final Report of the Task Force on Genetic Testing (Neil A. Holtzman & Michael S. Watson eds., 1997) \'5Bhereinafter Final Report\'5D. \par\par

n162. Id. at xiv. \par\par

n163. Id. at 65; Charles W. Henderson, Breast Cancer Gene May Intensify Brea st Cancer Growth, Cancer Wkly Plus, Sept. 7, 1997. As progress in gene sequenci ng continues, scientists have continued to find genetic alterations that are pr evalent in specific nationalities or races. See Rick Weiss, Jews Say Gene Find Medically, Culturally Troubling, Detroit News, Sept. 8, 1997, at 2E (documentin g that these discoveries have further fueled fears of stigmatization based on g enetic stereotype). The Johns Hopkins Medical Center recently discovered a tiny genetic variation found in one of every six Jews of Eastern European ancestry that doubles the odds of getting colon cancer. See id. This genetic discovery joins other diseases found in similarly isolated and genetically \'22intact\'22 populations such as musculoskeletal disease (Amish), diabetes (Native American), sickle cell anemia (Blacks), and cystic fibrosis (Northern Europeans). See i d. \par

\par

----------End Footnotes----------

\par\par

\par

\par

We must work to ensure that society learns to use the information only in bene ficial ways and, if necessary, pass laws at both the federal and state levels t o prevent invasions of privacy of an individual's genetic background by either employers, insurers, or government agencies and to prevent discrimination on ge netic grounds.... We have only to look at how the Nazis used leading members of the German human genetics and psychiatry communities to justify their genocide programs .... We need no more vivid reminders that science in the wrong hands can do incalculable harm. n164\par

\par

\'5B*437\'5D \par

\par

----------Footnotes----------

\par\par

n164. Watson, supra note 103, at 46. \par

\par

----------End Footnotes----------
- \par\par
IV. Legislative Action and Inaction\par
\par
To date, there has been no federal legislation enacted to guide employers or i nsurers in the ethical and legal use of genetic information. By the year 2005, the scheduled completion date of the Project, such information should be as rea dily accessible as the results of a routine blood test. As evidenced by the vas t differences in interpretation between courts on issues related to workplace d iscrimination, it is clear that the establishment of uniform laws to regulate t he collection, use, and retention of genetic information must come from the leg islature. Without these statutes, the courts will be left to generate decisions in a highly technical area with minimal information or advice. n165 Additional ly, the successful resolution of the myriad of ethical and legal issues generat ed by the Human Genome Project will require compromise and deliberation, two qu alities better embodied by the legislative rather than the judicial process. n1 66 Congress, unlike the courts, has the power to delegate to an agency the auth ority to establish criteria and procedures to guide the employer through the ev olving legal labyrinth of genetic information in the workplace. n167\par
\par
----------Footnotes----------
- \par\par
n165. Ethical, Legal, and Social Implications, in conjunction with the Einst ein Institute, initiated the Genetics Adjudication Research Project whose goal was to educate 1000 state and federal judges on genetics and molecular biology over a two year period. See Genetic Testing: Courts, Legislatures Ready for Flo od of Genetics Related Cases and Bills, 5 Health L. Rep. (BNA) (Dec. 12, 1996), available in Westlaw, 5 B.H.L.R. 48. Franklin M. Zweig, President and Chief E xecutive Officer of the Einstein Institute, commented that the courts are going to have \'22one hell of a time\'22 ruling on complaints involving genetic disc rimination without a scientific background. See id. \par\par
n166. See Jack F. Williams, A Regulatory Model for Genetic Testing in Employ ment, \i 40 Okla. L. Rev. 181, 201 (1987).\i0 \par\par
n167. See \i id. at 203.\i0 \par
\par
----------End Footnotes----------
- \par\par
In 1995, the ELSI component of the Human Genome Project issued a proposed mo del for federal legislation entitled The Genetic Privacy Act and Commentary. n1 68 The main goal of the model act was to provide assurance that an individual's genetic information would not be controlled or possessed by third parties unle ss consented to by the individual. n169 The act proposes an express prohibition on the unauthorized collection and analysis of DNA information where the indiv idual's identity can be determined. n170 However, the act does allow DNA collec tion for a number of specific purposes, including issues involving research act ivities, fetuses and pregnant women, and minors and incompetent people. n171 \'5B*438\'5D Although the act proposes lucrative liquidated damages and trebl e damages for unlawful use of genetic information, it does not address criminal penalties. n172 The drafters of the model act maintained that any future legis lation must balance the individual's need for privacy and autonomy against scie nce's need to continue proper and useful genetic research. n173 In stressing th e need for Congress to adopt the ELSI recommendations, Dr. Francis Collins conc luded that \'22genetic discrimination has been hailed as the \'22civil rights' issue of this decade. We have the unique opportunity to address genetic privacy

and discrimination issues now as the scientific information unfolds, before we find ourselves in a full-fledged crisis.\'22 n174\par
\par
----------Footnotes----------
\par\par
n168. See Burk Burnett, Note, Genetic Discrimination: Legislation Required to Keep Genetic Secrets, 21 Seton Hall Legis. J. 502, 520-21 (1997). \par\par

n169. See id. at 521. \par\par
n170. See id. \par\par
n171. See id. at 522. \par\par
n172. See id. \par\par
n173. See id. at 522-23. \par\par
n174. Advances in Genetics Research, supra note 126, at 49. \par
\par
----------End Footnotes----------
\par\par
A. State Response\par
\par
To keep pace with the swift advancements in biotechnology, state legislatures saw an explosion of bills addressing genetic privacy in the insurance and employment contexts. n175 According to the National Conference of State Legislatures, at least twenty-six states had passed legislation prohibiting the discriminatory use of genetic information by insurance companies by 1997. n176\par
\par
----------Footnotes----------
\par\par
n175. See Burnett, supra note 168, at 509. \par\par
n176. See Robert Pear, Concerned States Pass Legislation Regulating Genetic Testing Results, Rocky Mtn. News, Nov. 2, 1997, at 18A. Carl Feldbaum, president of the Biotechnology Industry Organization, representing 730 companies, expressed alarm at the rapid growth of legislative initiatives governing genetic research: \'22\'22The sponsors of these bills are well intentioned\'5B,\'5D but often they don't understand the science or the potential consequences of their bills. Some of the legislation would virtually stop genetic research or severely limit our ability to conduct clinical trials.'\'22 Id. \par
\par
----------End Footnotes----------
\par\par
The principal struggle in enacting statutes governing genetic information is the attempt to strike a balance between the rights of the individual to genetic privacy and ownership of his germline, and the needs of science to have unlimited access to the results of genetic tests and experiments. The laborious process of New Jersey's Genetic Privacy Act n177 through the legislature and the governor's office gives a telling indication of the competing interests at play throughout the enactment process of genetic regulation.\par
\par
----------Footnotes----------
\par\par
n177. Genetic Privacy Act, S.B. 695, 207th Leg., 1st Sess. (N.J. 1996) (amending N.J. Stat. Ann. 17B:30-12 (Supp. 1996)). \par
\par
----------End Footnotes----------
\par\par

The struggle in New Jersey stemmed from one deceptively simple provision of the Act: the classification of genetic information as the \'5B*439\'5D prop erty right of its owner. n178 This seemingly innocent provision raised the powe rful hackles of New Jersey's booming insurance and genetic research industries. Dr. Philip Reilly, a clinical geneticist and director of the Shriver Center fo r Mental Retardation in Waltham, Massachusetts, after analyzing the bill, decla red that the property right provision \'22\'22could dramatically change the dis cipline of pathology and could impose major costs on research.'\'22 n179 George Annas, Professor of Health Law at Boston University School of Public Health, c ountered that \'22people should own their genetic information, their \'22probab ilistic future diary'\'22 and that \'22the argument that such property rights w ill drive research jobs out of New Jersey is \'22just a scare tactic.'\'22 n180 On November 19, 1996, Governor Christie Whitman signed the Genetic Privacy Act into law, following the deletion of the offending provision on genetic propert y rights. n181\par

\par

----------Footnotes----------

- \par\par

n178. See Robert Schwaneberg, Ethical Debate Focuses on Use of Genetic Data, Sunday Star-Ledger (New Jersey), Aug. 25, 1996, at 21. \par\par

n179. Id. \par\par

n180. Id. \par\par

n181. See Statelines New Jersey: Governor Signs Genetic Privacy Act, America n Healthline, Nov. 20, 1996, available in Westlaw, ALLNEWS database. Governor W hitman said that \'22this legislation strikes an important balance between prot ecting privacy and preventing discrimination, while ensuring that scientific an d medical research are not unduly inhibited or burdened.\'22 Id. \par

\par

----------End Footnotes----------

- \par\par

Despite this deletion, the New Jersey Genetic Privacy Act met a number of th e requirements that ELSI had previously recommended for the \'22model\'22 Genet ic Privacy Act, as have a number of other state statutes. Some states have been less reticent than New Jersey and have declared that genetic information is th e property right of the individual to whom it pertains. n182 In general, howeve r, most states have opted to follow New Jersey in stopping short of providing p roperty rights for genetic information. They have, instead, made statements of varying forcefulness prohibiting the use of genetic information in employment, or, at least banning employment discrimination on the basis of genetic test res ults. Iowa, North Carolina, New Hampshire, New York, Rhode Island, Texas, and W isconsin have enacted statutes that ban genetic testing and genetic discriminat ion in the workplace, n183 and, in some \'5B*440\'5D cases, ban the sale an d interpretation of genetic information to the employer by a third party. n184 New Hampshire and Wisconsin expanded the ban on the use of genetic information by prohibiting even voluntary agreements offering employment or benefits in exc hange for submission to testing. n185\par

\par

----------Footnotes----------

- \par\par

n182. See Or. Rev. Stat. 659.715 (1997). Under this statute, however, if the genetic sample or information is to be used for anonymous research, that infor mation is not property of the individual. See id.; see also Fla. Stat. Ann. 760 .40(2)(a) (West 1997) (requiring informed consent of the person to be subjected to DNA testing and analysis). \par\par

n183. See Iowa Code Ann. 729.6(2)(a) (West 1993); N.H. Rev. Stat. Ann. 141-H :3(I)(a) (Supp. 1995); N.Y. Exec. Law 296(1)(a) (McKinney 1996 & Supp. 1997-98) ; N.C. Gen. Stat. 95-28.1 (1993); R.I. Gen. Laws 28-6.7-1 (1995); Tex. Rev. Civ . Stat. Ann. art. 9031, 3 (West Supp. 1998); Wis. Stat. Ann. 111.372(1)(a) (Wes t 1997). \par\par

n184. See N.H. Rev. Stat. Ann. 141-H:3(II); R.I. Gen. Laws 28-6.7-1. \par\p ar

n185. See N.H. Rev. Stat. Ann. 141-H:3(III); Wis. Stat. Ann. 111.372(3). \pa r

\par

----------End Footnotes----------

\par\par

Unfortunately, with the exception of Rhode Island, most of the states that h ave enacted genetic privacy legislation have provided for a variety of exceptio ns which allow the use of genetic information in the workplace and which, effec tively, undercut the prohibitions in the statutes. Iowa's and Wisconsin's statu tes allow genetic testing with the employee's written and informed consent for the limited purposes of investigating workers' compensation claims and determi ning an employee's susceptibility to a workplace toxin. n186 The overall streng th of New Hampshire's ban on forced genetic testing is significantly weakened b y the concession that an employer is not prohibited from genetic testing to det ermine \'22whether an individual meets reasonable functional standards for a sp ecific job or task.\'22 n187 Oregon authorizes the genetic testing of an indivi dual if informed consent is granted and if the test is solely to determine a bo na fide occupational qualification. n188 Likewise, New York's Civil Rights Law states that an employee can be denied employment on the basis of a \'22unique g enetic disorder\'22 if it can be \'22clearly shown\'22 that the disorder would prevent the employee from performing the particular job. n189 In light of these exceptions, an employer conducting business in any state other than Rhode Isla nd will have, at best, very limited and, at worst, conflicting guidance regardi ng the utilization of genetic information. Remedies available to victims of gen etic discrimination vary as well, ranging from criminal misdemeanor charges for the intentional disclosure of genetic information n190 to the im \'5B*441\'5D position of monetary penalties for damages. n191\par

\par

----------Footnotes----------

\par\par

n186. See Iowa Code 729.6(7)(a)-(b); Wis. Stat. Ann. 111.372(4)(a)-(b). \pa r\par

n187. N.H. Rev. Stat. Ann. 141-H:1(IV). \par\par

n188. See Or. Rev. Stat. 659.227(6) (1997). When tests are conducted for the purpose of determining qualifications, the statute proscribes that unless a co urt order says otherwise, the results must be destroyed as soon as the purpose is accomplished. See id. at 659.715(6). Texas includes a similar provision in i ts statute. See Tex. Lab. Code Ann. 21.405 (West Supp. 1998). \par\par

n189. See N.Y. Civ. Rights Law 48-a (McKinney 1996). Additionally, the New Y ork employer is allowed to administer genetic tests \'22to determine the employ ee's susceptibility to potentially carcinogenic, toxic, or otherwise hazardous chemicals or substances found in the workplace environment,\'22 provided that t he employer does not terminate or adversely affect the employee's terms of empl oyment based on the results. N.Y. Exec. Law 296(19)(c)(3) (McKinney Supp. 1999) . \par\par

n190. See Fla. Stat. Ann. 760.40(2)(b) (West 1997). \par\par

n191. See N.J. Stat. Ann. 10:5-49 (West Supp. 1998); R.I. Gen. Laws 28-6.7-3

(1995). \par
\par
----------End Footnotes----------
\par\par
B. Federal Response\par
\par
On September 13, 1990, just months after the release of the joint DOE and NIH publication outlining the goals for the first five years of the Human Genome Pr oject, n192 Representative John Conyers (D-MI) introduced a bill, the Human Gen ome Privacy Act, n193 with a warning that the \'22\'22public release of people' s genetic information is a Pandora's Box that is best left unopened.'\'22 n194 The limited scope of the bill was \'22to safeguard individual privacy of geneti c information from the misuse of records maintained by agencies or their contr actors or grantees.\'22 n195 The introductory section of the bill, outlining th e legislative findings and purposes, gave a total tally of the amount of fundin g appropriated to the DOE and the NIH in fiscal years 1989 to 1991, n196 and wa rned that the advances of the Human Genome Project had \'22greatly magnified th e potential harm to individual privacy.\'22 n197 The bill proposed a ban on the disclosure of genetic information to third parties without informed consent an d allowed individuals to request the review and amendment of their genetic reco rds. n198 The exceptions to the requirement of informed consent included the us e of information by government employees \'22in the performance of \'5Btheir\'5 D duties\'22; n199 the disclosure of information to medical professionals in co nnection with the care and treatment of a specific individual; n200 and disclos ure for the purpose of \'22alleviating emergency circumstances affecting the he alth or safety of any individual.\'22 n201 The enforcement provisions assessed fines of up to $30,000, eighteen months in jail, or both for the selling of gen etic information \'5B*442\'5D stolen from an agency, n202 but capped damage awards in suits against federal agencies at $1000. n203\par
\par
----------Footnotes----------
\par\par
n192. See The First Five Years, supra note 103. \par\par
n193. H.R. 5612, 101st Cong. (1990). \par\par
n194. Richard A. Bornstein, Note, Genetic Discrimination, Insurability and L egislation: A Closing of the Legal Loopholes, 4 J.L. & Pol'y 551, 579 (1995). \par\par
n195. H.R. 5612. \par\par
n196. See id. 2(a)(6)-(7). The amounts given to the NIH and DOE, respectivel y, were: 1989 - $28.3 million, $17.5 million; 1990 - $59.5 million, $26 million ; and in 1991 - $108 million, $45 million. \par\par
n197. Id. 2(a)(3). \par\par
n198. See id. 112 & 114(1). \par\par
n199. Id. 122(a). \par\par
n200. See id. 123(a). \par\par
n201. Id. 124(2). \par\par
n202. See id. 141(b). \par\par
n203. See id. 142(b)(1). \par
\par
----------End Footnotes----------
\par\par
The major weaknesses of the bill were its broad exceptions and its narrow pu rview. The exceptions were so numerous and generalized that they effectively un dercut the confidentiality protections that the bill was enacted to protect. n2

04 The bill was completely silent on the requirements of \'22informed consent,\
'22 focusing primarily on what could be done with the information once the cons
ent had been obtained. n205 Lastly, the bill only prohibited disclosure from g
overnment agencies, leaving the door wide open for disclosure by medical person
nel, insurance providers, and private genetic research companies. n206\par
\par
----------Footnotes----------
\par\par
n204. See Jean E. McEwen & Philip R. Reilly, State Legislative Efforts to Re
gulate Use and Potential Misuse of Genetic Information, 51 Am. J. Hum. Genetics
637, 643 (1992). \par\par
n205. See id. \par\par
n206. See id.; see also Bornstein, supra note 194, at 580 (\'22The greatest
weakness \'5Bof the bill\'5D was that it only prohibited disclosure from govern
ment agencies ....\'22). \par
\par
----------End Footnotes----------
\par\par
The Human Genome Privacy Act languished and finally expired without enactmen
t. There were no other federal bills proposed until 1995, when, within a period
of five months, six separate bills were proposed. n207 It is difficult to spec
ulate as to what caused the clarion call for Congress in 1995. One can surmise
that it might have been the completion of the first five years of the Human Gen
ome Project, or the declaration in March 1995 by the Equal Employment Opportuni
ty Commission (\'22EEOC\'22) that genetic testing constituted discrimination un
der the ADA, n208 or possibly even pressure from the rapidly developing state l
egislation governing genetic information. In any event, the outpouring of congr
essional proposals seemed to indicate that the government had finally realized
the necessity of federal action to establish at least a minimum level of protec
tion throughout the country. n209\par
\par
----------Footnotes----------
\par\par
n207. See Bornstein, supra note 194, at 579 & n.110. The bills included the
Genetic Information Nondiscrimination in Health Insurance Act of 1995 (H.R. 274
8, 104th Cong.); the Genetic Privacy and Nondiscrimination Act of 1995 (H.R. 26
90, 104th Cong.); and the Genetic Fairness Act of 1996 (S. 1600, 104th Cong.).
All of the bills proposed the protection of the individual against genetic disc
rimination. Three additional bills imposed nondiscriminatory restrictions on he
alth insurers: the Health Coverage Availability and Affordability Act of 1996 (
H.R. 3103, 104th Cong.); the Working Families Health Access Act of 1996 (H.R. 3
043, 104th Cong.); and the Health Insurance Reform Act of 1996 (H.R. 3185, 104t
h Cong.). \par\par
n208. See infra notes 237-42 and accompanying text. \par\par
n209. See Burnett, supra note 168, at 530-31. \par
\par
----------End Footnotes----------
\par\par
Senator Mark Hatfield (R-OR) introduced the Genetic Privacy and Nondiscrimin
ation Act of 1995 in the Senate on November 15, 1995. n210 \'5B*443\'5D Repre
sentative Clifford Stearns (R-FL) sponsored it in the House two weeks later. n2
11 The legislative findings, borrowing heavily from the ELSI model, stressed th
e need to both \'22protect individual privacy and to permit legitimate genetic
research.\'22 n212 The section of the bill addressing employment practices sim

ply stated that\par
\par
----------Footnotes----------
\par\par
n210. S. 1416, 104th Cong. (1995). The bill was drafted by George J. Annas, Leonard H. Glantz, and Patricia A. Roche of the Health Law Department of Boston University. See Michael M.J. Lin, Note, Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act, \i 22 Am. J.L. & Med. 109, 111 n.17 (1996).\i0 \par\par
n211. H.R. 2690, 104th Cong. (1995). \par\par
n212. H.R. 2690 2(a)(6). \par
\par
----------End Footnotes----------
\par\par
\par
\par
no employer may seek to obtain, obtain, or use the genetic information of an e mployee or a prospective employee, or require a genetic test of an employee or prospective employee, to distinguish between or discriminate against or restric t any right or benefit otherwise due or available to the employee or prospectiv e employee. n213\par
\par
The bill fortified the employment provision by according the powers, procedure s, and remedies set forth in sections 705 to 709 of the Civil Rights Act of 196 4 to anyone alleging a violation. n214 Unlike the section governing insurance p roviders, the bill provided no exceptions to the general ban for employers. Alt hough the bill can be admired for being the first to provide for the protection of genetic information, it failed to address several other significant issues, including \'22the property rights in the materials themselves and the apportio nment of benefits from research and development using such materials.\'22 n215\ par
\par
----------Footnotes----------
\par\par
n213. Id. 5(a). \par\par
n214. See id. 5(b). \par\par
n215. Lin, supra note 210, at 128. \par
\par
----------End Footnotes----------
\par\par
Senator Pete Domenici (R-NM), one of the chief proponents of federal funding for the Human Genome Project, introduced an ambitious bill into the Senate on June 24, 1996 - the Genetic Confidentiality and Nondiscrimination Act of 1996. n216 The legislative findings in the bill contrasted sharply from those of prio r versions due to their foreboding tone. The bill used phrases such as \'22gene tic information has been misused resulting in harm to individuals\'22 and \'22\ '5Bgenetics\'5D has the potential to penetrate many aspects of life including e mployment, insurance, ... and even one's self-perception.\'22 n217 The provisio ns for collection, stor \'5B*444\'5D age, and analysis of DNA samples were d etailed and thorough with specific instructions regarding the content of notic es and authorizations. n218 The bill added an equally detailed provision govern ing disclosure, amendment, and destruction of genetic records. n219 In section 104, the bill boldly declared: \'22A DNA sample is the property of the individu al.\'22 n220 The section that addressed discrimination by employers substantial

ly followed the broad statement of the 1995 version (although it clarifies the text significantly). n221 In short, the 1996 version of the Genetic Confidentia lity and Nondiscrimination Act was comparatively clear in its mandate and strai ghtforward in its provisions - thereby ultimately guaranteeing its death on the Senate floor.\par
\par
----------Footnotes----------
\par\par
n216. S. 1898, 104th Cong. (1996). \par\par
n217. Id. 2(a)(3) & (5). In hearings before the Senate Committee on Labor an d Human Resources, Senator Domenici justified the breadth of the bill by statin g: \par\par
\par
\par
What is discrimination is going to be a very, very difficult issue, for some w ill claim that you can discriminate because in discriminating, you will find va lid information upon which to make other decisions and other judgments, such as do you insure or not insure, do you hire or not hire. These are enormous issue s that we have never had before us before. \par\par
\par
\par
Advances in Genetics Research, supra note 126, at 4. \par\par
n218. See S. 1898101-05. \par\par
n219. See id. 201-05. \par\par
n220. Id. 104(a). \par\par
n221. See id. 301(a). The bill states: \par\par
\par
\par
An employer may not seek to obtain, obtain or use the genetic information of a n employee or a prospective employee, or require the collection of a DNA sample of an employee or prospective employee for analysis to distinguish between, di scriminate against, or restrict any right or benefit otherwise due or available to the employee or prospective employee. \par\par
\par
\par
Id. \par
\par
----------End Footnotes----------
\par\par
The \'22kinder, gentler\'22 version of the Genetic Confidentiality and Nondi scrimination Act made its appearance on March 11, 1997 under the joint sponsor ship of Senators Domenici, Christopher Dodd (D-CT), and James R. Jeffords (R-VT); n222 Domenici was, at the time, the Chairman of the Labor, Health and Human Resources Committee. n223 In his address, Senator Domenici stressed the need to begin the dialogue regarding the protection of genetic information. n224 In de claring his continued support of the Human Genome Project, Senator Domenici war ned that \'22while all that is going on, the one thing we do not need, we do no t need an abuse of the information by either researchers, scientists, insurance companies or the like, such that it would excite the American people to turn a gainst such research.\'22 n225 In outlining the key provisions of the revised b ill, Senator Domenici flatly declared that \'22this legislation will very simpl y preclude employers or health insurers from requesting or requiring genotype i nformation as a condition of employment or health insurance.\'22 n226\par
\par

----------Footnotes----------
- \par\par
n222. See S. 422, 105th Cong. (1997). \par\par
n223. See 143 Cong. Rec. S2140 (daily ed. Mar. 11, 1997) (statement of Sen. Domenici). \par\par
n224. See id. \par\par
n225. Id. at S2141. \par\par
n226. Id. at S2142. \par
\par
----------End Footnotes----------
- \par\par
\'5B*445\'5D After reviewing the newest version of the Genetic Confidentiality and Nondiscrimination Act, one is hard pressed to find the flat preclusion that Senator Domenici alluded to in his sponsoring speech. The legislative findings in the bill are clearly attenuated from the 1996 version. The language of existing misuse and damage to \'22self-perception\'22 has been replaced by laudatory statements about the benefits provided by research in human genetics. n227 The lengthy requirements for the collection, storage, and analysis of DNA samples have been shortened and simplified in the 1997 version. n228 The declaration of an individual's ownership of his genetic samples is missing altogether. The section addressing discrimination by employers is drastically different. The 1997 version stipulates:\par
\par
----------Footnotes----------
- \par\par
n227. See S. 422 2(a)(2) (\'22Research in human and medical genetics continues to provide and to predict immense health benefits to individuals and their families.\'22). \par\par
n228. See id. 101-102. \par
\par
----------End Footnotes----------
- \par\par
\par
\par
An employer may request or require or use the genetic information of an employee for the purpose of - \par\par
(1) permitting a genetically susceptible employee to avoid occupational exposure to substances with a mutagenic or teratogenic effect; or \par\par
(2) determining a genotype that is otherwise directly related to the work and is consistent with business necessity. n229\par
\par
In a presidential press briefing held on July 15, 1997, White House spokespers on Mike McCurry predicted:\par
\par
----------Footnotes----------
- \par\par
n229. Id. 401(a). \par
\par
----------End Footnotes----------
- \par\par
\par
\par
I think that the fact that the legislation is attracting bipartisan support, that the chair of one of the relevant committees will have some things to say th

at we hope will be positive about the bill bodes very well for consideration of the legislation in this Congress, and hopefully in a short while. n230\par
\par
Although both McCurry and President Clinton spoke at length about the possible impact of the new bill on health care providers, neither made any mention of t he effect of the proposed legislation on employment. n231\par
\par
----------Footnotes----------
\par\par
n230. Office of the Press Secretary, The White House Office of Communication s, Press Briefing by Chris Jennings, Presidential Health Care Policy Advisor, a nd Mike McCurry, July 15, 1997, available in \i 1997 WL 395750.\i0 \par\par

n231. See id. However, the briefing addressed the testing for sickle cell an emia in the 1970s in order to illustrate the use by insurance companies of gene tic information to deny coverage. See id. \par
\par
----------End Footnotes----------
\par\par
On January 20, 1998, Vice President Gore, in an address to the National Acad emy of Science, called for legislation that would bar an employer from discrimi nating against its employees on the basis of genetic \'5B*446\'5D informati on. Vice President Gore declared: \'22Miraculous scientific achievements can he lp build an America that is healthier in body and in spirit. That's no small fe at. But science and society must always advance together, for neither can ever truly advance alone.\'22 n232\par
\par
----------Footnotes----------
\par\par
n232. Office of the Vice President, Vice President Calls for Legislation on Genetic Discrimination, Jan. 20, 1998, available in \i 1998 WL 7378521.\i0 \pa r
\par
----------End Footnotes----------
\par\par
C. Administrative Guidance\par
\par
In the past, the EEOC, charged with the enforcement of both Title VII and the ADA, has specifically excluded predisposition to disease as a covered condition under its regulations. n233 It has further declined to apply its protection to personality traits such as poor judgment, quick temper, or irresponsible behav ior. n234 Genetic conditions that have been cited in the legislative history as protected by the ADA include genetic conditions like muscular dystrophy, multi ple sclerosis, cystic fibrosis, dyslexia, hemophilia, and retinitis pigmentosa, but only once the conditions have shown overt debilitating symptoms. n235 Thes e exclusions would seem to indicate that asymptomatic genetic predisposition to mental and physical diseases would fall outside the protection of the Act.\par

\par
----------Footnotes----------
\par\par
n233. See Equal Employment Opportunity Comm'n, A Technical Assistance Manual on the Employment Provisions (Title I) of the Americans With Disabilities Act, at II-2 (1992) \'5Bhereinafter Technical Assistance Manual\'5D. \par\par

n234. See id. \par\par
n235. See Mark A. Rothstein, Genetic Discrimination in Employment and the Am
ericans with Disabilities Act, \i 29 Hous. L. Rev. 23, 40 (1992).\i0 \par
\par
----------End Footnotes----------
\par\par
On March 15, 1995, however, the EEOC issued regulations clarifying the defin
ition of \'22disability\'22 under the ADA. n236 Tucked within a larger technica
l document was the EEOC's first statement prohibiting an employer from discrimi
nating against a worker on the basis of his genetic makeup. n237 The provision
extends coverage to include \'22individuals who are subjected to discrimination
on the basis of genetic information relating to illness, disease, or other dis
orders.\'22 n238 Dr. Francis Collins \'5B*447\'5D exulted, \'22this solves
a huge dilemma that's been sitting there without an obvious solution .... This
is wonderful news for the American public.\'22 n239 However, in hearings held b
efore the Senate Committee on Labor and Human Resources in July 1996, Dr. Colli
ns tempered his enthusiasm. He noted that the EEOC interpretation fails to cove
r unaffected carriers of recessive genes and that it does not prevent employers
from obtaining a general release from an applicant once there has been a pre-e
mployment offer. n240 Bob Silverstein, counsel for Senator Tom Harkin (D-Iowa),
the chief sponsor of the ADA, noted the considerable difficulties in proving d
iscrimination under this new regulation. To qualify under the terms of the ADA,
people must show not only that they have a genetic defect, but also that they
were regarded as disabled and discriminated against by an employer on account o
f that perception. n241\par
\par
----------Footnotes----------
\par\par
n236. See Rick Weiss, Gene Discrimination Barred in Workplace, Wash. Post, A
pr. 7, 1995, at A3; see also Bornstein, supra note 194, at 581 (\'22The EEOC re
leased guidelines which clarified the definition of \'22disability' under the A
DA to include \'22individuals who are subjected to discrimination on the basis
of genetic information relating to illness, disease, or other disorders.'\'22).
\par\par
n237. See Weiss, supra note 236, at A3; see also Abbey S. Meyers, EEOC Genet
ic Ruling Protects Society, 4 Empl. Testing L. & Pl'y Rep. 103, 103 (1995) (sta
ting that \'22nor can one deny an applicant a job as long as the disability doe
s not interfere with an employee's ability to do the job\'22). \par\par
n238. Equal Employment Opportunity Comm'n, 2 EEOC Compliance Manual 902, at
902-45 (1995) (defining the term \'22disability\'22). \par\par
n239. Weiss, supra note 236, at A3. \par\par
n240. See Advances in Genetics Research, supra note 126, at 15. \par\par
n241. See id. at 15-16. \par
\par
----------End Footnotes----------
\par\par
Following the example of the state and federal legislatures, the EEOC has ef
fectively tempered its ban on genetic discrimination with nebulous exceptions t
hat threaten to swallow the rule, leaving the employer with no administrative r
egulations to guide it when it inevitably confronts the legal dilemma of access
to genetic information. \par\par
V. The Cassandra Complex\par
\par
Confronted with the ethical and legal dilemmas of the genetic workplace with l

ittle or no legislative or administrative guidance, the employer of the new mil lennium will be left with few options for avoiding legal consequences, whether the employer chooses to use the new-found genetic information or not. To make m atters more difficult for the employer, genetic tests, painted by science as fa irly clear-cut, are not, at the current stage, precise predictors of the medica l future of employees or job applicants. As illustrated by the failed experimen ts with sickle cell testing, those carrying a gene may never show manifestation s of its effect. n242 If the gene does manifest itself, its effects may vary wi dely from individual to individual, making predictions of its manifestations a virtual guessing game. n243\par
\par
----------Footnotes----------
\par\par
n242. See Council on Ethical and Judicial Affairs, American Medical Associat ion, Use of Genetic Testing by Employers, \i 266 JAMA 1827 (1991)\i0 \'5Bherei nafter Council\'5D. \par\par
n243. See id. \par
\par
----------End Footnotes----------
\par\par
Additionally, gene reading, except in cases of single gene disease, is an in complete measurement, which does not take into account the possibility of avoid ing disease through environmental or personal health \'5B*448\'5D factors. n244 Virtually all employees and job applicants have hereditary gene characteri stics that predispose them to the onset of particular illnesses or diseases, an d therefore, without considering the importance of environmental or lifestyle f actors, everyone can be considered a potential drain on the limited resources o f an employer. n245 Because of the inherent imprecision in current genetic tec hnology however, it will be difficult for an employer to make and justify emplo yment decisions based solely on the results of genetic tests. n246\par
\par
----------Footnotes----------
\par\par
n244. See Jerry E. Bishop & Michael Waldholz, Genome: The Story of the Most Astonishing Scientific Adventure of Our Time - The Attempt to Map All the Genes in the Human Body 303 (1990); see also Brokaw, supra note 35, at 321 (describi ng the importance of considering family medical history or further investigatin g the person's chromosomes in a laboratory test). It has been speculated that a ll individuals possess five to seven lethal recessive genes, plus an undetermin ed number of genes that indicate a predisposition to develop diseases based on dealings with the environment, including diet, work, and other environmental fa ctors. See Alexander Morgan Capron, Which Ills to Bear?: Reevaluating the \'22T hreat\'22 of Modern Genetics, \i 39 Emory L.J. 665, 690 (1990).\i0 \par\par

n245. See Rothstein, supra note 235, at 46-47. \'22We still don't understand even the simplest kind of hereditary disease, such as Huntington's chorea, whi ch is caused by the mutation of only one gene. This summer researchers made the first major breakthrough in understanding how that mutation might lead to the destruction of the brain - but this came four years after the discovery of the mutation.\'22 \i Schoofs, supra \i0 note 160, at 18. \par\par
n246. This difficulty will be most evident in genetic screening for psycholo gical traits, where it has been estimated that genes account for between 40 and 60 percent of the variations in personality and between 40 and 70 percent of t he differences in IQ. See \i Schoofs, supra \i0 note 160, at 18. It is, however

, in the development of personality traits and intelligence that the environmen
t exerts its greatest influence. See id. Family background or life experience m
ay, for example, determine whether an \'22anxiety\'22 gene will create a person
who is clinically neurotic or a person who is merely conscientious. See id. As
David Lykken, a Minnesota researcher of personality variations in identical tw
ins, postulated: \'22The psychopath and hero are twins on the same genetic bran
ch, and the difference is experience.\'22 Id. For a discussion of the difficult
ies an employer will encounter in the evaluation of psychiatric disorder in the
workforce, see John D. Thompson, Psychiatric Disorders, Workplace Violence and
the Americans with Disabilities Act, \i 19 Hamline L. Rev. 25 (1995).\i0 \par

\par
----------End Footnotes----------
- \par\par
The time in which genetic knowledge will be most controversial for employers
will be the often lengthy phase between the discovery of a genetic variation r
esponsible for disease and the availability of treatment for that disease. n247
It is during this time that loss of employment or insurance, discrimination, o
r stigmatization is most likely to occur. n248 In this twilight period, the emp
loyer will need particular guidance in making employment decisions on the basis
of genetic information--guidance that, to date, has not been forthcoming from
the government. This lack of guidance is at the root of the Cassandra complex,
where the employer has access to potentially devastating information regarding
an employee's future physical or mental health, but will be \'5B*449\'5D un
able to use it in making employment decisions due to the potential for extensiv
e litigation. The simple solution of ignoring the newfound genetic information
will not be an option either. Not only will the employer be unable to ignore th
e obvious financial and safety benefits which the tests will confer, but the v
ery ability of an employer to foresee future genetic consequences will hold it
responsible for any detrimental effects caused by the harmful manifestations of
known genetic conditions. In choosing either side of the coin, using or ignori
ng genetic information, the employer is likely to lose.\par
\par
----------Footnotes----------
- \par\par
n247. See The First Five Years, supra note 103, at 65-71. \par\par
n248. See Bishop & Waldholz, supra note 244, at 304. \par
\par
----------End Footnotes----------
- \par\par
A. To Test or Not to Test?\par
\par
Left to their own devices, most employers would understandably welcome informa
tion that would prevent the hiring of employees who would be disproportionately
susceptible to illness. n249 It would be na<um i>ve to ignore the fact that em
ployment decisions, even in the pre-genetic era, are partially influenced by in
formation gleaned from the medical histories of applicants and their families.
n250 The most obvious benefit to an employer in having access to an employee's
genetic information (although the one least likely to be used as justification)
is the potential for cost containment. n251 Sick employees account for increas
ed costs caused by sick leave, absenteeism, workers' compensation expenses, and
lost goodwill. n252 Additionally, employees or dependents with illnesses accou
nt for greater costs in providing health and life insurance for a workforce. Fo
r employers with self-insured plans, where the employer assumes direct responsi

bility for healthcare expenses, the ability to predict catastrophic illness cou
ld have a significant impact on the solvency of a company's health plan. n253\p
ar
\par
----------Footnotes----------
\par\par
n249. See Frances H. Miller & Philip A. Huvos, Genetic Blueprints, Employer
Cost-Cutting, and the Americans with Disabilities Act, \i 46 Admin. L. Rev. 369
, 371 (1994).\i0 \par\par
n250. See \i id. at 371-72.\i0 \par\par
n251. See Brokaw, supra note 35, at 326. Addressing the Washington Business
Group on Health, Tipper Gore reported that over six million Americans suffer fr
om emotional or psychiatric disabilities, accounting for a substantial portion
of lost work time. See Beth Aspedon & John A. Ricca, Americans with Disabilitie
s Act: An Analysis of Developments Relating to Disability Discrimination Law, i
n 2 25th Annual Institute on Employment Law 415, 440-41 (1996). She stated that
depression alone accounts for an estimated $17 billion in lost productivity ev
ery year. See id. \par\par
n252. See Brokaw, supra note 35, at 326. \par\par
n253. See 29 C.F.R. 1630.4(f) (1997). The ADA prohibits an employer from fir
ing or refusing to hire an employee because of potential increases in future he
alth care costs caused by the disability of the employee or of the employee's d
ependents. See Technical Assistance Manual, supra note 233, at VII-9. However,
the ADA leaves the door open for an employer to tailor health benefits in resp
onse to insurance underwriting or actuarial risks, including the denial of cove
rage for pre-existing conditions or for certain procedures or treatments. See \
i 42 U.S.C. 12001\i0 (c)(2)(3) (1994); Technical Assistance Manual, supra note
233, at VII-9. For legislative history, see H.R. Rep. No. 101-485, pt. 2 at 137
-138. See also Miller & Huvos, supra note 249, at 381-82 (describing employment
practices the ADA does and does not permit). If genetic predisposition can be
cast as a pre-existing condition, an employer can design a health plan to exclu
de payment for any medical costs arising from a genetic condition diagnosed at
the time of hire. Alternatively, an employer can design a plan to exclude certa
in diseases that appear with greater regularity in the genetic screening of its
current employees. This capacity for the redesign of health plans, effectively
authorized by the ADA, will discourage high-risk applicants from seeking emplo
yment where the financial burdens they will incur due to health plan limitation
s are too large. See id. at 382. \par
\par
----------End Footnotes----------
\par\par
\'5B*450\'5D Another valid reason for an employer to access workers' genet
ic information is to ensure the safety of the worker, the employer, and society
at large. Employers concerned with the worker's safety and health could use ge
netic testing and screening to provide information about threats posed to emplo
yees and applicants by existing workplace conditions. n254 Because monitoring m
ay disclose genetic damage that has already occurred, its use would be especial
ly helpful as a means of preventing future damage. n255 The screening of applic
ants might disclose a disease predisposition that may be triggered by workplace
conditions, allowing an employer to offer a valuable warning to job candidates
of the danger inherent in applying for certain positions. n256\par
\par
----------Footnotes----------
\par\par

n254. See Alan Gewirth, Human Rights and Genetic Testing in the Workplace 2 (1990). \par\par

n255. See id. at 5. \par\par

n256. See id.; see also Lori B. Andrews & Ami S. Jaeger, Confidentiality of Genetic Information in the Workplace, \i 17 Am. J.L. & Med. 75, 76 (1991)\i0 (explaining how genetic information may be used to warn people with particular g enetic dispositions to avoid certain jobs that may trigger an illness). \par

\par

----------End Footnotes----------

\par\par

The employer's responsibility for providing a safe and healthy workplace ext ends beyond the employee. An employer has a legal and moral duty to ensure that employees are professionally, physically, and psychologically capable of perfo rming their duties. n257 Co-workers and members of the public could have a lega l right to access genetic information about a worker where the manifestation of his genetic variance might put them at risk. n258 Recognizing the safety conce rns of both employers and third parties, the ADA has authorized employers to di scriminate where a disabled individual poses a direct threat to the health and safety of others. n259 This exception might justify an employer's deci \'5B*451 \'5D sion to exclude individuals with certain genetic traits from positions i n which the traits might create health and safety risks in the workplace.\par

\par

----------Footnotes----------

\par\par

n257. See Andrews & Jaeger, supra note 256, at 94. \par\par

n258. See id. at 96. \par\par

n259. See 29 C.F.R. 1630.2(r) (1997); Robert John Maseleck, Jr., Note, Emplo yee Medical Screening Under the Americans with Disabilities Act of 1990, \i 26 Suffolk U. L. Rev. 653, 684 (1992);\i0 see also Technical Assistance Manual, s upra note 233, at II-3 (detailing that an employee with a contagious disease co uld be discriminated against if they \'22posed a direct threat to health or saf ety, if no reasonable accommodation could reduce or eliminate this threat\'22). \par

\par

----------End Footnotes----------

\par\par

In addition to the financial and safety benefits to the employer in accessin g genetic information, genetic testing may actually be mandated by state legisl ation governing workers' compensation plans or by federal legislation such as t he Occupational Safety and Health Act (\'22OSHA\'22). n260 Workers' compensatio n is a state mandated system of strict liability in which employers assume resp onsibility for employees' work-related injuries or illnesses. n261 Compensation depends on medical evidence that the employee's condition resulted from workpl ace exposure. n262 In many states, the responsibility of the current employer f or workplace injury or illness is mitigated by apportionment statutes that divi de liability for medical costs among all of the companies that could have contr ibuted to the employee's current condition. n263 In order to insure an appropri ate partitioning of financial responsibility, genetic monitoring may be called upon to analyze an employee's health through a succession of exposures to workp lace hazards. Moreover, genetic screening may be utilized to determine whether workplace exposure played any part in the onset of the disease. n264\par

\par

----------Footnotes----------

- \par\par
n260. \i 29 U.S.C. 651\i0 -78 (1994). OSHA was enacted in 1970 as a federal effort to assure a safe work environment by investigating industrial diseases a nd their causal connections to the workplace and by mandating preventive workpl ace safety practices. See Judith Richter, Taking the Worker As You Find Him: Th e Quandry of Protecting the Rights As Well As the Health of the Worker with a G enetic Susceptibility to Occupational Disease, 8 Md. J. Contemp. Legal Issues 1 89, 206 (1997); see also \i 29 U.S.C. 651\i0 (containing the opening congressi onal statement of findings and declaration of purpose and policy). \par\par

n261. See Richter, supra note 260, at 193. \par\par

n262. See Rothstein, supra note 32, at 1475-76. \par\par

n263. See id. at 1477. \par\par

n264. A number of states allow the use of pre-employment data in computing d isability for workers' compensation awards for occupational disease. See High-R isk Groups, supra note 46, at 153-54. Other states have provisions for second i njuries or handicaps that allow the pre-existing component of an occupational i llness to be deducted from either the employee's benefit or the employer's pre mium. See id. \par

\par

----------End Footnotes----------

- \par\par

The employer's refusal to institute genetic testing in the workplace may als o run headlong into OSHA's promotion of employer-conducted medical exams. n265 OSHA mandates biological monitoring through \'22periodic analysis of body fluid s, tissues and excreta in order to measure \'5Bthe\'5D impact of the body's exp osure to chemical agents and to evaluate the health risks these chemicals pose. \'22 n266 Some OSHA health standards, such as those regulating arsenic, lead, a nd acrylonite, offer protection to \'5B*452\'5D sensitive employees by requ iring medical surveillance of those exposed to designated concentrations of the substances. n267 In particular, proponents of genetic testing in the workplace have pointed to a section in the OSHA regulations governing cancer-causing age nts. n268 This section provides that \'22before an employee is assigned to ente r a regulated area, a preassignment physical examination by a physician shall b e provided. The examination shall include the personal history of the employee, family and occupational background, including genetic and environmental factor s.\'22 n269 When confronted with conflicting medical and safety requirements es tablished under other federal laws, the ADA regulations clearly state that the employer can follow these requirements without violating the ADA. n270 In light of the OSHA mandate and the ADA's concession, an employer may be found neglige nt for failing to provide genetic testing before assigning an employee to certa in OSHA designated positions.\par

\par

----------Footnotes----------

- \par\par

n265. See Richter, supra note 260, at 209-10. \par\par

n266. Id.; see also \i 29 U.S.C. 655\i0 (c)(7) (1994) (providing for the mon itoring of employee exposure for employee safety). \par\par

n267. See 29 C.F.R. 1910.1018, .1025, .1045 (1997); see also Rothstein, supr a note 32, at 1427 (finding medical surveillance is required \'22for all employ ees exposed to concentrations above the \'22action level\'22). \par\par

n268. See 29 C.F.R. 1910.1003(g)(1)(i). \par\par

n269. Id. (emphasis added); see also Richard Severo, Federal Mandate for Gen e Tests Disturbs U.S. Job Safety Official, N.Y. Times, Feb. 6, 1980, at A1 (des cribing the confusion of OSHA officials when asked to explain the genetic manda

te in Part 1910, Title 29). \par\par
n270. See Technical Assistance Manual, supra note 233, at VI-5. \par
\par
----------End Footnotes----------
- \par\par
Tempted by the financial benefits gained by identifying genetic predispositi
on to disease, fearing the potential harm from the harmful manifestations of ge
netic conditions, and confused by the government's contradictory signals, the e
mployer will most likely feel compelled to institute genetic testing in the wor
kplace. However, by doing so, the unwitting employer will run directly into the
legal and ethical contradictions inherent in the Cassandra Complex. \par\par

B.\par
\par
\'22Heads You Lose\'22: Liability for Using Genetic Information\par
\par
To date, there has not been a suit by an employee charging an employer with ge
netic discrimination, but it would be na<um i>ve to assume that this relative q
uiet will continue once advances in genetic tests make workplace screening more
economical and accurate. Genetic discrimination has as yet to be defined by th
e courts, but has been identified by commentators as \'22discrimination directe
d against an individual or family based solely on an apparent or perceived gene
tic variation from the \'22normal' human genotype.\'22 n271\par
\par
----------Footnotes----------
- \par\par
n271. Paul R. Billings et al., Discrimination as a Consequence of Genetic Te
sting, 50 Am. J. Hum. Genetics 476, 476 (1992). Individuals at risk for genetic
discrimination may include (a) asymptomatic individuals who carry a detrimenta
l gene; (b) those who are heterozygotic for a condition but will never be affec
ted by it; (c) those who have genetic polymorphism (similar genes that assume d
ifferent forms); and (d) relatives of these individuals who have or are perceiv
ed as having genetic conditions. See Miller & Huvos, supra note 249, at 372; se
e also Adrienne Asch, Genetics and Employment: More Disability Discrimination,
in The Human Genome Project and the Future of Healthcare 158, 161 (Thomas H. Mu
rray et al. eds., 1996) (commenting that \'22people who never before were perce
ived as disabled will discover that their genetic characteristics lead them to
be viewed as disabled by others - notably employers and insurers\'22). \par
\par
----------End Footnotes----------
- \par\par
\'5B*453\'5D An employer's chances of prevailing against a charge of genet
ic discrimination can be predicted by examining judicial decisions under curren
t anti-discriminatory legislation, specifically the ADA. n272 The ADA maintains
that an individual is considered to have a disability if that individual eithe
r has \'22(A) a physical or mental impairment that substantially limits one or
more of the major life activities of such individual; (B) a record of such an i
mpairment; or (C) ... \'5Bbeen\'5D regarded as having such an impairment.\'22 n
273 Asymptomatic individuals who manifest a genetic predisposition to a physica
l or mental illness would most likely be covered under the third classification
of a disability if they are otherwise qualified to perform the essential funct
ions of the position in question and are discriminated against on the basis of
their genetic predisposition.\par
\par

----------Footnotes----------

- \par\par

n272. See \i 42 U.S.C. 12101\i0 -213 (1994). Enacted on July 26, 1990, the ADA was intended to supplement the Rehabilitation Act of 1973 \i (29 U.S.C. 701\i0 -96) by extending coverage to private sector employees. See Rothstein, supra note 235, at 32. The Act provides in part that \'22no covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to ... hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.\'22 \i 42 U.S.C. 12112\i0 (a). The Code of Federal Regulations explains that \'22the ADA is a Federal antidiscrimination statute designed to remove barriers which prevent qualified individuals with disabilities from enjoying the same employment opportunities that are available to persons without disabilities.\'22 Appendix to part 1630-Interpretive Guidance on Title I of the American with Disabilities Act, 29 C.F.R.1630, app. at 336 (1997); see also 29 C.F.R. 1630.4 (governing forms of prohibited discrimination); Technical Assistance Manual, supra note 233, at VII-9 (discussing health insurance and employee benefit plans). \par\par

n273. \i 42 U.S.C. 12102\i0 (2) (emphasis added). Courts have further clarified that \par\par

\par

\par

one is regarded as having a substantially limiting impairment if the individual (1) has an impairment which is not substantially limiting but which the employer perceives as constituting a substantially limiting impairment; (2) has an impairment which is substantially limiting only because of the attitudes of others toward such an impairment; or (3) has no impairment at all but is regarded by the employer as having a substantially limiting impairment. \par\par

\par

\par

\i Bridges v. City of Bossier, 92 F.3d 329, 332 (5th Cir. 1996);\i0 see also \i MacDonald v. Delta Air Lines, Inc., 94 F.3d 1437, 1444 (10th Cir. 1996)\i0 (discussing what constitutes a mental or physical impairment). \par

\par

----------End Footnotes----------

- \par\par

On March 3, 1987, the Supreme Court decided a landmark case that clarified the requirements of the \'22regarded as\'22 prong of the ADA's \'5B*454\'5D protected classification. In School Board of Nassau County v. Arline, n274 the Court reviewed the case of an elementary school teacher who was discharged from her job due to a history of tuberculosis. n275 The Court found that the school board violated section 504 of the Rehabilitation Act of 1973 because \'22the fact that a person with a record of a physical impairment is also contagious does not suffice to remove that person from coverage under \'5Bsection\'5D 504.\'22 n276 The Court declared:\par

\par

----------Footnotes----------

- \par\par

n274. \i 480 U.S. 273 (1987).\i0 \par\par

n275. See \i id. at 276.\i0 \par\par

n276. \i Id. at 286.\i0 \par

\par

----------End Footnotes----------

- \par\par

\par
\par
By amending the definition of \'22handicapped individual\'22 to include not on
ly those who are actually physically impaired, but also those who are regarded
as impaired and who, as a result, are substantially limited in a major life act
ivity, Congress acknowledged that society's accumulated myths and fears about d
isability and disease are as handicapping as are the physical limitations that
flow from actual impairment. n277\par
\par
A year prior to Arline, a district court in Florida upheld a charge of discrim
ination filed by an epileptic employee who was terminated from his position as
a mechanic, even though he maintained that he had never had a seizure. n278 The
court concluded that \'22it is unreasonable to deny a person employment becaus
e of a fear of recurrence of a condition which that person has asserted he has
never had, when there is no evidence showing that Plaintiff had ever had a seiz
ure.\'22 n279\par
\par
----------Footnotes----------
\par\par
n277. \i Id. at 284.\i0 The Court remanded the case to the district court f
or a determination as to whether Ms. Arline was otherwise qualified for the job
of elementary school teacher with a warning that it conduct an individualized
inquiry of how her handicap might impact on the essential functions of her posi
tion. See \i id. at 287-88.\i0 The Court also laid out the \'22well-establishe
d\'22 basic factors to be used in the inquiry. See id. \par\par
n278. See \i Kelley v. Bechtel Power Corp., 633 F. Supp. 927, 930 (S.D. Fla.
1986).\i0 \par\par
n279. \i Id. at 935.\i0 \par
\par
----------End Footnotes----------
\par\par
In Cook v. Rhode Island, Department of Mental Health, Retardation, and Hospi
tals, n280 the Court of Appeals for the First Circuit held that a morbidly obes
e applicant for the position of attendant in a home for the mentally retarded w
as unfairly denied employment because of the employer's preconceptions of how h
er obesity would affect her performance. n281 The court concluded that \'22deny
ing an applicant even a single job ... due solely to the perception that the ap
plicant suffers from a physical \'5Blimitation\'5D ... can constitute treating
an applicant as if her condition substantially limited a major life activity, v
iz., working.\'22 n282 In \'5B*455\'5D short, the focus of the \'22regarded
as\'22 inquiry is determined not on the actual existence of an impairment, but
on the attitudes of others to the perceived impairment. n283 On the basis of t
hese decisions, an employer would most likely be held liable for disability dis
crimination if it made an employment decision solely on the basis of a genetic
test, without producing further evidence that the employee was not otherwise qu
alified for the position.\par
\par
----------Footnotes----------
\par\par
n280. \i 10 F.3d 17 (1st Cir. 1993).\i0 \par\par
n281. See \i id. at 28.\i0 \par\par
n282. \i Id. at 26;\i0 see also \i Johnson v. American Chamber of Commerce
Publishers, Inc., 108 F.3d 818, 819 (7th Cir. 1997)\i0 (holding employer liabl
e for its refusal to hire a telemarketing applicant with 18 missing teeth becau

se it perceived him as being unfit for the position); \i Katz v. City Metal Co.
, 87 F.3d 26, 33-34 (1st Cir. 1996)\i0 (finding that an employer had wrongfull
y discharged the plaintiff after he had suffered a heart attack because of the
employer's perception that the plaintiff could not resume his normal duties);
29 C.F.R. 1630.2(g)(1) (1997) (defining disability). \par\par
n283. See \i MacDonald v. Delta Air Lines, Inc., 94 F.3d 1437, 1444 (10th Ci
r. 1996)\i0 (quoting \i Wooten v. Farmland Foods, 58 F.3d 382, 385 (8th Cir. 1
995));\i0 see also \i Francis v. City of Meriden, 129 F.3d 281, 287 (2d Cir. 1
997)\i0 (\'22\'22This third prong is particularly important for individuals wi
th stigmatic conditions that are viewed as physical impairments but do not in f
act result in a substantial limitation of a major life activity.\'22 (quoting
H. Rep. No. 101-485 part 2, at 53 (1990)). \par
\par
----------End Footnotes----------
\par\par
Once a prima facie case of genetic discrimination was established, an employ
er could have legal recourse in one of the defenses currently available under t
he ADA to combat a charge of disability discrimination. These defenses include
lack of knowledge, undue hardship, and direct threat to health and safety. Unfo
rtunately, an analysis of court decisions addressing these defenses reveals tha
t they would most likely be unsuccessful in the genetic context. \par\par
An employer's first line of defense might be to prove that it had no knowled
ge of the applicant's or employee's genetic condition. The federal regulations
to the Rehabilitation Act mandate that an employer must know about an existing
specific disability before it can be liable for failing to accommodate the disa
bled person's needs. n284 In cases involving \'22hidden\'22 disabilities, court
s have held that an employer cannot be liable for disability discrimination if
it had no actual or constructive knowledge of an individual's disability. n285
In order to succeed under this defense, an employer would need to affirmatively
prove that it either has no possibility of access to genetic information or th
at the hiring rec \'5B*456\'5D ommendation was made by an independent evalua
tor. The courts have made it difficult for an employer to hide behind the recom
mendation of a medical or occupational professional in denying opportunities to
protected individuals. In EEOC v. Texas Bus Lines, n286 the Southern District
Court of Texas found an employer liable in an ADA action brought by a morbidly
obese applicant who was denied employment on the basis of the recommendation of
a physician hired by the employer to perform physical evaluations. The court c
oncluded:\par
\par
----------Footnotes----------
\par\par
n284. See 29 C.F.R. 1614.203(c) (1998). \par\par
n285. See \i Hunt-Golliday v. Metropolitan Water Reclamation Dist., 104 F.3d
1004, 1012-13 (7th Cir. 1997)\i0 (holding that a former employee with a menta
l disability could not prevail in an ADA claim where she failed to present any
evidence of the employer's knowledge of her condition); see also \i Morisky v.
Broward County, 80 F.3d 445, 448 (11th Cir. 1996)\i0 (\'22Vague or conclusory
statements revealing an unspecified incapacity are not sufficient to put an emp
loyer on notice of its obligations under the ADA.\'22); \i Hedberg v. Indiana B
ell Tel. Co., 47 F.3d 928, 932 (7th Cir. 1995)\i0 (finding that \'22an employe
r cannot be liable under the ADA for firing an employee when it indisputably ha
d no knowledge of the disability\'22); \i Landefeld v. Marion Gen. Hosp., Inc.,
994 F.2d 1178, 1181-82 (6th Cir. 1993)\i0 (holding that an internist could no
t prove that a hospital suspended him because of his mental illness absent evid

ence that the hospital knew of such illness). \par\par
n286. \i 923 F. Supp. 965 (S.D. Tex. 1996).\i0 \par
\par
----------End Footnotes----------
\par\par
\par
\par
If an employer's relationship with a physician who conducts a medical examination results in the discriminatory rejection of applicants protected by the ADA, the employer is liable for a violation of the statute despite the involvement of a third party, the doctor, with whom the employer had a professional arrangement. n287\par
\par
Based on these decisions, an employer may be able to avoid litigation for genetic discrimination by refusing to administer genetic tests either directly or through a third party examiner. However, in light of the benefits that will be available to the employer through testing and the possible liabilities for failure to test, n288 this will most likely be the least acceptable defense.\par
\par
----------Footnotes----------
\par\par
n287. \i Id. at 982.\i0 \par\par
n288. See infra Part IV.C. \par
\par
----------End Footnotes----------
\par\par
If an employer has knowledge of an employee's or applicant's genetic information, it could attempt a second defense by proving that providing accommodations for the disabled individual would pose an undue hardship on the finances or operations of the organization. n289 Two areas where this defense has proven successful are when the accommodation would substantially interfere with the safe and efficient operations of the business and when the disability itself would preclude the attainment by the employee of the licenses or clearances needed to perform his job.\par
\par
----------Footnotes----------
\par\par
n289. When considering if an accommodation poses an undue hardship, the EEOC considers: (1) the cost and type of the accommodation; (2) the financial resources of the facility; (3) the overall financial resources of the entity (the parent company of the facility); (4) the kind of operation of the entity; and (5) the effect of the accommodation on the operations of the facility, including the impact on the facility's ability to conduct business and the productivity of other employees. See 29 C.F.R. 1630.2(p)(2) (1997). \par
\par
----------End Footnotes----------
\par\par
In the first instance, where an accommodation would interfere with the business' operations, the courts have specified that the considerations cannot be based on generalized fears about the potential effects of a particular disability, nor about concern over high absenteeism or in \'5B*457\'5D creased workers' compensation costs. n290 Employers have only been successful, if, after an individualized assessment of the individual's disability, the employer can provide direct evidence that retaining or accommodating the employee would cause har

m to the operations of the business. n291 Such evidence will normally be specul ative when dealing with asymptomatic genetic conditions. In the second instance of undue hardship, where an employee's disability, or potential disability int erferes with his ability to obtain needed licenses or waivers, the employer can likewise mount a defense of business necessity or undue hardship. In McDaniel v. AlliedSignal, Inc., n292 an employee lost his government mandated security c learance partly because of mental illness. n293 The court found that the employ er was justified in terminating the employee because no accommodation could hav e insured the employee's regaining of his clearance. n294\par
\par
----------Footnotes----------
\par\par
n290. See, e.g., \i Cook v. Rhode Island, Dep't of Mental Health, Retardatio n, and Hosps., 10 F.3d 17, 27 (1st Cir. 1993)\i0 (declining to consider increa sed absenteeism and workers' compensation claims in failure to hire obese appli cant); \i Anderson v. Gus Mayer Boston Store, 924 F. Supp. 763, 781 (E.D. Tex. 1996)\i0 (finding increased costs of health insurance insufficient reason to e xclude employees from company plan); \i Turner v. City of Monroe, 634 So. 2d 98 1, 986 (La. Ct. App. 1994)\i0 (refusing to consider potential increases in wor kers' compensation costs in employer's decision not to allow employee with back injury to return to work). The EEOC clarifies that ADA prohibitions apply to d ecisions \'22based on unsubstantiated concerns about productivity, safety, insu rance, liability, attendance, costs of accommodation, accessibility, workers' c ompensation costs or acceptance by co-workers and customers.\'22 Technical Assi stance Manual, supra note 233, at II-11. \par\par
n291. In \i EEOC v. Kinney Shoe Corp., 917 F. Supp. 419 (W.D. Va. 1996),\i0 the court upheld the termination of an epileptic salesperson prone to unpredic table seizures. The court held that \'22if an employee causes vast disruption a t the workplace, and if no possibility exists of cabining that disruption, then the employee is unqualified for the position. However, the degree of disruptio n caused by the employee's disability must be substantial in order to render an employe