

Withdrawal/Redaction Sheet

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. fax	To: Mac Reed (partial) (1 page)	01/28/2000	P3/b(3)
001b. letter	To: Mac Reed re: Exectuive Order (partial) (1 page)	01/28/2000	P3/b(3)
002. list	re: contact info (partial) (1 page)	n.d.	P3/b(3)
003a. fax	To: Christopher Jennings re: Draft Executive Order (partial) (1 page)	01/14/2000	P3/b(3)
003b. letter	To: Chris Jennings re: Exectuive Order (partial) (1 page)	01/14/2000	P3/b(3)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 2]

2012-0463-S

rc756

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

#2

Alliance of Genetic Support Groups
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ALLIANCE OF GENETIC SUPPORT GROUPS

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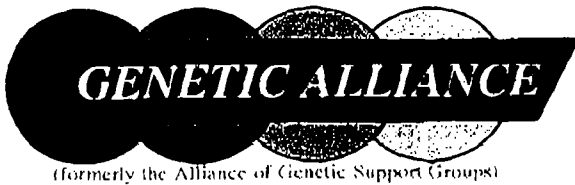
Urgent For Review Please Comment Please Reply Please Recycle

Here are the case examples that I mentioned. In every case either a trained masters level social worker or genetic counselor has spoken with the person to confirm the details. Please call me if you have any questions.

Here are five more cases — they have all been carefully disguised. Please call me if you have any more questions.

• If you did not receive all pages, please call (202)966-5557 ext.

207



An International Coalition of Individuals, Professionals and Support Groups

The Long-Range Costs of Genetic Discrimination

There are children, adults and families across these fifty states whose lives are touched in profound ways by the promise of genetic medicine. There are also many among them who already experience a narrowing window of opportunity for health care services, employment and education because of identification with a genetic condition. In my few minutes, I want to make human sense of all this. I want to make tangible the potential catastrophic impact of genetic discrimination on individuals, families and broader society.

The Alliance of Genetic Support Groups is an active champion for children, adults and families identified with, or at risk for, genetic-related disorders. Representing a coalition membership of more than a million children, adults and families, genetics professionals and members of genetic support groups, the Alliance works to promote access to employment, education and quality health care and to educate professionals and the public about these issues.

Let us not forget: History repeats what is not remembered. In the 1970's promising discoveries about Sickle Cell Anemia resulted in gross misuse of genetic test results and tragic injustice for many healthy and productive individuals who lost jobs, health care, livelihoods, homes -- the very fabric that holds life together. Many were healthy "carriers" of the sickle cell trait or simply presumed to be affected because they were African American.

Now it is 1998 and people still ask: "Does genetic discrimination really happen? Are people really dropped from health insurance, fired from jobs or denied entrance to either?"

Building partnerships to enhance the lives of everyone impacted by genetics

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First, employment discrimination is very subtle and very hard to prove. If you can't get a job in the first place, it's almost impossible to prove that your genetic fingerprint is the cause.

✓ Let me tell you about Richard, not his real name of course: Richard is an experienced engineer living in the southwest with years of excellent performance records. After interviewing successfully for a lucrative position and receiving a tentative offer, he was told to go for a routine, pre-employment medical exam. When Richard returned, the interviewer took him aside and showed him the medical report, which correctly diagnosed him with Klinefelters -- a common chromosome disorder occurring approximately one in 450 male births. Klinefelters, like many genetic disorders, looks the same in a laboratory test but has tremendous range of expression. In the past the diagnosis was incorrectly associated with mental retardation and serious psychiatric problems. Richard had an excellent work history however the employer refused to hire him based on misunderstanding the real implications of the diagnosis for Richard's long-range productivity and health care costs. Richard was told that the offer was being withdrawn. If he protested, the company would deny that the conversation ever took place.

Second, if you're laid off a job, the reasons are not on public record and can be justified by various and complex reasons relating to business necessity.

✓ Let me tell you about Kim: Kim is a social worker who worked within a large human services agency. During a staff workshop on caring for people with chronic illnesses, Kim shared that she was the primary caretaker for her father chance of developing this fatal neurological condition. She had never even seriously considered having the test to confirm whether or not she received the positive gene from her mother. One week after revealing her risk status based on family history, Kim was fired from her job -- despite outstanding performance reviews in the months prior to the firing. Note that Kim was healthy, had never had a genetic test, had no clinical diagnosis and an unblemished work history. She had no idea that her voluntary disclosure might affect her employment.

People like Kim and Richard say they simply don't know where to go with their complaints and can't afford legal fees. More importantly they don't want to make their genetic inheritance even more public and put their families and their futures at further risk. Chances are strong that we are actually seeing a significant under-reporting of the problem.

Third, individuals commonly report that major life decisions -- with respect to type of work, job change, moving or changing health care plans -- are made anticipating discrimination. We know that some consumers avoid genetic testing to safeguard their employment and their families medical insurance, sometimes at the risk of their own health.



Let me tell you about John: John's mother and brother -- both recently identified with Hereditary Hemochromatosis-- strongly urged him to be tested. John was was in his early thirties and could clearly benefit from earlier detection of HH. Understood only in the last several years, this is one of the most commonly inherited genetic diseases and occurs approximately one in 330 Caucasians. Early detection and diagnosis are everything. Otherwise lead toxicity builds insidiously and compromises various organ systems, causing diffuse, chronic symptoms and eventual death. The good news is that HH is simple and inexpensive to treat; regular phlebotomies or blood letting, keep lead levels within normal range. Genetic tests and early detection can provide both employee and employer with invaluable information to increase the odds of a normal, healthy, productive work life. The alternative -- not testing because of fear of genetic discrimination -- can cost employers and insurance companies considerable health care dollars and an employee literally their life.

In this real life story, John chose not to be tested. He didn't have health insurance at the time and was worried about being uninsurable and unemployable if he were to test positive and have test results on his medical record at the time of a job search the following year.

Are these individuals over-reacting? Remember that fear of adverse consequences is very real, palpable, intense and certainly has clear historical roots in what happened with the Sickle Cell Anemia Control Act. Consider further that if these same worries scare people from participating in research studies, we won't ever see the great promise and potential of today's genetic discoveries.

Fourth, The Alliance of Genetic Support Groups understands that employers and insurance companies need to think carefully about long-range employee productivity and health care costs.

However genetic science and medicine are not yard-stick technologies with linear implications. Genetic test results are not black and white, yes or

know, x years of productivity or x dollars of health care costs or x % of employment risk. Most genetic diseases do manifest with wide and unpredictable variability of expression -- from the most mild with almost no symptoms or associated functional limitations or health care costs to the most severe with, of course, associated limitations in productivity and expensive health care costs. Two genetic fingerprints can look the same in a petri dish; associated productivity and health care costs can be drastically different.

Genetic test results must not be used arbitrarily to target individuals at risk, narrowing futures before they begin and wasting potential for productive, autonomous lives.

The irony is that employers stand to deprive themselves of skilled, experienced and productive workers. A genetic diagnosis does not necessarily mean less productivity and more health care dollars for employers. In the case of some more common genetic conditions -- HH and some cancers for example -- early detection can actually save tremendously in productivity, health care dollars and human heart ache by preventing the damaging effects of the disease itself.

Fifth, in a few years, when we will all be identified with our own particular family risk or predisposition or susceptibility, arbitrary targeting will make no sense at all. Employers, owners, human resource personnel, CEOs are all ultimately as vulnerable as the rest of us. After all, we all possess imperfect genetic inheritances that will be transparent with tomorrow's technologies.

Last, the impact of genetic discrimination must be measured in terms of even broader societal costs. Genetic discrimination threatens to create an underclass of citizens who are uninsurable and unemployable, at enormous public financial and moral cost.

✓ Let me tell you about Carole and her daughter Tracy: Carole called the Alliance helpline for help in attaining employment and medical insurance coverage for herself and her daughter. Carole lives in a close-knit community in the northwest where her husband ran a local store and was well appreciated for his neighborly spirit. Several years ago her husband died of cardiac problems associated with Marfan Syndrome. Their daughter, is six years old, has Marfan syndrome and likely will require heart surgery in the future. Fortunately Carole's family and in-laws have done everything possible to help their granddaughter and her. They share Carole's increasing concern that her

daughter's condition will prevent her from securing employment and health insurance for the two of them. Carole appreciates her family's financial and emotional support but wants to get on with her new life and family situation. However Carole is facing a most sobering, heart-wrenching and intolerable but possible alternative: to agree to her sister and brother-in-law's offer to adopt her daughter and put her on their health insurance plan. What kind of society forces a mother to give up her daughter so that she obtains the medical care she needs to survive?

Let me tell you about Lisa and her son Jonathan: Lisa suspected that her young first grader, Jonathan, had learning disabilities. Her doctor performed some tests and concluded that Jonathan has Fragile X Syndrome, an inherited form of mental retardation. Lisa, like most of us, had insurance through her employer. Claiming that his diagnosis qualified as a pre-existing condition, the insurance company eliminated Jonathan's health coverage. Lisa searched -- without success -- for another company that would employ her and insure her son. Ultimately she was forced to quit her job and become unemployed to qualify for Medicaid and get Jonathan covered at public expense. Does this make any financial or moral sense?

Nearly 30 years have passed since the sickle cell tragedies. But we have not yet succeeded in making the public fully aware of these critical legal, social and ethical issues. In truth we are all still illiterate in the language and logic of genetics.

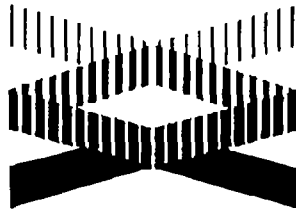
This is a problem that will grow larger and larger over the next few years. Right now we can test for a handful of genes but that number will grow to the thousands. These future tests will predict risk of more common diseases and susceptibility to more common health problems. Given the likelihood that each of us carries 5 to 7 mutated genes, we are all at risk for genetic discrimination. We could all be vulnerable to the misuse of genetic information and exclusion from jobs, health care, education and other life opportunities.

These wonderful and inspiring scientific advances have accelerated the need for federal protections. The Alliance of Genetic Support Groups calls for the unequivocal prohibition of all kinds of genetic discrimination, including employment, health insurance and education.

Every American -- regardless of genetic inheritance -- deserves the protection federal legislation alone can provide. We appreciate all the wisdom and leadership you bring to resolution of these problems.

01/24/00 2:01 PM, JEFFRA #342, Page 1/4

NATIONAL HUMAN GENOME RESEARCH INSTITUTE, NIH



FAX TRANSMITTAL SHEET

TO: **Christopher Jennings**
FAX NUMBER: (202) 456-5557
FROM: **Kathy L. Hudson, Ph.D.**
Director of Policy and Public Affairs
DATE: January 24, 2000
of pages including cover sheet: 4
Return FAX number: (301) 402-0837
If there are problems, please call (301) 402-2205

Comments:

Attached please find a letter expressing our concerns about State Department's interpretation of the E.O. Also, you may want to keep in mind the following *two* items on genetic discrimination:

- (1) The Senate passed PBOR would expand genetic non-discrimination protections regarding health insurance. The language is not all we would like to see but if the PBOR begins to move, it could provide an opportunity for the President to improve genetic non-discrimination protections in HIPAA.
- (2) While DOD is not covered by the E.O., you may be interested in recent & potential future DOD policy changes regarding genetics. In 1998 we became aware of a DOD directive that denies medical benefits if disease is genetic. The young man who suffered from this policy has become an outstanding & outspoken advocate for genetic anti-discrimination policies. Given that all disease has a genetic component, this policy is unfair today & unworkable in the long term. In 1999 DOD proposed a statutory change to correct this inequity & provide benefits to those with at least 180 days of active duty. OMB rejected the proposal but did recommend allowing benefits if individual had 8 years of active duty. Congress approved this proposal on Oct. 5, 1999. While this is a marked improvement to previous absolute bar to benefits, it seems inconsistent with philosophy of E.O. It is our understanding that DOD is open to further refinements & would be willing to resubmit a revised proposal to Congress. Announcement of such a proposal would be a nice addition to the genetic discrimination "package".



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Christopher C. Jennings
Deputy Assistant to the President
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Dear Mr. Jennings,

We are writing in response to the State Department's comments on the draft executive order. While their comments, and our response below, do not require a change in the wording of the executive order, we do believe that remaining differences in interpretation need to be clarified. Specifically, we are concerned about the following statement contained in Dr. Dumont's January 14, 1999 letter to you:

"I want to state our understanding that this Executive Order would not prevent the Office of Medical Services, using information obtained through a family history (i.e. family history of anemia), from testing for the presence of hemoglobinopathies such as sickle cell disease/trait or thalassemia and acting on the basis of the results of those tests."

It is unclear whether the situation described above is relevant to health care services provided by the Office of Medical Services consistent with Section 301 (b), and/or to determination of "fitness for duty" consistent with Section 301 (a). However, in both of these circumstances, it is important that we be clear about the collection and use of genetic information.

Fitness for Duty provided under Section 301 (a)

While the employer may require family history information, the medical evaluations suggested by the family history information may not include genetic testing. Thus, determination of the presence of sickle cell disease could be made based on low hematocrit, red blood cell morphology, and/or medical history of vaso-occlusive crisis but could not include analysis of DNA, RNA or proteins. Thus, electrophoretic analysis of the sickle cell protein would not be permitted under the executive order. In the January 6, 1999 meeting at the OEOB, we specifically discussed that the executive order requires that diagnosis of genetic diseases rely on clinical signs and symptoms that do not include genetic tests as defined in Section 201(d) of the executive order. We agreed that while a genetic test may in some cases be the most expeditious route to a definitive diagnosis, in all cases there are alternative means to obtain a diagnosis. We also agreed that the definitive diagnosis in such circumstances was not the necessary or proper province of the employer, whose role was to determine fitness for duty. Referral should be made to the individual's own physician to complete the work-up. Thus, we agreed that the protections afforded by

prohibiting genetic testing far outweighed the potential inconvenience in the medical evaluation process.

Of even greater concern is the suggestion in the State Department comments that they would test for sickle cell trait and use that information in employment decisions. As you may know, sickle cell disease is an autosomal recessive disorder. This means that an individual who inherits two misspelled copies of the sickle cell gene, one from the father and one from the mother, will have sickle cell disease. This is a serious medical condition that is characterized by chronic anemia, vaso-occlusive crises, etc. If the individual has only one misspelled copy of the sickle cell gene and one normal copy, the individual has sickle cell trait and is a "carrier". Sickle cell carriers are entirely healthy and do not develop sickle cell disease. Some, not well validated, case reports suggest that sickle cell carriers may be at increased risk of suffering vaso-occlusive crisis at extremely high altitudes. Using family history alone would allow one to determine that the child of a person affected with sickle cell disease has sickle cell trait. Using that information as a "diagnosis" conflicts with your point, and the group's agreement, that it is NOT possible to make a diagnosis based on family history alone. A trait is not a disease and should not be treated as one.

We recognize the State Department's legitimate interest in minimizing the risks for its employees and would recommend that, consistent with the Supreme Court's 1991 decision in *Johnson Controls*, when State assigns personnel to high altitude sites they inform ALL employees (irrespective of whether they self identify or are identified to be African American) of the medical risks and recommend (but not require) screening for sickle cell trait to provide information for the EMPLOYEE to use in making a decision about whether to accept an assignment at high altitude.

Approximately one in twelve African Americans have sickle cell trait. Thus, any attempt to collect information about sickle cell trait will by necessity target African Americans. In the 1970's, confusing sickle cell disease and sickle cell trait resulted in regrettable genetic screening programs and in denying jobs to African Americans with sickle cell trait who had no clinical symptoms nor evidence that sickle cell trait would affect their ability to perform the essential functions of the job. Those experiences are still reverberating in the African American community. More recently, a Department of Energy National Laboratory collected blood samples and performed genetic testing to determine sickle cell carrier status without the knowledge or permission of the employees. The predominantly African American clerical workers unwittingly subjected to this testing later filed suit, and won, claiming the practice violated their right to privacy. The case *Norman-Bloodsaw vs. Lawrence Berkeley Laboratory*, 135 F. 3d 1260 (9th Cir. 1998) provides a vivid example of how uninformed employment practices can violate the very principles of fairness and justice this executive order sets out to reinforce. Thus, it is vital that we be very explicit about this issue.

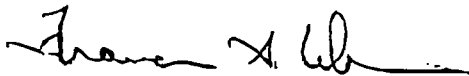
Health Care Services provided under Section 301 (b).

It is our understanding of the executive order that it would be permissible for the Office of Medical Services to collect family history information and test for the presence of hemoglobinopathies when providing health care, but only if the employee has given prior knowing, voluntary, and written authorization, disclosure of the information is restricted consistent with 301(b)(3), and the information is not used to make employment related decisions.

Finally, the responses to State Department comments prepared by White House counsel may inadvertently support the notion that genetic testing is permissible. Namely, the response states that the production of an altered form of hemoglobin indicates that a disorder is present. This conflicts with the widely acknowledged medical view that sickle cell carriers are healthy. In fact, such a proposition would undercut the executive order in its entirety because for most genetic risk factors, a variant protein is produced from the variant gene but the presence of this protein serves only to increase risk of disease in the future. For example, an individual with a variant Factor V Leiden gene has a variant form of the Factor V protein in cells of the liver, where this blood clotting factor is made. A person carrying this variant is not ill. The presence of this protein has no effect on the current health of the individual but does increase the risk of future development of deep vein thrombosis.

We are extremely pleased that the executive order is progressing and we want to again thank you and your colleagues for your leadership, intelligence, and foresight on this important issue.

Sincerely,



Francis S. Collins, M.D., Ph.D.
Director, NHGRI



Kathy L. Hudson, Ph.D.
Director of Policy and Public Affairs

cc: Gary Claxton
Edward Correia
Cedric Dumont
Ruth Kirschstein



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D. C. 20503

DRAFT

THE DIRECTOR

MEMORANDUM FOR THE PRESIDENT

FROM: Jacob J. Lew
Director

SUBJECT: Proposed Executive Order Entitled "To Prohibit Discrimination in Federal Employment Based on Genetic Information"

SUMMARY: This memorandum forwards for your consideration a proposed Executive order that was prepared by the White House Domestic Policy Council. The proposed order states that it is the policy of the Government of the United States to provide equal employment opportunities in Federal employment and to prohibit discrimination against employees based on protected genetic information. It would require Executive departments and agencies to extend this nondiscrimination policy to all employees covered by Section 717 of Title VII of the Civil Rights Act of 1964, as amended.

BACKGROUND: The Equal Employment Opportunity Commission and the National Institutes of Health have become aware of instances where genetic information has been used to discriminate against persons employed in the private sector. To forestall this type of discrimination in the executive branch of the Federal Government, the proposed order would direct Executive departments and agencies ("agencies") to take certain actions.

The order would bar the agencies from: (a) hiring or firing persons based on protected genetic information; (b) classifying or segregating persons based on genetic information; or (c) requesting, collecting or purchasing protected genetic information. Protected genetic information is defined as: (1) information about an individual's genetic tests; (2) information about genetic tests of family members of the individual; and (3) information about the occurrence of a disease or disorder in family members of the individual. Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analysis), unless genetically organized, would not be protected genetic information. Further, the definition of "genetic test" in the order covers the analysis of human DNA to detect disease-related genotypes or mutations. The analysis of DNA for human identification or forensic purposes does not fit within the definition. Accordingly, the order does not bar the collection or use of information obtained through such analysis for law enforcement purposes.

The exceptions to the order would permit agencies to require prospective employees to provide family history genetic information if: (a) consistent with the Rehabilitation Act or applicable law; (b) used to assess whether further medical evaluation is needed to diagnose a medical condition or disorder, and (c) such medical condition or disorder could prevent the employee from performing the essential functions of the desired position.

Agencies could also collect protected genetic information if the employee uses the health care services provided by the agency or if the information is needed for the monitoring of biological effects of toxic substances in the workplace

None of the affected agencies objects to the proposed Executive order.

RECOMMENDATION: I recommend that you sign the proposed Executive order.

Attachments

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Marty
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Senate

✓ **Sen. Edward M. Kennedy (D-Mass.)**

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HOUSE OF REPRESENTATIVES

Rep. Louise M. Slaughter (D-N.Y.)

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Rep. William L. Clay (D-Mo.)

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Rep. John D. Dingell (D-Mich.)

16th District, Southeast Wayne County; Monroe County

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Rep. Sherrod Brown (D-Ohio)

13th District, Northeast -- Suburbs of Cleveland, Akron and Youngstown

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 Rep. Rick A. Lazio (R-N.Y.)

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Rep. James C. Greenwood (R-Pa.)

8th District, Northern Philadelphia suburbs -- Bucks County

Key Contact Information

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Rep. Cliff Stearns (R-Fla.)

6th District, North Central -- Lake and Marion counties; part of Jacksonville

Key Contact Information

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Rep. John Edward Porter (R-Ill.)

10th District, North and Northwest Chicago suburbs -- Waukegan

Key Contact Information

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Fax: (202) 225-0837
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Rep. Fred Upton (R-Mich.)

6th District, Southwest -- Kalamazoo; Benton Harbor; St. Joseph

Key Contact Information

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"Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>
02/04/2000 01:01:37 PM

Record Type: Record

To: Devorah R. Adler/OPD/EOP
cc: "Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>, "Higgins, Craig (NHGRI)" <craigh@exchange.nih.gov>, "Fuller, Barbara (NHGRI)" <barbaraf@exchange.nih.gov>
Subject: Stuff

Devorah-

✓ WHERE:

Clearly, the White House would be the most desirable location. If you decide you want to explore using the National Academy of Sciences auditorium (which is huge and beautiful and they know how to handle the POTUS), you should contact Susan Turner-Lowe (202) 334-3875. You can tell Susan I told you she could help. If you want to try to do it at NIH, we would, of course, make that happen.

✓ WHO--invites:

Cabinet Affairs

I have attached a list of folks you should consider inviting. It includes disease advocacy groups; union/labor groups; medical, research, and health professionals; biotech and pharmaceutical leaders; individuals who have contributed to this issue over the years; HHS and EEOC officials and staff; etc. Also, please know that the NIH can provide as many genetics researchers as you could possibly need, and on very short notice.

WHO-Speakers:

I have recommended speakers in three categories: 1) real person (consumer), 2) genetics health care professional, and 3) genomics researcher. I think it would be fitting to have a speaker address the current and future benefits to health from genetics as well as person to address how information was misused. If the President also announces the "joint statement on data access" at this event, a leader in genome sequencing should be included.

Real person: I think your best bet for a "real person" would be a woman (or her lawyer) who had genetic testing done on her surreptitiously by her government employer. Employees at the Lawrence Berkeley Laboratory (which is operated by the Regents of the University of California under a contract with DOE) filed a class action lawsuit in 1995 after discovering that for over two decades, the lab had engaged in a secret practice of testing its employees for highly intimate medical conditions and genetic characteristics. Testing included genetic testing for sickle cell trait--a genetic characteristics that has no impact on the health of the individual and certainly no relevance to the ability of these clerical workers to do their jobs. Although employees were aware that blood and urine samples were being taken as part of a mandatory

medical exam, they were unaware of the specific genetic tests being performed. Given that the EO did not then exist, the case brought by the workers was based on a violation of their privacy and violations of civil rights since African American workers were specifically singled out for the testing. The plaintiffs won the case.

This is a PERFECT example of what would be prohibited by the executive order. The plaintiff in the case Ms. Norman-Bloodsaw and her attorney, Vicki Laden, would both be terrific speakers at the event. The DOE reportedly stopped requiring the testing in 1995 and have cleared the EO so they could appear rehabilitated or converted. Since DOE is the NIH's partner in the HGP and Secretary Richardson is one of its biggest advocates, I would think they might be okay with this but you would certainly want to confer with them.

Your other option would be the leader from a group that has been very outspoken on this issue. Topping the list would be Fran Visco from the National Breast Cancer Coalition, Marlene Post, former President of Haddasah, or Mary Davidson from the Alliance of Genetic Support Groups.

Genetics health professional:

Dr. Francis Collins is your obvious choice. If he is not able to speak, I hope that the President will recognize him by name.

Dr. Wylie Burke is a prominent breast cancer physician who has also done seminal work in breast cancer genetics. She has first hand experience in what it means to tell your patient of the risks and benefits of having genetic testing for breast cancer risk. She is phenomenal.

You might also consider Reed Tuckson, VP of the AMA. He is a leader in moving genetics into health care (maximizing benefits); very knowledgeable about the social risks; his organization, AMA, has position on genetic employment discrimination; and, he is on the Secretary (hhs) Advisory Committee on Genetic Testing. He too could speak to the benefits of genetics for health but the need to remove disincentives, risks. Reed is a very articulate African American who I believe has good relationship with the Administration.

Genome Person: (if joint statement is announced)

Of course Francis is the main man; articulate, passionate, brilliant (of course I am not biased). If you feel that he is overexposed, you should have Richard Gibbs, Director of the Genome Sequencing Center at Baylor speak to the value of genome sequence information being in the public domain. Eric Lander would be your other choice but he got a lot of visibility at the millennium evening. Bob Waterston, is also an option but he is not a great speaker.

WHAT: Devorah- I have a draft speech on this issue. It is really good. Can I give it to you to pass to the speech writer?

U.S. DEPARTMENT OF JUSTICE
OFFICE OF LEGAL COUNSEL
WASHINGTON, D.C. 20530

FACSIMILE TRANSMISSION SHEET

DATE: 1/28/2000

TO: Mac Reed

OFFICE PHONE: () _____

FROM: Rosemary Hunt
Robert Leubowalt

514-2027

OFFICE PHONE: () 514-1762

NUMBER OF PAGES: 10 (NOT INCLUDING COVER SHEET)

FACSIMILE NUMBER: () _____

REMARKS:

Mac -

Our comments on the
genetic discrimination EO are
attached. Thanks.

— Robin

ANY QUESTIONS, PLEASE CONTACT DYONE MITCHELL OR LAWAN ROBINSON AT 514-2051
OFFICE OF LEGAL COUNSEL FACSIMILE MACHINE NUMBER - 514-0539 (FTS - 368-0563)



U.S. Department of Justice

Office of Legal Counsel

Washington, D.C. 20530

January 28, 2000

To: Mac Reed
OMB

From: Rosemary A. Hart
Robin A. Lenhardt

Re: Executive Order to Prohibit Discrimination in Federal Employment Based on Genetic Discrimination.

This memorandum sets out the substantive comments on the draft executive order that have been advanced by various components within the Department of Justice. We apologize for the delay in getting them to you. As we explained to your assistant, Devora, obtaining comments from the numerous components within the Department proved to be a more difficult task than we had anticipated.

For the most part, the changes we have suggested are minor. We believe that they would improve the draft order, but emphasize that a decision not to accept our suggested revisions would not preclude the Department of Justice from supporting the final order. Our components have been uniform in their willingness to sign on to the draft.

If you have any questions or concerns, please contact us at either 514-2027 (Rosemary) or 514-1762 (Robin).

Suggested revisions to the 1/18/00 draft:

1. 1-202. Add a provision permitting disclosure in response to a congressional subpoena.
2. 1-202(d)(3). This subsection permits an employing department or agency to disclose protected genetic information "under legal compulsion of a Federal court order." We note, however, that many legal actions, such as proof of paternity, take place primarily in state courts. We therefore suggest that you revise that phrase to read "under legal compulsion of an order issued by a court of competent jurisdiction." This language

tracks the language of the Privacy Act and would allow a state court to issue a disclosure order, where such disclosure is appropriate.

3. 1-301(a). This exception to employer procurement of protective genetic information is not uniform in its references to applicants and employees. We ask that you amend the introductory sentence of this provision to read that "[t]he employing department or agency may request or require information defined in 1-201(e)(1)(C) with respect to an applicant or employee who has been given a conditional offer. . . ." This would make the language of subsection 1-301(a) consistent with that of subsection 1-301(a)(3).
4. 1-301(a)(3). We recommend that you substitute the word "would" for the word "could." The amended subsection would read "such current disease, medical condition or disorder would prevent the applicant or employee from performing the essential functions of the position held or desired." We think that permitting employers to request protected information only when it is clear that a "current disease, medical condition, or disorder" would prevent an employee from performing his or her job is more consistent with the Rehabilitation Act and other applicable law.
5. 1-301(d)(3). This subsection explains that the order would not limit the statutory authority of an agency to "collect protected genetic information as part of a lawful program, the exclusive purpose of which is to carry out identification purposes." We are concerned that, as currently drafted, this provision would not be read to embrace the operations of the National DNA Index System (NDIS), a database maintained by the Federal Bureau of Investigation pursuant to authorization found in the Violent Crime Control and Law Enforcement Act of 1994, Pub. L. No. 103-322, 108 Stat. 1796, whose primary, but not exclusive, purpose is to store DNA records submitted by criminal justice agencies for law enforcement purposes. We therefore recommend that this provision be amended to read "the primary purpose of which is to carry out identification purposes."

DRAFT 01/11/00

Draft. Revised 1/24/00. 3:00 P.M.

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT BASED ON GENETIC INFORMATION

By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

Section 19 Nondiscrimination in Federal Employment on the Basis of Protected Genetic Information

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment. ✓

1-102. The head of each Executive department and agency shall extend the policy set forth in section 1-101 for all its employees covered by section 717 of Title VII of the Civil Rights Act of 1964 as amended. (42 U.S.C. 2000e-16). ✓

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services. ✓

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Section 2. Requirements Applicable to Employing Departments and Agencies

1-201. Definitions.

- (a) The term "employee" shall include an employee, applicant for employment, or former employee covered by Section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16). *as amended. I.C.*
- (b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, respond to the effects of, or control adverse environmental exposures in the workplace.
- (c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.
- (d) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites fall within the definition of "genetic tests" when an excess or deficiency of the metabolite^s indicates the presence of a mutation or mutations. *Does this really get at the problem?*
- (e) Protected genetic information.
- (1) In general, protected genetic information means--

Wouldn't this make an employer liable under the EO if the results of their test indicated a mutation, even if the results were incorrect?

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(A) information about an individual's genetic tests;

(B) information about the genetic tests of ^{an individual's family members} family members of the individual;
or(C) information about the occurrence of a disease, medical condition or disorder in ^{an individual's} family members of the individual.

(2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses of the individual) is not protected genetic information unless it is described in subparagraph (1).

1-202. In discharging their responsibilities under this order, agencies shall implement the following nondiscrimination requirements.

- (a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of ^{that} the employee because of protected genetic information with respect to the employee or because of information about a ^{meaningful} request for or the receipt of genetic services by such employee.
- (b) The employing department or agency shall not ^{on the basis of genetic information concerning an employee's request for genetic information} limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect ^{that} the employee's status ^{because of} ~~because of~~ genetic information.

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1301c adding exemption for collection
of info if common rule met.
~~protected~~

~~protected genetic information with respect to the employee or because of information
about a request for or the receipt of genetic services by such employee.~~

- (c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by such employee. ✓
- (d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee except -- ✓
- (1) to the employee who is the subject of the information, at his or her request;
 - (2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45 ^{of the} Code of Federal Regulations; ✓
 - (3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order, unless the court order also imposes confidentiality requirements; or ✓
 - (4) to government officials investigating compliance with this order, if the information is relevant to the investigation. ✓

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- (e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records^{and} kept separate from personnel files. ✓

Section 3) Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in section 1-202.

- (a) The employing department or agency may request or require information defined in 1-201(e)(1)(C) with respect to an applicant^{to} who has been given a conditional offer of employment or an employee if:
- (1) the request or requirement is consistent with the Rehabilitation Act and other applicable law;
 - (2) the information obtained is to be used exclusively to assess whether further medical evaluation is needed to diagnose a current disease, medical condition or disorder, or under the terms of 1-301(b) of this order;
 - (3) such current disease, medical condition or disorder ^{would} ~~could~~ prevent the applicant or employee from performing the essential functions of the position held or desired; and
 - (4) the information defined in 1-201(c)(1)(C) of this order will not be disclosed to persons other than medical personnel involved in or responsible for assessing whether further medical evaluation is needed to diagnose a current disease, medical condition or disorder, or under the terms of 1-301(b) of this order.

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- (b) The employing department or agency may request, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee if:
- (1) the employee uses genetic or health care services provided by the employer (other than use pursuant to section 301(a) of this order);
 - (2) the employee who uses the genetic or health care services has provided prior knowing, voluntary, and written authorization to the employer to collect protected genetic information;
 - (3) the person who performs the genetic or health care services does not disclose protected genetic information to anyone except to the employee who uses the services[^] for purposes of treatment, payment, or health care operations[^] or pursuant to section 1-202(d) of this order; and ✓
 - (4) such information is not used in violation of sections 1-202(a) or 1-202(b) of this order.
- (c) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:
- (1) the employee has provided prior, knowing, voluntary, and written authorization;
 - (2) the employee is notified when the results of the monitoring are available

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and, at that time, the employer makes any protected genetic information that may have been acquired during the monitoring available to the employee and informs the employee how to obtain such information:

- (3) the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and
 - (4) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.
- (d) This order does not limit the statutory authority of a Federal agency to:
- (1) promulgate or enforce workplace safety and health laws and regulations;
 - (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations; or
 - (3) collect protected genetic information as a part of a lawful program, the exclusive purpose of which is to carry out identification purposes.

Section 4. Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy and, to this end, shall designate a high level official responsible for carrying out its responsibilities under this order.

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1-402. Nothing in this order shall be construed to:

- (a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701, et seq.), the Privacy Act of 1974 (5 U.S.C. 552a), or other applicable law; or
- (b) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program.

1-403. This order clarifies and makes uniform Administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE

[DATE]



United States Department of the Interior

OFFICE OF THE SECRETARY
Washington, D.C. 20240



February 1, 2000

Mr. Mac Reed
Office of the General Counsel
Executive Office of the President
Office of Management and Budget
Washington, D.C. 20503

Dear Mr. Reed:

Thank you for the opportunity to review the proposed Executive Order "To prohibit Discrimination in Federal Employment Based on Predictive Genetic Information."

Our primary concern on this draft is that it seems, in sec. 1-202 (d), to attempt in one effort to establish by Executive fiat a Freedom of Information Act (FOIA) exemption from release of genetic information. However, if a FOIA request were received for such information, it could be withheld only if it were concluded that it was protected by one of the nine FOIA exemptions. It appears that the information would be covered by exemption (6), but the agency would be required to undertake the standard exemption (6) analysis and conclude that the exemption protected the information from release.

We are also concerned that the same section (1-202 (d)) seems to be establishing Privacy Act routine uses for the release of genetic information. To the extent that the Privacy Act applies to the genetic information here, the only way we are aware of to make the kinds of releases mentioned in the order, is through the statutory authorities set out in 5 U.S.C. 552a (b), one of which is the "routine use" provision. In order to establish routine uses an agency must note them in the system notice required to be published for the particular system of records involved. To the extent the genetic information discussed in the order is "name retrievable," the Privacy Act presumably would apply regardless of whether the agency already has a system notice in place.

Last, we are concerned with section 1-202 (c), which not only is confusing, but may very well be inconsistent with section 1-202 (d), in that it seems to prohibit the agency from acquiring the very information that the agency is basically prohibited from releasing in section 1-202 (d) to release.

Again, thank you for the opportunity to review and comment on the draft. If you have questions about our comments, please call me at (202) 208-6193.

Sincerely,

Hazel A. Wilson
Office of Planning and Performance Management

Office of General Counsel

U.S. Department of Transportation

400 Seventh Street, S.W.

C-40, Room 10100

Washington, D.C. 20590

Telephone: (202)366-4687

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TO: Mac Reed

FROM: Jane DeCell

FAX #:

Number of pages (including this page)	2
DATE AND TIME	2/1/20
DATE COMMENTS / RESPONSE (IF ANY) ARE DUE	

Remarks:

Three editorial comments on
Genetic Information 20.



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

GENERAL COUNSEL

January 24, 2000

MEMORANDUM FOR DESIGNATED AGENCY HEADS
(SEE ATTACHED DISTRIBUTION LIST)

FROM: Robert G. Darnus
General Counsel

SUBJECT: Revised Proposed Executive Order Entitled "To Prohibit Discrimination in
Federal Employment Based on Predictive Genetic Information"

See next page

Attached is a revised proposed Executive order entitled "To Prohibit Discrimination in
Federal Employment Based on Predictive Genetic Information."

It was revised based on agency comments received pursuant to the February 25, 1999
circulation of the order. The revised order was prepared by the White House Domestic Policy
Council.

On behalf of the Director of the Office of Management and Budget, I would appreciate
receiving any comments you may have concerning this proposal. If you have any comments or
objections, they should be received no later than close of business Friday, January 28, 2000.
Please be advised that agencies that do not respond by the deadline will be recorded as not
objecting to the proposal.

Comments or inquiries may be submitted by telephone to Mr. Mac Reed of this office
(Phone: 395-3563; Fax: 395-7294).

Thank you.

Attachments - Distribution List
Proposed Executive Order

cc:	Jack Lew	Michael Deich	Danny Mendelson
	Sylvia Mathews	Elgie Holstein	Dick Emery
	Josh Gorbau	Joe Minarik	Michael Barr
	Sally Katzen	John Spotila	Rob Nabors
	Robert Kyle	Linda Ricci	Adrienne Erbach
	Dee Lee	Barbara Chow	Vikki Wachino

DRAFT 01/11/00

Draft Revised 1/24/00. 3:00 P.M.

Protected
EXECUTIVE ORDER**TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT
BASED ON GENETIC INFORMATION**

Protecting Genetic Information
By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

Section 1. Nondiscrimination in Federal Employment on the Basis of Protected Genetic Information

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

1-102. The head of each Executive department and agency shall extend the policy set forth in section 1-101 for all its employees covered by section 717 of Title VII of the Civil Rights Act of 1964, as amended.

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services.

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protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee.

(c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by such employee.

(d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee except —

- written (?)*
- (1) to the employee who is the subject of the information, at his or her request;
 - (2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;
 - (3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; or
 - (4) to government officials investigating compliance with this order if the information is relevant to the investigation.

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- (b) The employing department or agency may request, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee if:
- (1) the employee uses genetic or health care services provided by the employer (other than use pursuant to section 1-301(a) of this order);
 - (2) the employee who uses the genetic or health care services has provided prior knowing, voluntary, and written authorization to the employer to collect protected genetic information;
 - (3) the person who performs the genetic or health care services does not disclose protected genetic information to anyone except to the employee who uses the services for purposes of treatment, payment, or health care operations; or pursuant to section 1-202(d) of this order; and
 - (4) such information is not used in violation of sections 1-202(a) or 1-202(b) of this order.
- (c) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:
- (1) the employee has provided prior, knowing, voluntary, and written authorization;
 - (2) the employee is notified when the results of the monitoring are available

January 28, 2000

Genetic Discrimination E.O. and Health Privacy Rules Disclosure to Researchers

Issue: Whether and how to incorporate the same standard for privacy protections for research included in the HHS privacy rule in the genetic discrimination E.O.

Background: Section 1-202(d) of the draft E.O. states that an employer “shall not disclose genetic information except . . . (3) to an occupational or health researcher if the research is conducted in compliance with the [Common Rule].”

The HHS proposed health privacy rule builds on Common Rule criteria and adds additional criteria specific to information practices. The proposed rule allows covered entities (*i.e.*, health care providers, plans, and clearinghouses) to disclose protected health information without patient consent upon documentation by an Institutional Review Board (“IRB”) or “Privacy Board” that the research meets criteria in the Common Rule, plus 4 additional privacy-related criteria. The proposed rule also extends the requirements mentioned above to researchers that are not currently subject to the Common Rule, but receive protected health information from covered entities.

While the HHS privacy rule applies to federal agencies that are “covered entities” under the rule, the E.O. would apply to all federal agencies. Therefore, *any decisions made on standards for disclosure for research under the E.O. would affect more agencies than are covered under the HHS privacy rules.*

During the development of the proposed health privacy rule, EOP and HHS staff noted the limitations of the statutory authority, notably that the HHS rule would only reach “covered entities” – health care providers, plans, and clearinghouses, but not employers, researchers, and others. The question is whether the statutory scope of the health privacy regulation should also be the scope of the E.O.

Options:

1. Do nothing.

Pro: Upon publication of the E.O., agencies will have certainty about the disclosure rules upon publication of the E.O. Nothing in the final privacy rules will be incorporated into the E.O. (though the standards in the HHS rule for disclosure for research would still apply to agencies that are covered entities).

Con: If the final HHS privacy rule is similar to the proposed rule, the result will be more lenient disclosure rules for genetic information under the E.O. than rules governing a broader set

of information (usually less sensitive) under the HHS privacy rule. Issuance of an E.O. with a lower standard for privacy protections could be viewed as inconsistent with previous statements and a weakening of the Administration's position on health privacy.

2. E.O. incorporates research standards of final privacy rule upon publication [or one year thereafter?]

This could be done through the following language, to 1-202(d) (above): "... and if in conformance with the standards for disclosure in Section 164.510(j) of the Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160-164, upon publication [or one year thereafter?]."

Pro: This would ensure the same standard for disclosure for research in the E.O. and the final HHS rules. As for timing, it would impose the stricter standards on the government one or two years earlier than the private sector, demonstrating government leadership in protecting privacy.

Con: It will be difficult for federal agencies to comply with the stricter disclosure-for-research standards earlier than the private sector, and particularly difficult to comply immediately upon publication of the final rule.

3. E.O. incorporates research standards of final privacy rule upon effective date

This could be done by adding the following language to 1-202(d) (above): "... and if in conformance with the standards for disclosure in Section 164.510(j) of the Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160-164, upon the effective date of such rules."

Pro: Like Option 2, this would ensure the same standard for disclosure for research in the E.O. and the final rules. It also gives agencies, like the private sector, two years to comply, which should be ample.

Con: This option is not as privacy protective because of the delay in implementation.

4. E.O. incorporates research standards currently in the *proposed* rule, noting that they may change in accordance with the final rule

This could be done by adding the following language to 1-202(d) (above): "... and if in conformance with the standards for disclosure in Section 164.510(j) of the Proposed Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160-164."

Pro: This would make a strong statement that the Administration wants to serve as a leader and extend the research standards in the health privacy NPRM to federal agencies. Even though the rule is not yet final, the standards included in the NPRM represent the Administration's current policy position based on thoughtful analysis.

Con: This option could be viewed as undercutting or pre-judging the rulemaking process. It could also be opposed by agencies that have been told they would have the comment period to comment on the research-related section of the NPRM.



DEPARTMENT OF THE TREASURY
WASHINGTON

OFFICE OF THE ASSOCIATE GENERAL COUNSEL
(LEGISLATION, LITIGATION & REGULATION)

1500 PENNSYLVANIA AVENUE, N.W.
ROOM 1417
WASHINGTON, D.C. 20220

FAX: (202) 622-1188

VOICE: (202) 622-0650

DATE: January 28, 2000

PAGES TO FOLLOW: _____

TO: Ma~~e~~ Reed

FAX: _____

TO: _____

FAX: _____

TO: _____

FAX: _____

TO: _____

FAX: _____

FROM: Karen Dorsey

SUBJECT: Revised Draft Executive Order: To Prohibit Discrimination
in Federal Employment Based on Predictive Genetic
Information

COMMENTS/SPECIAL INSTRUCTIONS

Treasury has no comments on the above.

Diana Espinosa 01/28/2000 05:06:20 PM

Record Type: Record

To: McGavock D. Reed/OMB/EOP@EOP

cc: See the distribution list at the bottom of this message

Subject: EO Prohibiting Genetic Discrimination

In reviewing the draft EO, Health Division staff noted a potential inconsistency between the EO and the policies in the Administration's NPRM on health privacy. Specifically, the draft EO has a lower standard for when genetic information can be disclosed to researchers than the health privacy NPRM does. We discussed this issue with the Privacy Counselor's Office who agrees and is drafting an issue paper for consideration by EOP. We wanted to advise you of this open issue since it may not be resolved before the deadline for comments.

Message Copied To:

Lauren B. Steinfeld/OMB/EOP@EOP
Barry T. Clendenin/OMB/EOP@EOP
Thomas Reilly/OMB/EOP@EOP
Mark E. Miller/OMB/EOP@EOP
Gaylee L. Morgan/OMB/EOP@EOP



NATIONAL AERONAUTICS & SPACE ADMINISTRATION
HEADQUARTERS
OFFICE OF THE GENERAL COUNSEL
WASHINGTON, DC 20546-0001

=====

Doris A. Wojnarowski
Associate General Counsel (General)
Phone: (202) 358-2465
Fax: (202) 358-4355

FACSIMILE COVER SHEET

DATE: 1 27 2000

TO: Mac Reel (Number of pages including
the cover sheet (2))
AGENCY/CODE/CO.: _____
PHONE NO: () _____
FAX NO: (202) 355 7294

=====

☒ URGENT ☐ REVIEW/COMMENT ☐ FYI ☐ PER DISCUSSION

MESSAGE: Per phone conversation

***IMPORTANT: The information contained in this facsimile message is intended only for use of the individual to whom it is addressed. It may contain information that is privileged and confidential. If the reader of this message is not the intended recipient, you are hereby notified that any dissemination, distribution, or copying of this communication is strictly prohibited. If you have received this communication in error, please notify the sender immediately at the telephone number above.

Thank you.

Edward A. Frankle, Esq.
General Counsel
NASA
Washington, DC 20546
(202) 358-2450

facsimile transmittal

To: Christopher Jennings, Deputy
Assistant to the President for Health
Policy

Fax: 202-456-5557

From: Edward A. Frankle

Date: 1/14/00

Re: Genetic Discrimination Executive
Order

Pages: Cover plus 1

CC:

☒ Urgent

☐ For Review

☐ Please Comment

☐ Please Reply

☐ Please Recycle

Notes: Per your request, NASA has reviewed the draft Executive order. The changes made in the most recent version address most of NASA's concerns. As explained in the enclosed memorandum from our medical staff to me, the current version presents no problem regarding the vast majority of our employees and has only small, but acceptable impacts on the astronaut corps as it currently exists. We do feel that when the time comes to begin selecting crews to go on long duration missions, such as to Mars or the moon, other problems may well arise. Those issues are, at least, several years in the future and are best addressed when they arise in a full factual context. Therefore, recognizing that policy on this important topic will and must evolve as we learn more about the use of genetic information, NASA has no objection to the issuance of the version of the Executive order distributed for comment on January 12, 2000. Thank you for the opportunity to comment and participate in this review.



DETERMINED TO BE AN
ADMINISTRATIVE MARKING

INITIALS: ELC DATE: 05/11/12

2012-0463-5

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. fax	To: Mac Reed (partial) (1 page)	01/28/2000	P3/b(3)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 2]

2012-0463-S

rc756

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
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b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Central Intelligence Agency
Office of General Counsel
Washington, D.C. 20505

Date: 01/28/00

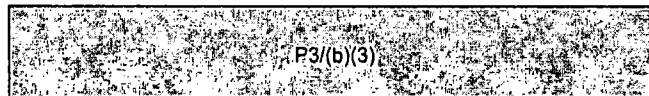
To: Mr. Mac Reed

Organization: Office of Information and
Regulatory Affairs

Phone: (202) 395-3563

Fax: (202) 395-7294

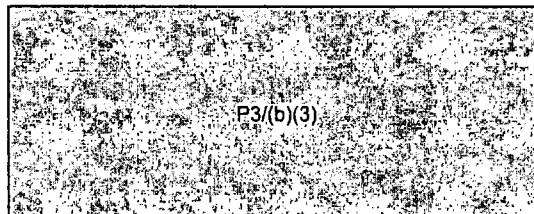
From:



(001a)

Organization: Office of General Counsel
Administrative Law & Ethics
Division

Phone:



Fax:

Number of Pages (Including Cover) 2

Comments:

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001b. letter	To: Mac Reed re: Exectuive Order (partial) (1 page)	01/28/2000	P3/b(3)

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Devorah Adler
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CENTRAL INTELLIGENCE AGENCY

WASHINGTON, D.C. 20505

Office of General Counsel

28 January 2000

VIA FACSIMILE

Mr. Mac Reed
Office of Information and
Regulatory Affairs
Office of Management and Budget
Washington, D. C. 20503

Reference: Revised Proposed Executive Order "To
Prohibit Discrimination in Federal Employment
Based on Predictive Genetic Information"

Dear Mr. Reed:

This is to convey this Agency's concurrence with the language in the referenced draft executive order. We still have serious concerns regarding the breadth of the definition of "protected genetic information" in section 1-201(e) of the draft, particularly in light of the fact that it has not been the subject of public debate. Nevertheless, because the exceptions provisions of section 1-301 respond to this Agency's equities, we can concur with this draft overall.

If we can provide any additional information or you have questions regarding CIA's equities or this response, please feel free to call me. You may reach me at

P3/(b)(3)

Sincerely,

P3/(b)(3)

200157

Original options

OPTION 1: ALLOWING FAMILY HISTORY (BUT NOT GENETIC TESTS) TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE

[1-201]

(e) Protected genetic information.

In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual **unless such information is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder.**

*medical exam
conditional
decision on
employment*

*employer
inquiring
about fam. history
no way for diagn. +
current condition
genetic test for
current condition
request but not
require.*

**OPTION 2: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE
COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF
CURRENT DISEASE**

[1-201]

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members
of the individual

(2) Protected genetic information does not include information, otherwise
included in subparagraph (1), that is used exclusively to determine if
further medical evaluation is needed to diagnose a current disease or
disorder.

OPTION 3: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE AND PROHIBITING COLLECTION AS A CONDITION OF EMPLOYMENT

[1-201]

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual

(2) **Protected genetic information does not include information, otherwise included in subparagraph (1), that is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder, provided that no individual may be required to furnish such information as a condition of employment.**

Withdrawal/Redaction Marker

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. list	re: contact info (partial) (1 page)	n.d.	P3/b(3)

COLLECTION:

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Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 2]

2012-0463-S

rc756

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
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C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
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- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

E.O. Genetic Discrimination

Name	Agency	Phone	Fax
Peter Swire	OMB/Privacy	395-1095	395-3047
Francis Collins	NIH/NIH/DHHS	301-496-0844	301-402-2347
Edward Frankle	NAHA	358-2450	358-2471 [002]
P3(b)(3)			
Lauren Steinfeld	OMB	202-395-3647	202-595-3047
STEVE AITKEN	OMB GC	202-395-4728	202-395-7294
Nancy Segal	EEOC	202-613-4037	202-613-8710
Paul Oetken	WH Counsel	456-6297	456-1647
Peggy Mastroianni	EEOC	663-4609	663-7126
Peter Gray	EEOC	663-4604	663-4638
Vicky Rovira	EEOC	663-4052	663-4110
Paul Zimmerman	Peace Corps	692-2150	692-2151
Julie Herr	State (Legal Advisor)	647-3280	736-7028
CEDRIC E. JUMONT, M.D.	STATE (Office Medical Director)	663-1611	663-1613
ERIC LIU	WH/OPC	456-5565	456-2878
Stacey Grundman	DOL/ASIP	219-6197	219-9216
Kaye Pestaina	DOL/PWBA	219-7222 x2312	219-5333
Jane Borvick	DOH DHHS	690 7450	690 8425
Kevin Maroney	DOL	693-4610	693-4644
Amy Turner	DOL / PWBA	219-7006	219-1942
DAN MAGUIRE	DOL / PWBA	219-9048	219-6531
Devon Abo	DOL	65707	65557
ROBIN LENHARDT	DOJ	514-1762	514-0563

Office of Science & Technology Policy
(OSTP)

FAX



Date:

Number of pages including cover sheet:

2

To:

Phone:

Fax phone:

CC:

Phone:

Chris JENNINGS

65557

From:

424 Old Executive Office Building
Washington, D.C. 20502

Phone:

202-456-7116

Fax phone:

202-456-6021

REMARKS:

☐ Urgent

☐ For your review

☐ Reply ASAP

☐ Please comment

**OSTP Comments on Draft
Executive Order**

Thank you for the opportunity to provide comments on the draft Executive Order to Prohibit Discrimination in Federal Employment Based on Protected Genetic Information. OSTP is pleased that the Executive Order is close to final agreement and hopes that it can be announced very soon. One possible venue is the annual meeting of the Genome Action Coalition, which has invited the President to appear as the keynote speaker. The meeting is scheduled for February 1, but there may be some flexibility to move it to February 2.

The first comment is that the title needs to be changed to read "Protected" instead of "Predictive." Other comments are as follows:

1-201(b) - the first "or" in the next to last line should be deleted.

1-201(e)(1)(C) - it was agreed at the Tuesday meeting that the term "condition" would be added, as has been done later in section 1-301(a). We would prefer to use "medical condition" or delete "condition" altogether to avoid confusion.

1-301(a)(2) and (3) - add "medical" as a qualifier for "condition."

1-301(a) - there ought to be a provision that prevents such information from being disclosed by the evaluator to anyone other than the applicant/employee.

1-301(a)(3) - we need to expand on "applicant" by inserting "employee" as the E.O. also guides post-employment practices.

1-301(c)(2) and (3) - something doesn't follow here - the employee needs to be told that the information exists, but he/she may not want to have the results. There must be notification of the availability of the information and opportunity provided to get it. The consent, then, precedes obtaining the genetic information.

1-402(d) - was supposed to have been deleted.

Edward A. Frankle, Esq.
General Counsel
NASA
Washington, DC 20546
(202) 358-2450

facsimile transmittal

To: Christopher Jennings, Deputy
Assistant to the President for Health
Policy **Fax:** 202-456-5557

From: Edward A. Frankle **Date:** 1/14/00

Re: Genetic Discrimination Executive
Order **Pages:** Cover plus 1

CC:

☒ Urgent ☐ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

Notes: For your request, NASA has reviewed the draft Executive order. The changes made in the most recent version address most of NASA's concerns. As explained in the enclosed memorandum from our medical staff to me, the current version presents no problem regarding the vast majority of our employees and has only small, but acceptable impacts on the astronaut corps as it currently exists. We do feel that when the time comes to begin selecting crews to go on long duration missions, such as to Mars or the moon, other problems may well arise. Those issues are, at least, several years in the future and are best addressed when they arise in a full factual context. Therefore, recognizing that policy on this important topic will and must evolve as we learn more about the use of genetic information, NASA has no objection to the issuance of the version of the Executive order distributed for comment on January 12, 2000. Thank you for the opportunity to comment and participate in this review.

**CONFIDENTIAL**

National Aeronautics and
Space Administration
Headquarters
Washington, DC 20546-0001



JAN 14 2000

Reply to Attn of:

UH

TO: G/General Counsel

FROM: UH/Director, Office of Health Affairs

SUBJECT: Proposed Executive Order to Prohibit Discrimination in Federal
Employment Based on Predictive Genetic Information

1. We have reviewed the revised draft of the proposed Executive Order. We believe that compliance with this order will not negatively impact our operations for our ground-based workforce, for those workers engaged in underwater activities, and for those individuals engaged in atmospheric flight operations.
2. With respect to operations in space, there is potential liability. Space is the most extreme and unforgiving environment into which humans have ever ventured. In space, small crews of people are utterly dependent on each another for survival, and failure of one for any reason may mean disaster for all. We have depended on strict selection standards to minimize the risk of medical problems during space missions and have been well served by this practice. For short duration missions, the proposed Executive Order will probably not negatively impact operations. During long duration missions, however, genetic traits that were latent at launch may manifest as disease, endangering not only the individual but also the entire crew. Inability to use predictive genetic information for flight assignment in this context may therefore represent a prohibitive risk.
3. We believe that an exception to this proposed Order applicable to the Astronaut Corps may ultimately be necessary to protect the health and safety of long duration space crews. We can, however, comply with the proposed order without untoward effect at present, for short duration space flight missions.

A handwritten signature in dark ink, appearing to read "Richard S. Williams".

Richard S. Williams, MD

OFFICE OF THE CHAIRWOMAN

U.S. Equal Employment Opportunity Commission

1801 L Street, N.W.

Washington, D.C. 20507

(202) 663-4001

(202) 663-4110

FACSIMILE COMMUNICATION

DATE: January 14, 2000

TO: Chris Jennings

ORGANIZATION: Executive Office of the President

FAX NO.: (202) 456-5557

SENDER: Louis Lopez

TELEPHONE NO.: (202) 663-4098

NO. OF PAGES
(INCLUDING COVER): 2

MESSAGE: Please see attached. Thanks.



U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION
Washington, D.C. 20507

Office of the
Chairwoman

January 14, 2000

Mr. Christopher W. Jennings
Deputy Assistant to the President for Health Policy
216 Old Executive Office Building
Washington, D.C. 20502

Re: Genetic Discrimination Executive Order

Dear Chris:

We have reviewed the January 11, 2000 draft of the referenced Executive Order as well as the comments that are being submitted by the Department of Labor (DOL). As the DOL submission states, the U.S. Equal Employment Opportunity Commission (EEOC) concurs with the comments set forth therein.

We write separately to address the language in section 1-103 of the draft Executive Order. Specifically, section 1-103 states that "[t]he Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services." The draft Executive Order further states in section 1-403 that it "does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person."

Based on these sections and earlier discussions at the meetings in your office, it is our understanding that the draft Executive Order contemplates that the EEOC will prepare guidelines or a policy statement concerning genetic discrimination in federal employment. We would prepare the guidelines with input from the same stakeholders who have participated in the drafting of the Executive Order. These guidelines would note, among other things, that although the Executive Order does not create any substantive or procedural right or benefits, federal employees and applicants may raise concerns regarding the use of genetic information within the context of the Rehabilitation Act, which the EEOC does enforce. Please let me know whether our understanding of the EEOC's role following execution of the Executive Order comports with yours.

Thank you for the opportunity to participate in the drafting of the Executive Order. If you have any questions concerning the foregoing, please do not hesitate to call me at (202) 663-4098.

Sincerely,

A handwritten signature in cursive script that reads "Louis Lopez".

Louis Lopez

Attorney-Advisor to the Chairwoman

Withdrawal/Redaction Marker

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
003a. fax	To: Christopher Jennings re: Draft Executive Order (partial) (1 page)	01/14/2000	P3/b(3)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 2]

2012-0463-S

rc756

RESTRICTION CODES

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FAX TRANSMITTAL / MESSAGE SHEET

TO:	(Organization, Name, Office Telephone, as needed)		
	Mr. Christopher C. Jennings Deputy Assistant to the President for Health Policy		
RECEIVING FAX NUMBER:		202/456-5557	
DATE TRANSMITTED:		14 January 2000	
ORIGINATING FAX NUMBER		P3/(b)(3) [003a]	
ORIGINATOR:		P3/(b)(3) Associate General Counsel, CIA	
SUBJECT: Draft Executive Order "To Prohibit Discrimination in Federal Employment Based on Predictive Genetic Information"			
NUMBER OF PAGES (Including This		2	
MESSAGE / REMARKS			

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003b. letter	To: Chris Jennings re: Exectuive Order (partial) (1 page)	01/14/2000	P3/b(3)

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- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

CENTRAL INTELLIGENCE AGENCY

WASHINGTON, D.C. 20505

Office of General Counsel

14 January 2000

Mr. Christopher C. Jennings
Deputy Assistant to the President
for Health Policy
216 Old Executive Office Building
Washington, DC 20502

Dear Mr. Jennings:

This is to convey this Agency's concurrence with the language in the 11 January 2000, 5:00 p.m. draft Executive Order "To Prohibit Discrimination in Federal Employment Based on Predictive Genetic Information." We still have serious concerns regarding the breadth of the definition of "protected genetic information" in section 1-201(e) of the draft, particularly in light of the fact that it has not been the subject of public debate. Nevertheless, because the exceptions provisions of section 1-301 respond to our equities, we can concur with this draft overall.

If we can provide any additional information or you have questions regarding CIA's equities or this response please feel free to call me or [REDACTED] P3(b)(3) number is [REDACTED] P3(b)(3) can reach me at [REDACTED] P3(b)(3)

Sincerely,

[REDACTED] P3(b)(3)

[00363]

U.S. DEPARTMENT OF JUSTICE
OFFICE OF LEGAL COUNSEL
WASHINGTON, D.C. 20530

FACSIMILE TRANSMISSION SHEET

DATE: 1/14/2000TO: Dever / Chris JenningsOFFICE PHONE: () 202-456-5560FROM: Robin Leubardt / Rosemary HuntOFFICE PHONE: () 514-1762 / 514-2027

NUMBER OF PAGES: _____ (NOT INCLUDING COVER SHEET)

FACSIMILE NUMBER: () _____

REMARKS:

Comments on EO attached. Draft still
being circulated within Justice. Will try
to obtain final sign on by Tuesday.
Thanks.

ANY QUESTIONS, PLEASE CONTACT DYONE MITCHELL OR LAWAN ROBINSON AT 514-2051
OFFICE OF LEGAL COUNSEL FACSIMILE MACHINE NUMBER - 514-0539 (FTS - 368-0563)

Attached is the latest version of the executive order for your final review before it is placed into formal OMB clearance.

This version reflects the changes that were discussed at yesterday's meeting. The significant revisions are summarized as follows:

1. 1-202(d) and 1-301(b) have been revised to reflect the fact that the order covers collection of genetic information from employees, not from family members or others;
2. 1-301(a) has been revised to contain the exception for collection of family history from both applicants and employees and to require that collection in both cases be consistent with the Rehab. Act and other applicable law;
3. 1-301(b)(1) has been revised to make more explicit that this exception applies in cases where employees receive genetic or health care services from the employee in cases other than simply job evaluation;
4. 1-301(b)(3) has been revised to disclosure of information for purposes of treatment, payment or health care operations;
5. 1-402(b) has been revised to carry out our intent with regard to the relationship between the order and the Privacy Act; and
6. 1-403(d) has been deleted to avoid suggesting that the order can be superseded by a more permissive disclosure rule.

Comments on this version are due by 5 pm Friday, January 14. Please fax them to our office at 456 5557.

DRAFT 01/11/00

Let justification only

Draft, Revised 1/11/00 -- 5:00 P.M.

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT
BASED ON PREDICTIVE GENETIC INFORMATION

By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

Section 1.

Nondiscrimination in Federal Employment on the Basis of
Protected Genetic Information

*under line
No bold.*

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

l.c. 1-102. The head of each Executive department and agency shall extend the policy set forth in ~~Section~~ 1-101 for all its employees covered by ~~Section~~ 717 of Title VII of the Civil Rights Act of 1954 as amended. *l.c.*

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services.

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Sec 2. Requirements Applicable to Employing Departments and Agencies *no bold*

1.201. Definitions.

- (1) The term "employee" shall include an employee, applicant for employment, or former employee covered by ~~Section~~ 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16). *l.c.*
- (b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, ~~in order~~ *such evaluation being made* to identify, evaluate, or respond to the effects of, ~~or control,~~ adverse environmental exposures in the workplace.
- (c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.
- (d) Genetic test means *fall within the definition of "genetic test"* the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites ~~are covered~~ when an excess or deficiency of the metabolite indicates the presence of a mutation or mutations.
- (e) Protected genetic information.
- (1) In general, protected genetic information means--

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(A) information about an individual's genetic tests;

(B) information about ^{the} genetic tests of ^{an individual's} family members ~~of the individual~~; or

(C) information about the occurrence of a disease or disorder in ^{an individual's} family members ~~of the individual~~.

- (2) Information about an individual's current health status (including information about sex, age, physical exams, and ^{analyses} chemical, blood, or urine analyses of the individual) is not protected genetic information unless it is described in subparagraph (1).

1-202. ^{The} agencies, ⁱⁿ discharging their responsibilities under this order, shall implement the following nondiscrimination requirements.

- (a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment ^{that} of the employee, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by ^{that} a family ^{employee's} member of such employee.
- (b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect ^{that} the employee's status, because of protected genetic information with respect to the employee or because of information

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about a request for or the receipt of genetic services by such employee or by ^{yet employee's} family member ~~of such employee.~~

(c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee, or information about a request for or the receipt of genetic services by such employee.

(c) The employing department or agency shall not disclose protected genetic information with respect to an employee, or information about a request for or the receipt of genetic services by an employee or by ^{an employee's} family member of an employee except --

(1) to the employee who is the subject of the information, at ^{his or her} the request of that employee ~~to whom disclosure is being made;~~

(2) to an occupational or other health researcher, if the research ^{that} is conducted in compliance ^{with} the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order, unless the court order also imposes confidentiality requirements; or

(4) to government officials investigating compliance with this ^{Executive} Order, ^{l.c.} if the information is relevant to the investigation.

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- e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records and kept separate from personnel files.

Sec. 3. ← Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in Section 1-202.

- (a) The employing department or agency may request or require information defined in 1-201(e)(1)(C) with respect to an applicant who has been given a conditional offer of employment or ^{to} an employee if:
- (1) the request or requirement is consistent with the Rehabilitation Act and other applicable law;
 - (2) the information obtained is to be used exclusively to assess ^{whether} further medical evaluation is needed to diagnose a current disease, condition or disorder; and
 - (3) such current disease, condition or disorder could prevent the applicant from performing the essential functions of the position held or desired.
- (b) The employing department or agency may request, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee if:

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- (1) the employee uses genetic or health care services provided by the employer (other than use solely connected with evaluation of fitness for employment);

- (2) the employee who uses the genetic or health care services ^{provided by the employer} has provided prior, knowing, voluntary, and written authorization to the employer to collect protected genetic information;

- (3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except: i) to the employee who uses the services; ii) for purposes of treatment, payment, or health care operations; or iii) pursuant to section 1-202(d) of this order; and

- (A) or
(B) and
(C) (4) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order. *i.e.*

- (c) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:

- (1) the employee has provided prior, knowing, voluntary, and written authorization;
- (2) the employee is informed of the specific results of the monitoring;
- (3) the employee is informed of any other protected genetic information that may have been acquired, provided that the employee has given prior, knowing, voluntary, and written consent to such additional disclosure;

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- (4) the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and
- (5) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.
- (d) This Executive Order ^{order} does not limit the statutory authority of a Federal agency ^{to} (1) ~~to~~ promulgate or enforce workplace safety and health laws and regulations, ^{to} (2) ~~to~~ conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations, ^{to} (3) ~~to~~ collect protected genetic information as a part of a lawful program, the exclusive purpose of which is to carry out identification purposes.

Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy, ^{to} and to this end shall designate a high level official responsible for carrying out its responsibilities under this Executive Order. ^{order}

1-402. Nothing in this Executive Order ^{order} shall be construed to:

- (a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or ~~the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.)~~ including coverage afforded to individuals under section 102 of Americans with Disabilities Act of 1990 and any other Federal statute;

^{other applicable laws}

This formulation is consistent with 1-301(a)(1) formulation. Also, the ADA does not apply.

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(b) limit the rights or protections of an individual under the Privacy Act of 1974 (5 U.S.C. 552a);

(c) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program; or

(d) supersede any other statute, regulation, or rule that requires disclosure of information.

1 403. This order clarifies and makes uniform Administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE

[DATE]