

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Donna I. Coleman (CN=Donna I. Coleman/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:10-JUN-1997 16:10:39.00

SUBJECT: Phone Message from Angie

TO: Clifford J. Gabriel (CN=Clifford J. Gabriel/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

CC: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

CC: Sybil Francis (CN=Sybil Francis/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

CC: Lisa M. Duffey (CN=Lisa M. Duffey/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Contact: AngieCompany: AESOP EnterprisePhone: (202) 675-4511FAX: Message: Terry Nipp would like to set up a teleconference on cloning. Participants include Roger Wyse and Ron Phillips. Nipps office will call again with possible date (probably 6/13) and time.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:10-JUN-1997 13:00:30.00

SUBJECT: Re: Cloning video

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:

Thanks - can we borrow the video for awhile before you have to return it?
(a day or 2 at most)

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Daniel L. Goroff (CN=Daniel L. Goroff/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:10-JUN-1997 17:54:08.00

SUBJECT: nbec

TO: eemanuel (eemanuel @ nih.gov @ inet [UNKNOWN])

READ:UNKNOWN

TEXT:

Hi Zeke,

Congratulations on a tough job well done with the Cloning Report! Yes, I am over here at OSTP for a while.

You had mentioned trying to have a meal together in DC sometime. Let me know what works. Best regards to all,

Danny Goroff
202-456-6003

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: eemanuel@NIH.gov (eemanuel@NIH.gov [UNKNOWN])

CREATION DATE/TIME:11-JUN-1997 10:02:52.00

SUBJECT:

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

To fellow NBAC Commissioners,

I want to say thank you to everyone for such a tremendous effort on the cloning report. I especially want to thank Harold--I have no idea ow you could do all the work on the report and fulfill your Princeton duties--amazing!

Having re-read the report I am confident in the next few weeks as people digest the contents and substance the insights and contribution will really shine.

Thanks again everyone.

Ezekiel J. Emanuel, M.D., Ph.D.
Dana-Farber Cancer Institute
Harvard Medical School
National Institutes of Health

(617) 632-2267--Boston
(773) 327-1763--Chicago
(301) 496-2429--Bethesda
(617) 632-2270 fax

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Holly L. Gwin (CN=Holly L. Gwin/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:11-JUN-1997 09:10:00.00

SUBJECT: Re: today's analysis

TO: rnishimi (rnishimi @ gwvi.gov [UNKNOWN])

READ:UNKNOWN

TEXT:

hmm, I like that way of thinking. BTW, I have scammed you a copy of cloning that may become very valuable because it's print quality identifies it as one of the first 2 books off the production line. I'll bring it tonight; I'm also bringing a book I got for you to take to HI and then stupidly left on the table at home when I came in Memorial Day.

rnishimi @ gwvi.gov
06/11/97 11:48:00 AM

Record Type: Record

To: hgwin

cc:

Subject: today's analysis

You and POTUS are the only humans on the face of the earth to have been present at the release of reports from his Committee/Commissions on the subject matter circles that we all generally move about in!! Seems pretty clear to me that the conclusion here is stick with Gwin to travel in the company of the leader of the free world.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Skip.Stiles@mail.house.gov (Skip.Stiles@mail.house.gov [UNKNOWN])

CREATION DATE/TIME:11-JUN-1997 11:17:57.00

SUBJECT: Web activity on cloning

TO: Jeffrey M. Smith (CN=Jeffrey M. Smith/OU=OSTP/O=EOP [OSTP])

READ:UNKNOWN

TEXT:

Check this out - one group is already running with the issue.

<http://www.all.org/cloning.htm>

Skip Stiles
Democratic Legislative Director
House Committee on Science
822 OHOB
Washington, DC 20515

(202) 225-8483

(202) 2260983 (fax)

committee home page - http://www.house.gov/science_democrats/

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:11-JUN-1997 10:47:01.00

SUBJECT: Re: Cloning Event

TO: Jonathan Foster (CN=Jonathan Foster/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

ok thanks

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: greider@cshl.org (greider@cshl.org [UNKNOWN])

CREATION DATE/TIME:11-JUN-1997 10:22:22.00

SUBJECT: Re: the president's legislation

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

>I also thought that Carol, who was upset by the slip in the original
>title of my draft bill, would be really delighted to see this called the
>Cloning Prohibition Act!!
>
>Alex
>

You guessed right alex, after I saw the title of clinton's bill i thought
yours was wonderful in comparison.

Perhaps this title might change if we asked nicely?
:)

Carol

Carol Greider, Ph.D.
Cold Spring Harbor Laboratory
P.O. Box 100
Cold Spring Harbor, NY 11724

Phone: (516) 367-8808
Fax: (516) 367-8815
E-mail: greider@cshl.org

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: acapron@law.usc.edu (acapron@law.usc.edu [UNKNOWN])

CREATION DATE/TIME:11-JUN-1997 15:29:54.00

SUBJECT: Tip o' the hat

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

I concur with Zeke (with special awe at Harold's editing and Kathi's manifold labors), and I agree we will get some praise for the way the material is laid out even if more time would have "been our ally" on the writing end. I hope we are also prepared for more criticism, esp. from the right-to-life end, but also, judging from the comments by Annas et al from the bioethicists who think we weren't sufficiently "ethical."

I also hope that the security of now having a "long life" ahead of us means that, with similar guarantees of stable (and more generous?) funding (doesn't someone owe us to replace the funds used on cloning report--even if they can't replace the hours of wear and tear--so we can complete the rest of this year's mandate?) will mean that the necessary staff can be hired promptly to make sure that future reports are less hectic and burdensome both for the commissioners and for our over-worked existing employees.

Alex

On Wed, 11 Jun 1997, Ezekiel Emanuel wrote:

> To fellow NBAC Commissioners,

>

> I want to say thank you to everyone for such a tremendous effort on the > cloning report. I especially want to thank Harold--I have no idea ow you

> could do all the work on the report and fulfill your Princeton
> duties--amazing!

>

> Having re-read the report I am confident in the next few weeks as people > digest the contents and substance the insights and contribution will really > shine.

>

> Thanks again everyone.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Skip.Stiles@mail.house.gov (Skip.Stiles@mail.house.gov [UNKNOWN])

CREATION DATE/TIME:11-JUN-1997 11:07:29.00

SUBJECT: CLONING

TO: Jeffrey M. Smith (CN=Jeffrey M. Smith/OU=OSTP/O=EOP [OSTP])

READ:UNKNOWN

TEXT:

Jeff,

We are working on the issue up here and I wanted to pass on a few items. First, your west wing conversation has prompted a series of phone calls to us from the leg staff trying to figure out what is going on and whether George Brown will cosponsor the bill! Good Work.

A read of the bill shows that it probably will not even come to our committee. It looks like a Commerce and Judiciary bill in the House (the latter due to the penalties). You might want to think about sponsors on those committees as well.

But the issue of sponsorship gets complicated by the right to life issue - if I am Phyllis Schlafley, I want this bill to move. First, there is nothing now putting a ceiling on the private sector - without this bill they can do anything they want. So, I want to move the bill but (Second reason) I want to define what it means to "create a human being" as mentioned in Section 5. The chance to define the moment of creation is too good to pass up. Also, I do not want the private sector to be able to create humanoids without the "intent of transfer to the human womb or create a human being" (again section 5) - something that would be allowed under this bill. (A paranoid right-to-lifer can envision biotech companies growing human embryos in culture and allowing them to develop to the point that they can be harvested for their pre/neonatal cells to be used in human therapies. This would be allowed under this bill - since the bill deals with somatic cell transfer and involves an intent to create a human being. So if I am the paranoid person above, I start messing with this bill to stop that.) Anyway, if these folks get fully engaged, you lose some Democrats (Dingell comes to mind) who are sensitive on these issues.

But, we need to probe this a little farther. First, we are discussing how and whether to raise these issues at our hearing tomorrow on the issue. We may want to start flagging these points for people - or we may want to just stay away from them, I don't know at this point. Second, we are not sure whether Morella wants to move the Ehlers bill along and whether anyone has an idea of how it plays after we move the Ehlers bill (which is a federal funding ban) or what Ehlers wants to do to broaden his bill (he has mentioned in the press that he may want a wider ban to include the private sector).

I am meeting with a biotech person in a few minutes to get some intelligence from the private sector. The university folks need to be felt out on this as well.

Anyway, this is a very complicated issue and needs some thought and discussion before we move forward to introduction. We need to figure our way back from the end game and try to guess what the opposition might do. Lets share some ideas tomorrow morning.

Skip Stiles
Democratic Legislative Director
House Committee on Science
822 OHOB
Washington, DC 20515

(202) 225-8483
(202) 2260983 (fax)

committee home page - http://www.house.gov/science_democrats/

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: acapron@law.usc.edu (acapron@law.usc.edu [UNKNOWN])

CREATION DATE/TIME:11-JUN-1997 15:31:26.00

SUBJECT: Re: the president's legislation

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])

READ:UNKNOWN

TEXT:

On Wed, 11 Jun 1997, Carol Greider at Cold Spring Harbor Laboratory wrote:

>
> >I also thought that Carol, who was upset by the slip in the original
> >title of my draft bill, would be really delighted to see this called
the > >Cloning Prohibition Act!!

> >
> >Alex

> >
>
>
> You guessed right alex, after I saw the title of clinton's bill i
thought > yours was wonderful in comparison.

>
> Perhaps this title might change if we asked nicely?
> :)
>
> Carol

Once the White House has lined up sponsors for the Bill, we can work with them to get amendments considered. If we know early enough who that is, the modifications might be made in the language before it is introduced; more likely, we'll have to try to get the sponsors to put forward amendments in the mark up process in the committee. Some people on the hill think that this is an attractive "hot button" issue for some conservatives, so the legislative process may move quickly; others note that Congress is tied in knots over bigger issues, this issue may get stalled. Of course, Im hoping for the latter!

Alex

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:11-JUN-1997 16:28:08.00

SUBJECT: Thanks and a request: Re: VP Excerpted Remarks during Science and Math Presidential Awards

TO: Roger V. Salazar (CN=Roger V. Salazar/O=OVP @ OVP [UNKNOWN])

READ:UNKNOWN

TEXT:

Thanks! Dr. Gibbons is also interested in obtaining a copy of the VP remarks at the NBAC Cloning Event on June 9 - is it possible for you to email me that? Thanks in advance. Susie Bachtel

P.S. it just occurred to me - if you have an email listserve for VP releases may I be added? sbachtel@ostp.eop.gov

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Timothy L. Newell (CN=Timothy L. Newell/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:11-JUN-1997 12:41:36.00

SUBJECT: Another request for Cloning Report

TO: Jeffrey M. Smith (CN=Jeffrey M. Smith/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:
This looks like your bailiwick...

----- Forwarded by Timothy L. Newell/OSTP/EOP on 06/11/97
12:41 PM -----

Kevin S. Moran

06/11/97 10:41:30 AM

Record Type: Record

To: Timothy L. Newell/OSTP/EOP
cc:
Subject: Another request for Cloning Report

Tim... We are getting requests for on-line versions of the cloning
report. Is that something that your office has available for us to put on
the web?

----- Forwarded by Kevin S. Moran/WHO/EOP on 06/11/97
10:41 AM -----

WEBMASTER @ A1
06/11/97 10:09:00 AM

Record Type: Record

To: Kevin Moran, Lori Anderson
cc:
Subject: Another request for Cloning Report

===== ATTACHMENT 1 =====

ATT CREATION TIME/DATE: 0 00:00:00.00

TEXT:

From: ds691407@bcm.tmc.edu@INET@EOPMRX@LNGTWY

*To: webmaster@A1@CD@LNGTWY

Date: 6/9/97 11:56am

Subject: White House WWW Comments

[Connection Information]

CLIENT: EXPRESS.SSCTR.BCM.TMC.EDU[128.249.27.60]

BROWSER: Lynx/2.7 libwww-FM/2.14

URL: http://www.whitehouse.gov/WH/html/briefroom-plain.html

[Sender Information]

PERSONAL-NAME: David

EMAIL-ADDRESS: ds691407@bcm.tmc.edu

ORGANIZATION:

RELATIONSHIP:

[Message Information]

PURPOSE: Suggest an improvement

TOPIC: Content

AFFILIATION: Private Citizen

SUBJECT: Cloning report

[Message]

Would it be possible to make available on this website the full text of the cloning report? I understand that it's about 100 pages or so, but, still, it would be nice to have it available in HTML format. Thanks.

===== END ATTACHMENT 1 =====

===== ATTACHMENT 2 =====

ATT CREATION TIME/DATE: 0 00:00:00.00

TEXT:

RFC-822-headers:

Received: from conversion.pmdf.eop.gov by PMDF.EOP.GOV (PMDF V5.0-4 #6879)

id <01IJVBMT7MB4001QDC@PMDF.EOP.GOV> for webmaster@al.eop.gov; Mon, 09 Jun 1997 13:08:02 -0500 (EST)

Received: from storm.eop.gov (storm.eop.gov)

by PMDF.EOP.GOV (PMDF V5.0-4 #6879) id <01IJVBMOYCDC001NPI@PMDF.EOP.GOV> for webmaster@al.eop.gov; Mon, 09 Jun 1997 13:07:56 -0500 (EST)

Received: from www1.whitehouse.gov ([198.137.240.91])

by STORM.EOP.GOV (PMDF V5.1-7 #6879)

with SMTP id <01IJVBMGWUC4002PK4@STORM.EOP.GOV> for webmaster@al.eop.gov; Mon,

09 Jun 1997 13:07:45 -0400 (EDT)

Received: by www1.whitehouse.gov (951211.SGI.8.6.12.PATCH1042/940406.SGI.AUTO)

for feedback id MAA14967; Mon, 09 Jun 1997 12:56:42 -0400

Apparently-to: feedback@Whitehouse.GOV

Errors-to: The Postmaster <postmaster@www1.whitehouse.gov>

Keywords: WWW-Correspondence; ; Suggest an improvement; Content; Private
Citizen;

Comments: Forwarded from White House WWW

===== END ATTACHMENT 2 =====

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:13-JUN-1997 11:23:30.00

SUBJECT: Re: [XOTA:409] OTA Reports Available

TO: kirsi (kirsi @ worldnet.att.net [UNKNOWN])
READ:UNKNOWN

CC: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

CC: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:

Dear Kirsten: Rachel Levinson, OSTP's Assistant Director for Health/Life Science, is desperately seeking hard copies of the Biotech Report Series - papers 1-5, esp. Public attitudes toward biotech, Ownership of tissues and cells, etc. Would be a big help to us - she is our point person on the National Bioethics Advisory Commission that overlaps with these issues. Thanks a million. Let me know. Susie Bachtel (202) 456-7116. (am sure we can arrange to pick them up to save you cost of mailing - or we can reimburse you)

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:13-JUN-1997 11:02:01.00

SUBJECT: Re: Denver Communique

TO: Laura L. Efros (CN=Laura L. Efros/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Looking at this morning I realized that it still has problems, such as the title. Just called Elizabeths and we would rppose something along the lines of new cloning technology and adding genetic to replication of human individuals. And correcting the typo on "closing"!

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: lhmiike@mail.health.state.hi.us (lhmiike@mail.health.state.hi.us [UNKNOWN])

CREATION DATE/TIME:13-JUN-1997 15:22:46.00

SUBJECT: proposed federal legislation

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

A few comments on the proposed legislation

I agree with Alta and others who pointed out that (deliberately or not?) section 3(a) leaves open the interpretation that cloning embryos for research would be covered by the phrase "create a human being". From the Commission's standpoint, we made it clear that we were addressing only live births, so I would favor changing the language to something like: "to prohibit any attempt using somatic cell nuclear transfer cloning to create a child." This would be consistent with the language we use in the report, and in my mind, is sufficient to distinguish "child" from "embryo."

Section 4(c), definition of "somatic cell nuclear transfer": in the report, on page one of the Executive Summary, we define this as "using nuclei derived from somatic cells other than those of an embryo or fetus" (which I like; I had concerns at the last meeting to include embryo and fetal-derived cells in the definition, but decided not to prolong the discussion on that point). Should we recommend using the report's definition? Are we prepared to deal with the implications of using one definition versus the other?

Section 5: language on "or in any other way creating a human being." I recommend either deleting this phrase, or changing "human being" to "child," for the same reason as stated above.

Section 6(1): I would replace "the use of somatic cell nuclear transfer or other cloning technologies" with "cloning technologies". This would match the definition of "cloning" in section 4(a). So the revised section would read: "(1) cloning of molecules, DNA, cells, and tissues;" The next sentence would be unchanged.

larry

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Jeffrey M. Smith (CN=Jeffrey M. Smith/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:13-JUN-1997 09:08:30.00

SUBJECT: Cloning legislation

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Rachel -- would you be good enough to send JHG (with a cc to me) a nutshell description of the 6/12 Morella hearing, what might be anticipated at the upcoming Frist hearing , and the legislative outlook for the days ahead? He may be meeting with press next week and should be kept informed so he can be responsive to any questions. Or, if you prefer, tell me, and I'll knock out a paragraph or two. Thanks.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Laura L. Efros (CN=Laura L. Efros/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:13-JUN-1997 10:13:11.00

SUBJECT: Denver Communique

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Rachel,

Have you seen the cloning paragraph for the Denver Summit? It's at the end of this message.

Laura

----- Forwarded by Laura L. Efros/OSTP/EOP on 06/13/97
10:12 AM -----

Sherman G. Boone

06/13/97 09:25:24 AM

Record Type: Record

To: Elizabeth Drye/OPD/EOP, dhohman @ os.dhhs.gov @ INET @ LNGTWY, Laura L. Efros/OSTP/EOP

cc:

Subject: Denver Communique

Proposed re-writes for Denver Communique. Please let me know IMMEDIATELY if you have any problems with these paragrpahs. Thanks.

Infectious Diseases

26. Infectious diseases, including childhood pneumonia, diarrhea, tuberculosis, malaria, and HIV/AIDS are responsible for a third of all deaths in the world. They pose significant challenges to the health, security and financial resources of the global community. In many parts of the world, infectious diseases and deaths from infectious disease have risen sharply in the last decade for a variety of reasons, including the emergence of drug-resistant microbes and the increased movement of people and products. In the coming year, our governments will promote more effective coordination of international responses to outbreaks; promote development of a global surveillance network, building upon existing national and regional surveillance systems; and help to build public health capacity to prevent, detect and control infectious diseases globally. Central to this work will be strengthening and linking existing activities in and among each of our countries, in other fora, and through the World Health Organization.

28. Preventing the transmission of HIV infection and the development of AIDS is an urgent global public health imperative. While other prevention

and treatment methods must be pursued, in the long term the development of safe and effective vaccines against AIDS holds the best chance of limiting, and eventually eliminating, the threat of this disease. We will work to provide the resources necessary to accelerate AIDS vaccine research, and together will enhance international scientific cooperation and collaboration. Cooperation among scientists and governments in the developed and developing world and international agencies will be critical. We call on other states to join us in this endeavor.

29. The Joint United Nations Program on HIV/AIDS (UNAIDS) must help expand the scale and quality of the response to HIV/AIDS. As a group and with others, we will work to assure that it has resources adequate to fulfill its mandate.

Reproductive Human Cloning

39. We have taken note of recent successful cloning of an adult sheep, which could open the way to the use of cloning for the replication of human individuals. While recognizing the considerable benefits for basic research, agriculture and human health from cloning technology, we regard the deliberate cloning of human beings as ethically unacceptable. We are encouraged by the serious attention being given to the ethical implications of this technology by both national and international bodies. This will enable a measured approach to the debate on which uses of this technique are, and which are not, unacceptable. We support international cooperation to enforce common aspects of national policies on the use of cloning to create human beings.

RECORD TYPE: PRESIDENTIAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:13-JUN-1997 09:39:12.00

SUBJECT: Re: Sorry, but could you put your clips request in writing?

TO: Teresa Wildman (CN=Teresa Wildman/OU=WHO/O=EOP @ EOP [WHO])

READ:UNKNOWN

CC: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Teresa - any feedback yet? I had to scrounge fast last weekend for a clip from the NYT that the POTUS wanted that day for the cloning event. We would appreciate starting the weekend clips/WH magazine asap. With much appreciation! Sue

----- Forwarded by Susanne Bachtel/OSTP/EOP on 06/13/97
09:37 AM -----

Susanne Bachtel

06/06/97 01:09:53 PM

Record Type: Record

To: Teresa Wildman/WHO/EOP

cc: Jodie R. Torkelson/WHO/EOP

Subject: Re: Sorry, but could you put your clips request in writing?

Dear Teresa: Thanks for your note. Sorry for the delay in response; I was awaiting some feedback from one of our staff.

This is Dr. Gibbons's request:

1. Cancel the WH daily clips addressed to Ernie Moniz
2. Change the WH daily clips addressed to Tim Newell -
readdress them to Dr. Gibbons - send to
Dr. Gibbons's office - Room 424 OEEOB (Dr.
Gibbons's office)
3. Add WH weekend clips - address to Dr. Gibbons - send
to Room 424 OEEOB
4. Add WH magazine clips - address to Dr. Gibbons - send
to Room 424 OEEOB

Many thanks, Susie

Bachtel, Ext 6-7116

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: maienschein@asu.edu (maienschein@asu.edu [UNKNOWN])

CREATION DATE/TIME:16-JUN-1997 10:50:40.00

SUBJECT:

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])

READ:UNKNOWN

TEXT:

Thank you so much for finding the time in your busy schedule to meet with my students on Friday. They very much appreciated the chance to talk to a "real person" who is involved with the cloning issues and other biological issues. They asked me to ask you whether there are internships possibilities working with your office since most of them are biology majors and some are interested in medical careers -- but not simply as doctors. They are all deeply interested in issues of science and society, and they are eager to learn.

Perhaps your schedule will become less hectic and you and I might meet at some point. I am in and out of town this summer, serving as "science advisor" for Congressman Matt Salmon, then will be here most of the fall and next spring. My job is to increase communication between Washington and Arizona State, and I could learn a lot from you -- if you have time at some point.

Thanks again. Jane Maienschein

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: kirsi@worldnet.att.net (kirsi@worldnet.att.net [UNKNOWN])

CREATION DATE/TIME:16-JUN-1997 08:50:37.00

SUBJECT: Re: [XOTA:409] OTA Reports Available

TO: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TEXT:

Am not sure I have any of the biotech reports but will check and let you know

Kirsten

At 15:27 13-6-97 +0000, you wrote:

>
>
>
>
>
>
>
>
>
>

>Susanne Bachtel

>06/13/97 11:27:23 AM

>
>

> Record Type: Record

>
>
>

> To: kirsi @ worldnet.att.net

>

> cc: Rachel E. Levinson/OSTP/EOP, Susanne Bachtel/OSTP/EOP

> Subject: Re: [XOTA:409] OTA Reports Available

>
>

> Dear Kirsten: Rachel Levinson, OSTP's Assistant Director for

>Health/Life Science, is desperately seeking hard copies of the Biotech

>Report Series - papers 1-5, esp. Public attitudes toward biotech,

Ownership

>of tissues and cells, etc. Would be a big help to us - she is our point

>person on the National Bioethics Advisory Commission that overlaps with

>these issues. Thanks a million. Let me know. Susie Bachtel (202) 456-

>7116. (am sure we can arrange to pick them up to save you cost of mailing

>- or we can reimburse you)

>
>
>

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:16-JUN-1997 16:13:18.00

SUBJECT: see text

TO: Jeffrey M. Smith (CN=Jeffrey M. Smith/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:

The following is on h:\lifesci\cloning.tec

On June 12, Rep. Morella (R-MD) chaired a hearing of the House Technology Subcommittee to review the recommendations of the National Bioethics Advisory Commission regarding cloning of human beings. The Commission concluded that &at this time, it is morally unacceptable for anyone in the public or private sector, whether in a research or clinical setting, to attempt to create a child using somatic cell nuclear transfer cloning,⁸ the technology used in Scotland to create Dolly the sheep.

Members of Congressional supported the Commission,s conclusion and recommendation to enact federal legislation to enforce the existing ban on the use of federal funds for cloning human beings. However, some, Reps. Sensenbrenner and Ehlers, in particular were critical of the proposal that such legislation sunset after a period of time in which the ethical and scientific issues more thoroughly explored. The Administration,s bill, introduced on June 7, the day NBAC,s report was released, tracks closely the Commission,s recommendations, including the sunset provision. The Administration proposed NBAC would complete a status report and review of the ethical and scientific implications six months prior to a five-year sunset. Even some who oppose on ethical grounds the creation of children via somatic cell nuclear cloning endorse a sunset because new benefits may alter the equation in the intervening years.

When asked his view of the procedures that would or would not be captured in the definitions of the Administration bill, Dr. Harold Varmus indicated his satisfaction with the bill language. In supporting a sunset clause, he noted that future advances in science might restricted and justify revising the legislation.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:16-JUN-1997 10:14:00.00

SUBJECT: Re: [XOTA:409] OTA Reports Available

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

FYI re the OTA reports.

----- Forwarded by Susanne Bachtel/OSTP/EOP on 06/16/97

10:13 AM -----

kirsi @ worldnet.att.net

06/16/97 08:45:13 AM

Record Type: Record

To: sbachtel

cc:

Subject: Re: [XOTA:409] OTA Reports Available

Am not sure I have any of the biotech reports but will check and let you know

Kirsten

At 15:27 13-6-97 +0000, you wrote:

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>Susanne Bachtel

>06/13/97 11:27:23 AM

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Record Type: Record

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To: kirsi @ worldnet.att.net

cc: Rachel E. Levinson/OSTP/EOP, Susanne Bachtel/OSTP/EOP

> Subject: Re: [XOTA:409] OTA Reports Available

>

>

>

> Dear Kirsten: Rachel Levinson, OSTP's Assistant Director for
>Health/Life Science, is desperately seeking hard copies of the Biotech
>Report Series - papers 1-5, esp. Public attitudes toward biotech,
Ownership

>of tissues and cells, etc. Would be a big help to us - she is our point
>person on the National Bioethics Advisory Commission that overlaps with
>these issues. Thanks a million. Let me know. Susie Bachtel (202) 456-
>7116. (am sure we can arrange to pick them up to save you cost of mailing
>- or we can reimburse you)

>

>

>

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Audrey J. Lee (CN=Audrey J. Lee/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:16-JUN-1997 11:24:40.00

SUBJECT: cloning

I've finished the background summary for cloning and will begin work on the background summary for global-scale issues.

Audrey

TO: David Heyman (CN=David Heyman/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Sarah S. Knight (CN=Sarah S. Knight/OU=WHO/O=EOP [UNKNOWN])

CREATION DATE/TIME:16-JUN-1997 16:12:57.00

SUBJECT: Cloning

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Rachel,

Can you help me update the Cloning form letter? Thanks. Sarah x65514

This is what we had before:

Cloning form letter

Thank you for writing to me regarding the issue of cloning. I appreciate knowing your views on this matter.

The recently reported breakthrough in animal cloning brings with it both promise and concern. That is why I asked our National Bioethics Advisory Commission, headed by Princeton University President Harold Shapiro, to conduct a thorough review of the legal and ethical issues raised by this new cloning technology and to recommend possible actions to prevent abuse of the technology. I look forward to receiving the Commission's report.

On March 4, I issued a directive that bans the use of any federal funds toward cloning human beings or research related to cloning of humans. I also strongly urged the private sector to follow suit with a self-imposed moratorium on human cloning research, ensuring that, as the scientific community continues its work, we will carefully weigh the concerns of faith, family, philosophy, and values, and not merely those of science alone.

I appreciate your interest in this important issue.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Laura L. Efros (CN=Laura L. Efros/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:17-JUN-1997 17:59:31.00

SUBJECT: more Denver Summit stuff

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Rachel,

I just received a copy of a fact sheet on cloning for the Denver Summit.
I assume you've seen it. (I imagine you probably wrote it.) If not, do
you need a copy?

We also just received a request through the NSC system for Q&A's for the
President's press conference on Sunday. They are due by noon tomorrow.
Let me know if you want me to send anything down with the EID stuff.

Laura

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: greider@cshl.org (greider@cshl.org [UNKNOWN])

CREATION DATE/TIME:17-JUN-1997 21:46:54.00

SUBJECT: Re: Sheri Alpert and genetic privacy

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])

READ:UNKNOWN

TEXT:

OK I'll bite:

And I agree with alex/larry/steve that genetic information not a distinct species of information.

I will need to look at Sheri Alpert's proposed paper again in more detail. But it seemed to me to be mostly a theoretical treatment of genetic privacy in general, rather than specific to the stored tissue issue. I think I'd need to be reminded of the papers that we have already asked for to understand where this one fits.

Didn't we say we would like to see an analysis of the various positions and arguments regarding stored samples that are already out there in the literature? did we get someone to do this?

Is Sheri's proposed paper covering an area we had set out to cover? or should we ask her to focus on one of those areas specifically where we felt we needed more info? Sorry I do not have the list of papers to commissions that we decided earlier at hand here at home.

Carol

PS Steve- sure I'll talk about cloning with you. what is there left to say?

Carol Greider, Ph.D.
Cold Spring Harbor Laboratory
P.O. Box 100
Cold Spring Harbor, NY 11724

Phone: (516) 367-8808

Fax: (516) 367-8815

E-mail: greider@cshl.org

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: greider@cshl.org (greider@cshl.org [UNKNOWN])

CREATION DATE/TIME:17-JUN-1997 21:35:10.00

SUBJECT: the cloning report and the Web site

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:
Hi everyone,

I appreciate that others, like me, are just now digging out from under the piles of paper that accumulated during the Dolly days (Dolly daze?).

But I would really appreciate it if the Cloning report were on the web. I have told many people that it would be up by the end of last week, and they keep bugging me about it.

thanks very much.

:)

Carol

Carol Greider, Ph.D.
Cold Spring Harbor Laboratory
P.O. Box 100
Cold Spring Harbor, NY 11724

Phone: (516) 367-8808
Fax: (516) 367-8815
E-mail: greider@cshl.org

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Audrey J. Lee (CN=Audrey J. Lee/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:17-JUN-1997 09:20:28.00

SUBJECT: Cloning Issue

I am working with Dave Heyman on providing background information on the cloning issue for the Carnegie Meeting. I was wondering if you have any information on Congressional action/debate on this subject since March. If so, please let me know, and I can come to pick it up.

Thank you,
Audrey Lee

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: holtzman@mpi.com (holtzman@mpi.com [UNKNOWN])

CREATION DATE/TIME:17-JUN-1997 21:25:02.00

SUBJECT: Re: Sheri Alpert and genetic privacy

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

agree with alex/larry, re: genetic info not a distinct species of information. also agree with larry that issue of stored samples, particularly those collected in routine pathological procedures (which will constitute the "future stored tissue samples), if driven by setting public benefit vs. other interests of which privacy is but one...which then leads into the kind of analysis alex embarks on in the latter half of his memo.

....anyone want to talk about cloning?

-steveAt 02:32 PM 6/17/97 -1000, you wrote:

>Tom Murray wrote:

>>

>> Dear colleagues,

>>

>> This is directed especially to the members of the Genetics Subcommittee, but

>> I welcome comments from all commissioners. Sheri Alpert has been detailed >> to the Commission from another federal agency until September. She is most >> knowledgeable about public policy with respect to privacy. In speaking with

>> her about what she could do to help the Genetics Subcommittee, we agreed >> that a background paper on aspects of genetic privacy would be useful. What >> follows is her brief description of the proposed paper. I would appreciate >> your comments on her proposal.

>>

>> Tom

>>

>> (from Sheri Alpert):

>>

>> >Privacy interests in genetic information

>> >

>> > I propose to look at some of the various privacy interests at stake

>> in personal genetic information. As articulated by various court decisions,

>> the judiciary has generally recognized three separate privacy interests -

>> autonomy, freedom from intrusion, and informational privacy. I would >> propose to start with that framework, expanding the interests implicated as

>> need be. For instance, to capture the notion of "being wronged" (as a

>> negative privacy interest), I would probably expand the framework to include

>> issues of justice. (To a large extent, the justice and autonomy interests

>> are where issues of "group privacy" will arise.) Within each of the

>> interests articulated, I will also describe the practical mechanisms used to

>> mitigate possible infringements on these interests (e.g., informed consent

>> addresses some of the autonomy interests; "fair information practices"

>> address some of the informational privacy interests; etc.), as well as some

>> of the public policy mechanisms currently in place to implement them (e.g.,

>> 45 CFR 46). Whether these mechanisms and policies are adequate for genetic

>> information is the key set of public policy issues. (Whether that is something I explicitly address in the paper, or defer on, is up to you, although that evaluation could be very useful.)

>> >

>> > What this means for the paper I would do for the NBAC is that I

>> will start with a broad overview of the privacy interests in genetic information generally, and move that discussion into the contextual setting

>> of stored tissue samples. Depending on the time necessary to complete the

>> analysis, it might also be useful to look at an organization that is in the

>> process of considering how to address the privacy interests in a tissue

>> banking context. For instance, I could approach officials at the National

>> Center for Health Statistics (the agency which administers the NHANES

>> surveys). NCHS is currently in the process of designing NHANES-4, and is

>> explicitly considering the privacy issues at stake in the collection and

>> storage of tissue samples, particularly for future genetic analysis. (There

>> are also NIH institutes or other CDC components that could be approached,

>> although their tissue storage efforts are probably not as broad in scope

>> and

>> coverage as NHANES.)

>> >

>> > It is also important to recognize that many of the privacy interests at stake, particularly with genetic information, are highly

>> contextual in nature. For instance, the sensitivity of these interests will

>> intensify dramatically, as genetic information is computerized (e.g., as

>> part of the patient medical record or in a linked research protocol). However, this whole issue may be fodder for another paper that addresses

>> more generally issues of the management of personal genetic information.

>> (This would also be an appropriate paper in which to discuss the merits of

>> treating genetic information as another part of a patient's general medical

>> information, or treating genetic information as distinct. At least some of

>> the pending legislation in Congress sees genetic information as distinct --

>> e.g., S. 422, "The Genetic Confidentiality and Discrimination Act of 1997.")

>> Thomas H. Murray, Ph.D.

>> Center for Biomedical Ethics

>> School of Medicine
>> Case Western Reserve University
>> 10900 Euclid Avenue
>> Cleveland, OH 44106-4976
>> Phone: 216/368-6206 Fax: 216/368-8713
>> thm2@po.cwru.edu

>I agree with Alex on not treating genetic information differently from
>other medical information, and that was the general conclusion that the
>commission had (informally) reached. However, I have no objections for
>providing alternative analyses in the paper, since, if we continue to
>believe there should be no difference, we should be up to challenging
>the analysis and conclusions. On the public policy aspects, I would
>expect the paper to address them; otherwise, the analysis would be
>incomplete for our purposes.

>
>My larger question is the place of this proposed analysis in our work on
>stored tissue samples. Privacy is important, but only one issue.
>Perhaps it has been too long since we were on the topic, but I am
>primarily interested in where we are going on stored tissue samples, and
>how we are going to get there. I guess the primary purpose of the
>journey is on: 1) how to maximize the public benefit derived from use of
>stored tissue samples; 2) with an important aspect being the rights and
>benefits/harms to the people from whom the tissue samples were taken
>(including relatives, related groups, etc. who are affected). Privacy
>would fall in the latter category of issues, which I would classify as
>an important consideration, but not the primary objective of our
>journey. Am I being clear? We want to derive maximum public benefit
>from use/research of/on stored tissue samples, while remaining cognizant
>of the potential benefit/harm to the individuals from which they are
>derived, and protecting/benefitting as best we can the individuals
>affected.

>larry

>
>
>
>

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: acapron@law.usc.edu (acapron@law.usc.edu [UNKNOWN])

CREATION DATE/TIME:17-JUN-1997 14:38:40.00

SUBJECT: Re: Sheri Alpert and genetic privacy

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

Tom:

Thanks for sharing Sheri's proposed research with the full NBAC. I would be happy to discuss the following with Sheri if she wishes. I think her outline is interesting, but do have comments on two aspects:

I. SHOULD WE TREAT GENETIC PRIVACY AS DISTINCT FROM OTHER MEDICAL PRIVACY?

I seem to recall that NBAC discussed the issue that Sheri gets to at the end of her outline--whether genetic information is distinct from other medical information--and I THOUGHT we were inclined not to go for the "distinct" view. Perhaps I misremember. In any case, I would urge that nothing we do--or that we have her do--commits us to the "genetic info is distinct" position, which at this point I believe to be mistaken and potentially harmful.

Two arguments against the "distinct" approach:

1. It is a waste of effort trying to figure out what information is "genetic" in the first place.
2. The impulse to have separate rules comes from a phenomenon I labelled long ago as the "genecity" of topics like this--the tendency of the novel "genetic" aspects to elevate concerns. Like some of the public fear of cloning--which derived from its novelty-- a good deal of the concern about genetic information also steps from novelty; part of our objective could be to show that it is the general risk of medical information becoming "unprivate" that is troublesome not genetic information specifically.

II. THE "AUTONOMY" ASPECTS OF "PRIVACY"

I would caution Sheri NOT to get confused, under the "autonomy" heading by the Supreme Court's former use of "privacy" to mean constitutionally protected decisional freedom (which now is more likely to be described as a protected liberty interest). The privacy label stemmed, I think, from the facts of *GRISWOLD v. CONN.*

There is also--as I think she may be getting at--an older notion (somewhat inchoate in the cases, but there in philosophical analysis of the interests involved) that maintaining control over information about ourselves is part of the way we maintain autonomy in our lives and thereby determine the kind of people we are. This is a more sophisticated notion

than the other way in which (unwanted) disclosure of information interferes with autonomy: when someone (say an insurer) has access to information they may act towards us in a way we don't like and prevent us from carrying out a choice we have made (such as, to buy insurance).

The more sophisticated "autonomy" interest does not depend on such direct acts contrary to the person's interest, but instead relates to the way that information "shapes" a person. One somewhat novel aspect here is the way in which information that is thrust upon a person (from a genetic test, for example) may shape them in ways they don't want to be shaped. In that case, the "information" has two aspects: that which is HIDDEN in the person's genes already and that which is contained in the report on what is shown by the analysis of the genes. Even if the latter information (the test results) are kept "private" (ie not disclosed to others, such as insurers, with whom the person does not want to share the information) the person may still feel that a breach of "privacy" has occurred when the "hidden" (ie, not scientifically known) genetic information is revealed even to the person him or herself. I would be interested to know whether Sheri finds any "legal" materials that take account of this interest (which, again, is not unique to the "genetic" realm at all).

I hope these comments are helpful to the genetics group and to Sheri, Alex

 * Alexander M. Capron acapron@law.usc.edu *
 * Henry W. Bruce Professor of Law (213) 740-2557 (voice) *
 * University Professor of Law and Medicine (213) 740-5502 (fax) *
 * University of Southern California (213) 740-0149 (fax) *
 * Los Angeles, CA 90089-0071 *

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:18-JUN-1997 09:50:22.00

SUBJECT: Re: more Denver Summit stuff

TO: Laura L. Efros (CN=Laura L. Efros/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

I will attach the Qs and As we did for the cloning event last week. I have cleared off on the fact sheet which poor Sherman Boone did over the weekend. This guy has worked the last four weekends in a row and is somewhat fried. Treat him gently.

===== ATTACHMENT 1 =====

ATT CREATION TIME/DATE: 0 00:00:00.00

TEXT:

Unable to convert ARMS_EXT:[ATTACH.D23]MAIL41206386K.116 to ASCII,
The following is a HEX DUMP:

===== END ATTACHMENT 1 =====

Qs and As on Cloning

June 9, 1997

Q. What did the Commission recommend?

A. The Commission recommends legislation to prohibit anyone in either the public or private sector from attempting to create a child using the cloning technology that made possible the creation of "Dolly" --so-called "somatic cell nuclear transfer" technology. The Commission also supports a continuation of the current moratorium on federal funding of creating a child by cloning while the legislation is pending. NBAC is also asking the private sector to comply with the voluntary moratorium President Clinton called for in March, pending the legislative prohibition. Finally, NBAC also called for continuing public dialogue on these issues to further understand the ethical and social implications of this technology.

Q. What exactly does the President's legislation ban?

A. The President's legislation prohibits the use of somatic cell nuclear transfer to create a human being (specifically, "with the intent of introducing the product of that transfer into a woman's womb or in any other way creating a human being").

Q. How will the prohibition be enforced?

A. The legislation gives the Attorney General authority to seek injunctive relief, impose civil fines up to \$250,000 or twice the profit from a violation of the Act (whichever is greater), and seize any and all property used in violating the Act (including entire laboratories).

Q. Why doesn't it make cloning a criminal act and impose jail time?

A. We think the penalties in the bill provide an effective deterrent. In particular, they make it clear no one will profit from this activity. It is appropriate to be cautious about criminalizing any activity, and at this point we don't have any indication that we need the threat of criminal sanctions to deter this activity.

Q. But what if Congress wants to impose criminal sanctions?

A. We have seriously considered this option and would be willing to look at it again.

Q. Why is there need for a "sunset" provision?

A. NBAC recommends --and the President supports --a sunset provision, combined with review by an advisory body prior to the sunset date. There are several reasons to take this approach. First, a

sunset provision provides a strong incentive for Congress and the Administration to renew the national debate on cloning within several years, ensuring continued attention to the ethical questions; second, there is a possibility that we will get the precise legislative language wrong the first time around, given our limited understanding of the science, the difficulty of defining terms, and the vagaries of the legislative process; and third, there has been little time to fully consider the moral issues, and it is possible that convictions may evolve.

Q. But if you think cloning is morally wrong now, won't it be morally wrong for all time?

A. Even if one thinks cloning is morally wrong, a sunset provision still makes sense. As I just noted, it will force a renewed national debate within several years and will keep the ethical issues squarely in view. A sunset provision will also make sure we revisit how we've defined the ban and ensure we have done it exactly right.

Q. Why ban the cloning of humans?

A. It is morally unacceptable for anyone in either the public or private sector to attempt this type of cloning. NBAC found it is simply unsafe; knowing that "Dolly" was the only successful case in 277 attempts, there is no doubt that there would be substantial risk to the potential child. And the possibility of replicating ourselves raises other ethical and religious concerns about the implications of this technology for our society. These issues need further discussion before the technology is used.

Q. Why not ban all cloning? What are the potential benefits of cloning research?

A. There are legitimate and beneficial applications of cloning cells, DNA, tissues, and animals: including the development of medicines, and therapies for diseases such as cancer, cystic fibrosis, and diabetes. Cloning also furthers our knowledge about developmental biology that may one day lead to such advances as regeneration of tissue in severe burns and spinal cord injuries.

Q. Why is any additional legislation necessary? Why not extend the President's moratorium?

A. The President's moratorium covers only federally funded activities. In March, President Clinton called for a voluntary ban on privately funded activities. Legislation is necessary, however, to ensure that the privately funded research and clinical centers comply with the proposed prohibition on cloning of human beings using the somatic cell nuclear transfer technique.

Q. With the proposed legislation, are we interfering with people's reproductive freedom?

A. No. We don't think people should have the "freedom" to do this activity. It's unsafe and ethically objectionable.

Q. How will the recommendations and legislation affect research?

A. NBAC found that a ban on human cloning will not impede any important research at this time. research in such areas as animal husbandry and drug development will continue. Similarly, basic research using somatic cell nuclear transfer technology to study, for instance, the potential for regenerating tissues and organs will continue. However, under current federal restrictions, human embryo research using federal funds will remain prohibited.

Q. Why would you (or the Commission) support a total ban on cloning people, but not on creating embryos using cloning technology for research?

A. The issue of embryo research is an important but separate question. NBAC found that the technology that created Dolly doesn't raise new questions related to embryo research. By contrast, the use of somatic cell nuclear transfer technology to create a child raises a host of new and different ethical issues relating to safety, individuality, and family integrity. The President's legislation is directed at these concerns. Further, the President has prohibited the use of federal research funds to create an embryo for research purposes --whether through cloning or any other means.

Q. If human embryo research is bad, why not ban it in the private sector as well?

A. Whether to ban privately-funded embryo research is a question that needs careful deliberation, as such research may offer medical benefit, particularly with respect to treating infertility. We simply need further discussion about regulation of this activity in the private sector before pursuing legislation.

Q. Does the Federal Government have any jurisdiction over privately funded research with human embryos?

A. If the research is part of an effort to develop a drug, biologic, or medical device, the research is subject to regulation by the Food and Drug Administration. Otherwise, it is unregulated.

Q. What happens to human embryos created for research? If they are not implanted, isn't that tantamount to abortion, or even murder?

A. Creation of human embryos for research is a prohibited use of federal funds. The extent of such research under private sponsorship is unknown; therefore, we have no reliable information on the fate of human embryos used in this way.

Q. How will this affect childless couples who see cloning as their only chance to have genetically

related offspring?

A. Prohibiting this technology will have little practical effect on such couples. Currently neither the science base nor safety considerations make it possible to produce a child by somatic cell nuclear transfer.

Q. Is the United States acting unilaterally on this issue? Are we treating this issue any differently than other countries?

A. Some European countries have already established legal prohibitions on the cloning of humans. To the extent that there are common aspects to our respective policies, we will certainly cooperate with these nations regarding enforcement.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: thm2@po.cwru.edu (thm2@po.cwru.edu [UNKNOWN])

CREATION DATE/TIME:18-JUN-1997 16:18:13.00

SUBJECT: Re: Sheri Alpert and genetic privacy

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:
Alex,

I can say for certain that I find your comments very helpful. Thanks.

Re genetic exceptionalism: We agree, and reading your comments it seems for very similar reasons, that genetic information ought not to be treated as distinctive for most purposes. But I am reluctant to impose that as a conclusion this early in our deliberations. So, when Sheri suggested including it in her paper for us, I thought that might be a useful way to get an independent read on the merits.

Thanks for your comments.

Tom

>Tom:

>

>Thanks for sharing Sheri's proposed research with the full NBAC.I would be
>happy to discuss the following with Sheri if she wishes. I think her
>outline is interesting, but do have comments on two aspects:

>

>I. SHOULD WE TREAT GENETIC PRIVACY AS DISTINCT FROM OTHER MEDICAL PRIVACY?

>

>I seem to recall that NBAC discussed the issue that Sheri gets to at the
>end of her outline--whether genetic information is distinct from other
>medical information--and I THOUGHT we were inclined not to go for the
>"distinct" view. Perhaps I misremember. In any case, I would urge that
>nothing we do--or that we have her do--commits us to the "genetic info is
>distinct" position, which at this point I believe to be mistaken and
>potentially harmful.

>

>Two arguments against the "distinct" approach:

>1. It is a waste of effort trying to figure out what information is
>"genetic" in the first place.

>

>2. The impulse to have separate rules comes from a phenomenon I labelled
>long ago as the "genecity" of topics like this--the tendency of the novel
>"genetic" aspects to elevate concerns. Like some of the public fear of
>cloning--which derived from its novelty-- a good deal of the concern about
>genetic information also steps from novelty; part of our objective could
>be to show that it is the general risk of medical information becoming

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T

Thomas H. Murray, Ph.D.

Center for Biomedical Ethics
School of Medicine
Case Western Reserve University
10900 Euclid Avenue
Cleveland, OH 44106-4976
Phone: 216/368-6206 Fax: 216/368-8713
thm2@po.cwru.edu

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: racharo@facstaff.wisc.edu@INET@LNGTWY (racharo@facstaff.wisc.edu@INET@LNGTWY [UNKNOWN])

CREATION DATE/TIME:18-JUN-1997 14:56:11.00

SUBJECT: Re: URGENT need info!

TO: Rachel E. Levinson@EOP (Rachel E. Levinson@EOP [OSTP])
READ:UNKNOWN

TEXT:

best as i can remember, uk has a law that probably applies and is being tightened up to make sure it applies; argentina recently passed a law to prohibit it; and china's research council has come out against it and that is a de facto prohibition tho not de jure prohibition on it.

hope this helps.

also note that council of europe, european commission and w.h.o. have all cone out against it but no specific law was passed. council of europe's resolution may have binding force on its members, tho.

At 02:47 PM 6/18/97 -0500, you wrote:

>Message Creation Date was at 18-JUN-1997 14:47:00

>

>Your phone is busy. Can you tell me which countries currently have bans that

>are known to apply to SCNT cloning? The Knoppers paper lays out which

>countries have laws on the books that may or may not apply but I don't know

>which countries have actually passed anything yet that is specific.

Your

>help is much appreciated

>

>

>

r. alta charo, j.d.

associate professor, law & medical ethics

school of law tel: 608.262.5015

univ of wisconsin fax : 608.262.5485

madison, wi 53706 email: racharo@facstaff.wisc.edu===== ATTACHMENT 1

=====

ATT CREATION TIME/DATE: 0 00:00:00.00

TEXT:

RFC-822-headers:

Received: from conversion.pmdf.eop.gov by PMDF.EOP.GOV (PMDf V5.0-4 #6879)

id <01IK7ZTV145C003LSX@PMDf.EOP.GOV> for "Rachel E. Levinson"@oa.eop.gov; Wed,

18 Jun 1997 14:50:25 -0500 (EST)

Received: from gatekeeper.eop.gov by PMDF.EOP.GOV (PMDf V5.0-4 #6879)

id <01IK7ZTSZ6400042F9@PMDf.EOP.GOV> for Rachel_E._Levinson@oa.eop.gov; Wed,

18 Jun 1997 14:50:22 -0500 (EST)

Received: from mail5.doit.wisc.edu by gatekeeper.eop.gov;

(5.65v3.2/1.1.8.2/17Oct95-0424PM) id AA04175; Wed, 18 Jun 1997 14:50:09 -0400

Received: from default.wisc.edu by mail5.doit.wisc.edu; id NAA30820; 8.7.5/50;

Wed, 18 Jun 1997 13:49:24 -0500

X-Sender: racharo@facstaff.wisc.edu

X-Mailer: Windows Eudora Pro Version 3.0 (32)

===== END ATTACHMENT 1 =====

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:18-JUN-1997 14:42:27.00

SUBJECT: URGENT need info!

TO: racharo (racharo @ facstaff.wisc.edu @ inet [UNKNOWN])

READ:UNKNOWN

TEXT:

Your phone is busy. Can you tell me which countries currently have bans that are known to apply to SCNT cloning? The Knoppers paper lays out which countries have laws on the books that may or may not apply but I don't know which countries have actually passed anything yet that is specific. Your help is much appreciated

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: thm2@po.cwru.edu (thm2@po.cwru.edu [UNKNOWN])

CREATION DATE/TIME:19-JUN-1997 13:11:46.00

SUBJECT: Re: Sheri Alpert and genetic privacy

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

For the record, I do not believe that our tissue sample report can be ready before December. To put that another way, I think December is a reasonable goal for completion of the report. I also believe that the Commissions ought not of necessity be the primary authors of reports. Kathi Hanna did a terrific job for us on cloning. But we should have ethicists and perhaps others on staff who can shoulder the burden of writing, with the guidance of the Commission.

Tom

>Tom:

>Thanks for the note. Yes, I agree with your plan, as I noted a few
>moments ago in responding to Larry's e-mail in which he said that we
>ought to have see if our tentative conclusion holds up in the face of
>contrary arguments.

>

>BTW, I also agree with Carol and Larry on the need for the scientific
>papers and hope those can be arranged. After an exhausting experience
>like the cloning report, it is hard to throw oneself immediately into a
>new task, but I'm sure that your subcomm, like the HSSC, finds the Oct.
>deadline looming awfully large already.

>

>As a general comment--especially for Harold's eyes--I want to plead for
>as rapid (and high quality, of course!) outcome on the hiring of the Exec
>Dir. and other professional staff, as I don't think it is either feasible
>or wise to place the primary production of our future reports on the
>shoulders of the commissioners to anything like the degree we did, of
>necessity, with the cloning report.

>

>Best,

>Alex

>

>

>On Wed, 18 Jun 1997, Tom Murray wrote:

>

>> Alex,

>>

>> I can say for certain that I find your comments very helpful. Thanks.

>>

>> Re genetic exceptionalism: We agree, and reading your comments it
seems for >> very similar reasons, that genetic information ought not to

be treated as

>> distinctive for most purposes. But I am reluctant to impose that as a
>> conclusion this early in our deliberations. So, when Sheri suggested
>> including it in her paper for us, I thought that might be a useful way
to >> get an independent read on the merits.

>>

>> Thanks for your comments.

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>> Tom

>>

>> >Tom:

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>> >Thanks for sharing Sheri's proposed research with the full NBAC.I
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>> >happy to discuss the following with Sheri if she wishes. I think her

>> >outline is interesting, but do have comments on two aspects:

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>> >I. SHOULD WE TREAT GENETIC PRIVACY AS DISTINCT FROM OTHER MEDICAL
PRIVACY?

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>> >I seem to recall that NBAC discussed the issue that Sheri gets to at
the >> >end of her outline--whether genetic information is distinct from
other

>> >medical information--and I THOUGHT we were inclined not to go for the

>> >"distinct" view. Perhaps I misremember. In any case, I would urge

that >> >nothing we do--or that we have her do--commits us to the "genetic
info is

>> >"distinct" position, which at this point I believe to be mistaken and

>> >potentially harmful.

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>> >Two arguments against the "distinct" approach:

>> >1. It is a waste of effort trying to figure out what information is

>> >"genetic" in the first place.

>> >

>> >2. The impulse to have separate rules comes from a phenomenon I
labelled >> >long ago as the "genecity" of topics like this--the tendency
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of the concern about >> >genetic information also steps from novelty; part
of our objective could >> >be to show that it is the general risk of
medical information becoming >> >"unprivate" that is troublesome not
genetic information specifically.

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>> >II. THE "AUTONOMY" ASPECTS OF "PRIVACY"

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>> >I would caution Sheri NOT to get confused, under the "autonomy"
heading by

>> >the Supreme Court's former use of "privacy" to mean constitutionally

>> >protected decisional freedom (which now is more likely to be described
as >> >a protected liberty interest). The privacy label stemmed, I think,
from

>> >the facts of GRISWOLD v. CONN.

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>> >There is also--as I think she may be getting at--an older notion

>> >inchoate in the cases, but there is philosophical analysis of the
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>> >ourselves is part of the way we maintain autonomy in our lives and
thereby >> >determine the kind of people we are. This is a more
sophisticated notion
>> >than the other way in which (unwanted) disclosure of information
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>> >information they may act towards us in a way we don't like and prevent
us >> >from carrying out a choice we have made (such as, to buy insurance).
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>> >way in which information that is thrust upon a person (from a genetic
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>> >occurred when the "hidden" (ie, not scientifically known) genetic
>> >information is revealed even to the person him or herself. I would be
>> >interested to know whether Sheri finds any "legal" materials that take
>> >account of this interest (which, again, is not unique to the "genetic"
>> >realm at all).

>>>

>> >* Alexander M. Capron acapron@law.usc.edu *

>> >* Henry W. Bruce Professor of Law (213) 740-2557 (voice) *

>> >* University Professor of Law and Medicine (213) 740-5502 (fax) *

>> >* University of Southern California (213) 740-0149 (fax) *

>> >* Los Angeles, CA 90089-0071 *

>>>

>>>

>> Thomas H. Murray, Ph.D.

>> School of Medicine

>> 10900 Euclid Avenue

>> Phone: 216/368-6206 Fax: 216/368-8713

>> tlmz@po.cwru.edu

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>>

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>

>

Thomas H. Murray, Ph.D.

Center for Biomedical Ethics

School of Medicine

Case Western Reserve University

10900 Euclid Avenue

Cleveland, OH 44106-4976

Phone: 216/368-6206 Fax: 216/368-8713

thm2@po.cwru.edu

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: acapron@law.usc.edu (acapron@law.usc.edu [UNKNOWN])

CREATION DATE/TIME:19-JUN-1997 13:41:26.00

SUBJECT: Re: Sheri Alpert and genetic privacy

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

On Thu, 19 Jun 1997, Tom Murray wrote:

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> goal for completion of the report. I also believe that the Commissions
> ought not of necessity be the primary authors of reports. Kathi Hanna
did a > terrific job for us on cloning. But we should have ethicists and
perhaps > others on staff who can shoulder the burden of writing, with the
guidance of > the Commission.

Glad that we agree on the "report drafting" question...and I trust that
with appropriate staffing in place in the not too distant future (!?!)
this will turn out to be the case.

On the question of deadlines (such as the tissue report by Dec.?), I think
it might be helpful for all of us to hear from Harold what his
expectations are about the issuance of various reports over the coming
8-12 months. Now that we have an extension at least through Oct. 1999, we
ought to be able to plan more sensibly. On a recent "informal" HSSC
conference call, I played the role of Simon Legree, pushing the staff very
hard to have both Phase I and II of the federal agency review process
completed by the projected completion date of the first HSSC report in
Oct. That date reflects an expectation in our charter, but the other
dates are more for us to set...and then to meet.

Alex

* Alexander M. Capron acapron@law.usc.edu *
* Henry W. Bruce Professor of Law (213) 740-2557 (voice) *
* University Professor of Law and Medicine (213) 740-5502 (fax) *
* University of Southern California (213) 740-0149 (fax) *
* Los Angeles, CA 90089-0071 *

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: acapron@law.usc.edu (acapron@law.usc.edu [UNKNOWN])

CREATION DATE/TIME:19-JUN-1997 12:43:08.00

SUBJECT: Re: Sheri Alpert and genetic privacy

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

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BTW, I also agree with Carol and Larry on the need for the scientific papers and hope those can be arranged. After an exhausting experience like the cloning report, it is hard to throw oneself immediately into a new task, but I'm sure that your subcomm, like the HSSC, finds the Oct. deadline looming awfully large already.

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Best,
Alex

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> >interferes with autonomy: when someone (say an insurer) has access to

> >information they may act towards us in a way we don't like and prevent

us > >from carrying out a choice we have made (such as, to buy insurance).

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> >The more sophisticated "autonomy" interest does not depend on such direct

> >acts contrary to the person's interest, but instead relates to the way

> >that information "shapes" a person. One somewhat novel aspect here is the

> >way in which information that is thrust upon a person (from a genetic

> >test, for example) may shape them in ways they don't want to be shaped.

> >In that case, the "information" has two aspects: that which is HIDDEN

in > >the person's genes already and that which is contained in the report on

> >what is shown by the analysis of the genes. Even if the latter

> >information (the test results) are kept "private" (ie not disclosed to

> >others, such as insurers, with whom the person does not want to share the

> >information) the person may still feel that a breach of "privacy" has

> >occurred when the "hidden" (ie, not scientifically known) genetic

> >information is revealed even to the person him or herself. I would be

> >interested to know whether Sheri finds any "legal" materials that take

> >account of this interest (which, again, is not unique to the "genetic"

> >realm at all).

> >

> >I hope these comments are helpful to the genetics group and to Sheri,

> >Alex

> >

> >*****

> >* Alexander M. Capron acapron@law.usc.edu *

> >* Henry W. Bruce Professor of Law (213) 740-2557 (voice) *

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> >Thomas H. Murray, Ph.D.

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> >Phone: 216/368-6206 Fax: 216/368-8713

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> >

> >

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:19-JUN-1997 13:35:34.00

SUBJECT: Re: National Bioethics Advisory Commission

TO: Sltaylor33 (Sltaylor33 @ aol.com [UNKNOWN])

READ:UNKNOWN

TEXT:

I have forwarded your request to the appropriate person. Please let me know if there is any difficulty in getting the information. Yolanda L. Comedy

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: KnorrH@od6100ml.od.nih.gov (KnorrH@od6100ml.od.nih.gov [UNKNOWN])

CREATION DATE/TIME:19-JUN-1997 15:46:26.00

SUBJECT: RE: the cloning report and the Web site

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

We are working on getting the report on the Web ASAP and are looking at early next week. Our office move plus vacations, family deaths, pregnancies, etc. has slowed us down a bit. In the meantime we have plenty of copies of the report - it would be best to ask people to fax a request to us at 301-480-6900. We fill requests within 24 hrs.

Sincerely yours,

Henrietta

From: Carol Greider at Cold Spring Harbor
Laboratory[SMTP:greider@cshl.org]
Sent: Tuesday, June 17, 1997 9:34 PM
To: NBAC Members E-list
Subject: the cloning report and the Web site

Hi everyone,

I appreciate that others, like me, are just now digging out from under the piles of paper that accumulated during the Dolly days (Dolly daze?).

But I would really appreciate it if the Cloning report were on the web. I have told many people that it would be up by the end of last week, and they keep bugging me about it.

thanks very much.

:)

Carol

Carol Greider, Ph.D.
Cold Spring Harbor Laboratory
P.O. Box 100
Cold Spring Harbor, NY 11724

Phone: (516) 367-8808
Fax: (516) 367-8815

E-mail: greider@cshl.org

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:19-JUN-1997 13:42:58.00

SUBJECT: Re: National Bioethics Advisory Commission

TO: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

You're in luck - we just received a bunch of copies that are located in room 436. Help yourself.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:19-JUN-1997 12:55:35.00

SUBJECT: PARIS and FERMI

TO: Deanna M. Behring (CN=Deanna M. Behring/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

1. Are there any handouts that JHG will want to take to Paris, e.g., cloning report, etc., that need to be mailed in advance?
2. Holly is also curious about the Martha Krebs/FERMI request--not sure why JHG should be doing this...

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: acapron@law.usc.edu (acapron@law.usc.edu [UNKNOWN])

CREATION DATE/TIME:19-JUN-1997 15:34:09.00

SUBJECT: Susan Wolf

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

Susan Wolf of the U Minnesota bioethics center has an (unconvincing) OpEd piece in the Minneapolis Star Tribune today, "Why the Bioethics Commission is wrong to seek a ban on cloning" (text below, or as attachment) in which she really objects that IF Congress enacted a ban that went beyond babymaking to ban all embryo research and IF it were not time limited, it would be a bad statute (obviously, such legislation is inconsistent with our recommendations). She says instead that we should have followed the R AC model of regulation by an expert panel (Difference: that was an activity, namely human gene therapy, which was ACCEPTABLE--not burdened by serious, unresolved ethical issues, as repro. cloning is-- and in which the only questions related to safety of each individual case, not the whole technique). She suggests in passing that human subjects rules would prevent anyone engaging in cloning-babymaking now on safety grounds anyway, but later says that privately funded research isn't covered, so that we should "consider fixing the existing federal rules on human subjects" (which we've already said we favor in principle, and will be trying to do in our first full report on human subjects).

Alex

Commission suggests
ban on human cloning

Published Thursday, June 19, 1997

Commentary: Bioethics Commission
wrong to seek ban on cloning

Susan Wolf

Last week the National Bioethics Advisory
Commission
recommended a federal ban on using cloning to create a child.
President Clinton agreed and proposed a
five-year ban by
federal legislation.

They're wrong.

It's true that cloning packs an emotional wallop. It conjures up images of xeroxed humans. It seems another attempt to play God. It certainly warrants regulation.

But should it be banned? No other bioethics controversy has been addressed by a ban this broad.

This goes beyond prohibiting the use of federal funds (which the president had already done). It goes beyond the federal regulations on human subjects research, which already would make cloning impossible (because it is still unsafe) in universities and other institutions covered by those regulations.

Instead, the cloning ban would reach all public and private institutions whether or not federal money is involved. It would threaten them with fines of at least a quarter-million dollars. And the ban would be imposed by Congress itself, not a regulatory body ready to respond to new developments in the technology.

That's both new and unwise. It turns cloning into a political football for Congress.

Past congressional imbroglios over the related areas of embryo research and abortion predict the same trouble ahead for cloning. This means that although the president and the commission have called for a ban reaching the private sector only on application, not research, Congress is likely to go further and ban research too.

And though the president and commission focused on banning

only somatic cell nuclear transfer (the technique used to clone Dolly the sheep), Congress may well rope in other cloning technologies, such as embryo splitting, despite its potential value in treating infertility.

Even if Congress miraculously enacts the limited ban the commission recommended, research may well be chilled by the specter of legal investigation and penalty any time a researcher arguably clones with the wrong intent (in the president's bill "the intent of introducing the product . . . into a woman's womb or in any other way creating a human being").

In addition, a federal ban of all public and private cloning may well violate constitutional guarantees of academic freedom for researchers and procreative liberty for infertile couples, as well as exceeding the limits on federal power.

Some may respond that banning cloning remains the right course -- that no good can come of it. But there is potential good we need to consider.

Within an infertility treatment program, cloning in the forms of induced twinning may save a woman from repeated exposure to drugs that cause superovulation, and may thus reduce her risk of ovarian cancer later.

Even Dolly-style cloning has potential uses.

Consider, for example, a woman whose genetic material would likely inflict a serious disorder on her child. Cloning also may allow her to avoid using genetic material from an egg donor and thus may keep the reproductive process between the woman and her partner -- something of value to many couples.

A federal ban, depending on how broad it is, would shut down or threaten these possibilities. Especially if the five-year ban that Clinton now favors results in a longer-term avoidance of cloning.

There is a better way. The commission, president, and Congress should consider the model we have followed with human gene therapy: regulation by an expert panel able to respond to improvements in the technology over time and more insulated than Congress from partisan politics. Indeed, lessons we have learned in using that model could lead to better refinements.

They also should consider fixing the existing federal rules on human subjects. Because any cloning of human beings now would be considered experimental, those regulations would offer important protections. But those regulations apply only to research underwritten with federal funds and in any institution that has assured the federal government its research will comport with federal rules.

Some researchers remain outside these rules, a problem that should be addressed.

Finally we need a reevaluation of regulations on assisted reproduction generally. Though progress has been made in recent years, state-to-state inconsistency, problems with federal reporting requirements, and conflicts of interest inherent in industry self-regulation merit careful examination.

A ban may seem a simple and safe solution. But the questions raised by cloning are far from simple. We have to balance the

promise of research and the potential
benefits against the need
for regulation and caution.

We have to do better than a ban.

-- Susan Wolf is associate professor of Law
and Medicine at
the University of Minnesota Law School and a
faculty member
in the University's Center for Bioethics.

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Commission suggests
ban on human cloning

- wolf===== ATTACHMENT 1 =====
ATT CREATION TIME/DATE: 0 00:00:00.00

TEXT:

<!DOCTYPE HTML PUBLIC "-//IETF//DTD HTML//EN">

<HTML><HEAD><TITLE>Commentary: Bioethics Commission wrong to seek ban on clonin
g</TITLE>

<SCRIPT>

<!-- Hide script from HTML-compliant browsers

// untaint story_id for newsEase

utstoryid = "45310025 "

// open starmap

var url = "http://webserv1.startribune.com/cgi-bin/stOnLine/starmapRoot?id=4531
0025 "

var floater = null

floater = window.open('','StarMap','width=450,height=150,resizable=0,status=0,s
crollbars=0')

if (floater != null) {

if (floater.opener == null) {

floater.opener = self

}

floater.location.href = url

}

// End script hiding. -->

</SCRIPT>

</HEAD><BODY BGCOLOR="#ffffff" VLINK="#633163" TEXT="#000000" LINK="#00319C" AL
INK="#CE9CFF"><CENTER><TABLE><TR><TD WIDTH="189" VALIGN="top" ALIGN="left"><IMG
WIDTH="189" SRC="http://www.startribune.com/stonline/graphics/ids/opinion_id.g

if" ALT="Opinion" HEIGHT="85" BORDER="0">

Commission suggests ban on human cloning<BR CLEAR="all"></TD><TD WIDTH="12" VALIGN="top" ROWSPAN="2"></TD><TD VALIGN="top" ROWSPAN="2"><P ALIGN="left"></P>Published Thursday, June 19, 1997

<H2>Commentary: Bioethics Commission wrong to seek ban on cloning</H2>Susan Wolf<P>

<P>Last week the National Bioethics Advisory Commission recommended a federal ban on using cloning to create a child. President Clinton agreed and proposed a five-year ban by federal legislation.</P>

<P>They're wrong.</P>

<P>It's true that cloning packs an emotional wallop. It conjures up images of xeroxed humans. It seems another attempt to play God. It certainly warrants regulation.</P>

<P>But should it be banned? No other bioethics controversy has been addressed by a ban this broad.</P>

<P>This goes beyond prohibiting the use of federal funds (which the president had already done). It goes beyond the federal regulations on human subjects research, which already would make cloning impossible (because it is still unsafe) in universities and other institutions covered by those regulations. </P>

<P>Instead, the cloning ban would reach all public and private institutions whether or not federal money is involved. It would threaten them with fines of at least a quarter-million dollars. And the ban would be imposed by Congress itself, not a regulatory body ready to respond to new developments in the technology.</P>

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<P>Past congressional imbroglios over the related areas of embryo research and abortion predict the same trouble ahead for cloning. This means that although t

he president and the commission have called for a ban reaching the private sector only on application, not research, Congress is likely to go further and ban research too. </P>

<P>And though the president and commission focused on banning only somatic cell nuclear transfer (the technique used to clone Dolly the sheep), Congress may well rope in other cloning technologies, such as embryo splitting, despite its potential value in treating infertility.</P>

<P>Even if Congress miraculously enacts the limited ban the commission recommended, research may well be chilled by the specter of legal investigation and penalty any time a researcher arguably clones with the wrong intent (in the president's bill "the intent of introducing the product . . . into a woman's womb or in any other way creating a human being"). </P>

<P>In addition, a federal ban of all public and private cloning may well violate constitutional guarantees of academic freedom for researchers and procreative liberty for infertile couples, as well as exceeding the limits on federal power.</P>

<P>Some may respond that banning cloning remains the right course -- that no good can come of it. But there is potential good we need to consider.</P>

<P>Within an infertility treatment program, cloning in the forms of induced twinning may save a woman from repeated exposure to drugs that cause superovulation, and may thus reduce her risk of ovarian cancer later.</P>

<P>Even Dolly-style cloning has potential uses.</P>

<P>Consider, for example, a woman whose genetic material would likely inflict a serious disorder on her child. Cloning also may allow her to avoid using genetic material from an egg donor and thus may keep the reproductive process between the woman and her partner -- something of value to many couples. </P>

<P>A federal ban, depending on how broad it is, would shut down or threaten these possibilities. Especially if the five-year ban that Clinton now favors results in a longer-term avoidance of cloning. </P>

<P>There is a better way. The commission, president, and Congress should consider the model we have followed with human gene therapy: regulation by an expert panel able to respond to improvements in the technology over time and more insulated than Congress from partisan politics. Indeed, lessons we have learned in using that model could lead to better refinements.</P>

<P>They also should consider fixing the existing federal rules on human subjects. Because any cloning of human beings now would be considered experimental, those regulations would offer important protections. But those regulations apply only to research underwritten with federal funds and in any institution that has assured the federal government its research will comport with federal rules. </P>

<P>Some researchers remain outside these rules, a problem that should be addressed. </P>

<P>Finally we need a reevaluation of regulations on assisted reproduction generally. Though progress has been made in recent years, state-to-state inconsistency, problems with federal reporting requirements, and conflicts of interest inherent in industry self-regulation merit careful examination.</P>

<P>A ban may seem a simple and safe solution. But the questions raised by cloning are far from simple. We have to balance the promise of research and the potential benefits against the need for regulation and caution. </P>

<P>We have to do better than a ban.</P>

<P>-- Susan Wolf is associate professor of Law and Medicine at the University of Minnesota Law School and a faculty member in the University's Center for Bioethics.</P>

<P ALIGN="right">
</P>Â© Copyright 1997 Star Tribune. All rights reserved.
</TD></TR><TR><TD WIDTH="189" VALIGN="bottom">

Commission suggests ban on human cloning<BR CLEAR="all">
<P>
</P></TD></TR></TABLE></CENTER></BODY></HTML>
===== END ATTACHMENT 1 =====

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:19-JUN-1997 13:31:38.00

SUBJECT: National Bioethics Advisory Commission

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Please respond. Thanks, Yolanda

----- Forwarded by Yolanda L. Comedy/OSTP/EOP on 06/19/97

01:40 PM -----

Sltaylor33 @ aol.com

06/19/97 12:31:30 PM

Record Type: Record

To: ycomedy

cc:

Subject: National Bioethics Advisory Commission

Can you please help me locate a copy of the report to the president given by Dr. Harold Shapiro on 6/9/97 regarding the committee's work on the issue of Human cloning. I am a student at the University of New Mexico in Albuquerque and I am taking a summer class in Genetics. I would like to discuss the committee's opinions and findings to my class. Your help would be greatly appreciated.

Thank you

Susan L. Taylor

sltaylor33@aol.com

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:22-JUN-1997 12:10:15.00

SUBJECT: Re: Sorry, but could you put your clips request in writing?

TO: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

----- Forwarded by Susanne Bachtel/OSTP/EOP on 06/22/97
12:10 PM -----

Susanne Bachtel
06/22/97 12:15:09 PM
Record Type: Record

To: Teresa Wildman/WHO/EOP

cc:

Subject: Re: Sorry, but could you put your clips request in writing?

Do you think you could ask Jodie about this - as you know the written request went in a couple of weeks ago - can you get a verbal go ahead. The clips will be well used - we are one of the 4 policy offices - like Reed, Sperling, Berger, etc., and the weekend/magazine clips will help a lot. Thanks for anything you can do - I have a family funeral to attend on Monday first thing - back early p.m. Thanks Susie
----- Forwarded by Susanne Bachtel/OSTP/EOP on 06/22/97
12:05 PM -----

Susanne Bachtel
06/13/97 09:43:03 AM
Record Type: Record

To: Teresa Wildman/WHO/EOP

cc: Susanne Bachtel/OSTP/EOP

Subject: Re: Sorry, but could you put your clips request in writing?

Teresa - any feedback yet? I had to scrounge fast last weekend for a clip from the NYT that the POTUS wanted that day for the cloning event. We would appreciate starting the weekend clips/WH magazine asap. With much appreciation! Sue

----- Forwarded by Susanne Bachtel/OSTP/EOP on 06/13/97
09:37 AM -----

Susanne Bachtel
06/06/97 01:09:53 PM
Record Type: Record

To: Teresa Wildman/WHO/EOP
cc: Jodie R. Torkelson/WHO/EOP
Subject: Re: Sorry, but could you put your clips request in writing?

Dear Teresa: Thanks for your note. Sorry for the delay in response; I was awaiting some feedback from one of our staff.

This is Dr. Gibbons's request:

1. Cancel the WH daily clips addressed to Ernie Moniz
2. Change the WH daily clips addressed to Tim Newell -
readdress them to Dr. Gibbons - send to
Dr. Gibbons's office - Room 424 OEOB (Dr.
Gibbons's office)
3. Add WH weekend clips - address to Dr. Gibbons - send
to Room 424 OEOB
4. Add WH magazine clips - address to Dr. Gibbons - send
to Room 424 OEOB

Many thanks, Susie

Bachtel, Ext 6-7116

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: ecassell@mail.med.cornell.edu (ecassell@mail.med.cornell.edu [UNKNOWN])

CREATION DATE/TIME:23-JUN-1997 17:31:41.00

SUBJECT: Back on line

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])

READ:UNKNOWN

TEXT:

I returned this afternoon to find only 39 messages. Till I started reading the email I was worried about our health -- but everybody seems okay. At a Goals of Medicine meeting in Naples nobody asked about cloning. Do they know something we don't?

Eric

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: holtzman@mpi.com (holtzman@mpi.com [UNKNOWN])

CREATION DATE/TIME:24-JUN-1997 10:32:55.00

SUBJECT: Cloning Bill

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])

READ:UNKNOWN

TEXT:

Rachel:

i'll be sending you, if you haven't already gotten it, BIO's analysis of the President's cloning bill. great concern over ambiguities (re: a human being) and regulation of the intent rather than the actual production of the new being. both might serve to "chill" allowable research.

i think that the best way to go is to go back to the drawing board and redraft the bill w/o reference to the technology AT ALL: regulate the "product" not the "process".

basically: it shall be illegal to create, by any means, a new human individual essentially genetically identical to another human individual who currently exists or previously existed.

for purposes of the bill, a "human individual" shall mean a member of the species homo sapiens who has been born and lived post birth but shall not include any embryo or fetus of the species homo sapiens that was never born and lived post birth.

this would outlaw cloning people by Wilmut-cloning as well as serial twinning by blastomere separation and nuclear transplantation of embryonic nuclei. it would leave alone blast separation and embryonic nuclear transplantation twinning if the second twin is not serialized.

this also has the virtue of getting away from the issue of embryo research. if people want a bill to regulate that, they should draft a second bill.

just a thought.

-steve

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Angela Phillips Diaz (CN=Angela Phillips Diaz/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:25-JUN-1997 12:36:40.00

SUBJECT: NBAC Report for PCAST

TO: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

Angela Phillips Diaz (CN=Angela Phillips Diaz/OU=OSTP/O=EOP [OSTP])

READ:UNKNOWN

TEXT:

Yolanda:

I would recommend that we get copies of "Cloning Human Beings" report & recommendations of the NBAC for PCAST. Prior to sending it to them, we should pull the PCAST letter to POTUS & POTUS response & meet w/ Gabriel, Gwin, & Levinson to determine what action if any we want to assign to PCAST in the cover transmittal letter. I would welcome your thoughts/proposals on how to proceed also.

Thanks.

Angela

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Cathleen A. Campbell (CN=Cathleen A. Campbell/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:26-JUN-1997 10:58:25.00

SUBJECT: nbac report

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Rachel,

Can I get a copy of the NBAC report on cloning to give to the Russian
Embassy S&T officer???

thanks,
cathy

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: jfc7c@virginia.edu (jfc7c@virginia.edu [UNKNOWN])

CREATION DATE/TIME:30-JUN-1997 20:27:53.00

SUBJECT: Stars & Surprises

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

OUR STARS. Two NBACers starred in last week's Interagency Human Subjects Conference on Genetics Research and Human Subjects: The Changing Landscape. First, DAVID COX gave a remarkably fresh, clear, illuminating, and witty presentation on the Human Genome Project: Implications for Future Research. I heard several people say that they wished he had been their teacher in college -- I share that sentiment. Then, while keeping her eyes on the clock so she could catch her plane, ALTA CHARO offered a most lucid (even though rapid!), penetrating, and insightful discussion of NBAC's work on human subjects, genetics, and, yes, of course, human cloning-- I found her presentation quite stimulating, particularly her important and difficult questions, raised in the context of our work and report on cloning, about the relation of ethics and politics in public bioethics. I hope we can discuss these questions sometime. As the first speakers, David and Alta really got the fine two-day conference off to a great start.

SURPRISE. Earlier last week I decided to drop in on a conference on the Moral Challenge of Cloning Technology, sponsored by the (quite conservative) Center for Jewish and Christian Values, particularly to see what arguments would be offered against our report. I was also interested because the conference was being held in the U.S. Capitol, SC-5, with Senator Lieberman introducing the discussion and Rep. Ehlers participating in one of the panels, and because it was focusing on theological-religious arguments about a third of the time. The panel on religious perspectives was intended to provide diverse religious views all united in their opposition to human cloning. You can imagine the surprise and chagrin the sponsors experienced when Rabbi Byron Sherwin (Vice President of Academic Affairs, Spertus College of Judaica) generally agreed with NBAC's report and, on grounds somewhat different from Rabbis Tendler and Dorff (in appealing to the extended commentary over the centuries on a Talmudic story about the creation of an anthropoid), supported the possibility of human cloning once the safety factors are surmounted (as he is confident they will be). He argued at one point: "In my opinion, we have more to fear, for instance, from computers than from cloning. A computer can wipe out any trace of our very existence, whereas a clone could help perpetuate it." Rabbi Sherwin further noted that little opposition to human cloning, beyond the safety issues, has emerged in Orthodox Judaism and Conservative Judaism, both of which appeal to legal precedents, but that some Reform Jews have expressed opposition in "vague" terms such as respect for dignity. Having expected to present a more united front against human cloning, and perhaps one more critical of NBAC's report, the organizers of

the conference had to watch much of the subsequent discussion focus on Rabbi Sherwin's paper rather than on the more critical Protestant (Ben Mitchell of Southern Baptist Theological Seminary) and Roman Catholic (John Grabowski of CU) papers.

See you in a couple of weeks.

James F. Childress
Kyle Professor of Religious Studies &
Professor of Medical Education
University of Virginia
Cocke Hall
Charlottesville, VA 22903
Tel. (804) 924-3741
Fax (804) 924-1467
e-mail: jfc7c@virginia.edu

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: jfc7c@virginia.edu (jfc7c@virginia.edu [UNKNOWN])

CREATION DATE/TIME:30-JUN-1997 19:41:33.00

SUBJECT: HSSC Mtg

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

To: NBAC Members

From: Jim Childress

Subj.: HSSC Mtg

The HSSC will meet all day Tuesday, July 15, beginning around 8:00 AM and ending around 4:00 or 4:30-- we hope that most members of the whole commission will be able to join the discussion. Your suggestions have already been most helpful in developing the tentative agenda that follows, and I would appreciate any additional suggestions you might have:

First, we will discuss our federal agency report with attention to patterns that have emerged in the phase I (structure) and phase II (process/implementation) interviews, the direction of the final report, and a rough schedule for drafting and reviewing its different parts (Freeman, Feinstein, and Mangel).

Second, we will devote a large block of time to a serious and sustained discussion of possible guidelines for cognitively or decisionally impaired research subjects. Everyone should read carefully Rebecca Dresser's excellent contract draft paper on this subject; we will discuss it with her to see whether we have suggestions for additions, changes, etc. We will also discuss with Jonathan Moreno, who will be working closely with the HSSC over the next several months, some background materials for a possible report on this topic. In addition, we will hear from Nina Schooler, Adil Shamoo, and an as yet undetermined representative from NIMH on ethical issues that arise in research with cognitively impaired subjects and on the kinds of guidelines, if any, that should be developed. Finally, Paul Appelbaum will discuss his (and his colleagues') studies of competence measurements for use in treatment and research decisions. We have circulated a large body of materials on this topic since December; please review these materials again along with the transcripts of our meetings. Other new materials will include Trish Backlar's paper on advance directives for research.

Third, we will discuss the issues and proposals Alex Capron raised in his memorandum of May 30, 1997 (circulated in conjunction with our June 7 meeting) regarding the lack of data in federal research oversight. We'll send early next week, along with other materials for the meeting, another copy of Alex' earlier memorandum in case it got misplaced in all the cloning materials.

Fourth, we will seek to set priorities for our work, in light of our extended life expectancy, and determine how we might proceed with topics that we have selected or that have been assigned to us, including compensation for research-related injuries, which we hope to complete this year, and the use of children and adolescents in research, which we have discussed working on early next year. I will provide an update of the progress of the two IRB studies that are underway so that we can determine what else we might need to do to provide the kind of report on IRBs that the administration has requested (see Building Public Trust). We will talk about current and possible additional contract papers.

Finally, please bring your calendars for the next two months so that we can determine when it might be possible to have another HSSC meeting, prior to the next scheduled NBAC meeting, if we find that we need to do so.

Please give me your thoughts and suggestions. I look forward to seeing you in two weeks.

James F. Childress
Kyle Professor of Religious Studies &
Professor of Medical Education
University of Virginia
Cocke Hall
Charlottesville, VA 22903
Tel. (804) 924-3741
Fax (804) 924-1467
e-mail: jfc7c@virginia.edu

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 1-JUL-1997 10:52:21.00

SUBJECT: Fireworks and cloning

TO: JoAnn Ward (CN=JoAnn Ward/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Barbara Walton (CN=Barbara Walton/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Mary Kay Vaske (CN=Mary Kay Vaske/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Franklin F. Urteaga (CN=Franklin F. Urteaga/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Ben L. Trachtenberg (CN=Ben L. Trachtenberg/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Sandra J. Toomey (CN=Sandra J. Toomey/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Sheri A. Thornton (CN=Sheri A. Thornton/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Jeffrey M. Smith (CN=Jeffrey M. Smith/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Frances Sharples (CN=Frances Sharples/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Daniel Rochberg (CN=Daniel Rochberg/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Steven M. Rinaldi (CN=Steven M. Rinaldi/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Maria R. Reff (CN=Maria R. Reff/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Andrea I. Razzaghi (CN=Andrea I. Razzaghi/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Malini Ramanarayanan (CN=Malini Ramanarayanan/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Donald Pryor (CN=Donald Pryor/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Angela Phillips Diaz (CN=Angela Phillips Diaz/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Lori A. Perine (CN=Lori A. Perine/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Barbara A. Panko (CN=Barbara A. Panko/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Elaine R. Padovani (CN=Elaine R. Padovani/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Timothy L. Newell (CN=Timothy L. Newell/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Irwin Nepo (CN=Irwin Nepo/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Stephen G. Moran (CN=Stephen G. Moran/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Ernest J. Moniz (CN=Ernest J. Moniz/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Mary E. Mogue (CN=Mary E. Mogue/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Joann Miller (CN=Joann Miller/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Monisha M. Merchant (CN=Monisha M. Merchant/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Jerry M. Melillo (CN=Jerry M. Melillo/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Alicia McKay (CN=Alicia McKay/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Deborah J. McGovern (CN=Deborah J. McGovern/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Jerold R. Mande (CN=Jerold R. Mande/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Jonathan T. Makler (CN=Jonathan T. Makler/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Bruce W. MacDonald (CN=Bruce W. MacDonald/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Martha A. Livingston (CN=Martha A. Livingston/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Audrey J. Lee (CN=Audrey J. Lee/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Cecilia D. Lafoe (CN=Cecilia D. Lafoe/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Jason Y. Kim (CN=Jason Y. Kim/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Gerald P. Kiernan (CN=Gerald P. Kiernan/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Henry C. Kelly (CN=Henry C. Kelly/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Brian G. Kahin (CN=Brian G. Kahin/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Kerri A. Jones (CN=Kerri A. Jones/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Carolyn S. Huntoon (CN=Carolyn S. Huntoon/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Jefferson Hofgard (CN=Jefferson Hofgard/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Mark D. Hodge (CN=Mark D. Hodge/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Cheryl E. Hill (CN=Cheryl E. Hill/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Donald Hillebrand (CN=Donald Hillebrand/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: David Heyman (CN=David Heyman/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Beverly K. Hartline (CN=Beverly K. Hartline/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Gerald J. Hane (CN=Gerald J. Hane/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Holly L. Gwin (CN=Holly L. Gwin/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Daniel L. Goroff (CN=Daniel L. Goroff/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Clifford J. Gabriel (CN=Clifford J. Gabriel/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Thomas A. Fuhrman (CN=Thomas A. Fuhrman/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Sybil Francis (CN=Sybil Francis/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Jonathan Foster (CN=Jonathan Foster/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Miriam A. Forman (CN=Miriam A. Forman/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Roxana E. Folescu (CN=Roxana E. Folescu/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Ruth A. Fisher (CN=Ruth A. Fisher/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Barbara A. Ferguson (CN=Barbara A. Ferguson/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Tanya M. Felder (CN=Tanya M. Felder/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Gerald L. Epstein (CN=Gerald L. Epstein/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Laura L. Efros (CN=Laura L. Efros/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Marjorie R. Dial (CN=Marjorie R. Dial/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Thomas M. Cronin (CN=Thomas M. Cronin/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Gregg P. Cramer (CN=Gregg P. Cramer/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Sandy L. Cole (CN=Sandy L. Cole/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Donna I. Coleman (CN=Donna I. Coleman/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Daryl E. Chubin (CN=Daryl E. Chubin/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Cynthia M. Chase (CN=Cynthia M. Chase/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Christina M. Chase (CN=Christina M. Chase/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Cathleen A. Campbell (CN=Cathleen A. Campbell/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Rosina M. Bierbaum (CN=Rosina M. Bierbaum/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Mark Bernstein (CN=Mark Bernstein/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Deanna M. Behring (CN=Deanna M. Behring/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Susan L. Bassow (CN=Susan L. Bassow/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Samuel F. Baldwin (CN=Samuel F. Baldwin/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Peter W. Backlund (CN=Peter W. Backlund/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: Lorena E. Ahumada (CN=Lorena E. Ahumada/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: John W. Ahlen (CN=John W. Ahlen/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TEXT:

Thought that would get your attention! Willing to trade a copy of the best-selling report "Cloning Human Beings" by the all-time great group, National Bioethics Advisory Commission, for access to the fireworks for Science Division intern, Monisha Merchant, and my wonderful brother-in-law. Also willing to entertain other requests for copies of the report in exchange for GOOD cloning jokes.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Laura L. Efros (CN=Laura L. Efros/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 1-JUL-1997 10:56:02.00

SUBJECT: Re: Fireworks and cloning

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Rachel,

I believe that last year all the interns were allowed in as a group.
Someone in Admin should be making sure that our interns are included with
the White House interns. As for your brother-in-law, maybe he should
bring a saxophone and pretend he's with the band.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Mark D. Hodge (CN=Mark D. Hodge/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 1-JUL-1997 10:59:24.00

SUBJECT: Re: Fireworks and cloning

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

OK

Rachel E. Levinson 07/01/97 10:53:00 AM

Record Type: Record

To: All OSTP Users

cc:

Subject: Fireworks and cloning

Thought that would get your attention! Willing to trade a copy of the best-selling report "Cloning Human Beings" by the all-time great group, National Bioethics Advisory Commission, for access to the fireworks for Science Division intern, Monisha Merchant, and my wonderful brother-in-law. Also willing to entertain other requests for copies of the report in exchange for GOOD cloning jokes.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Susanne Bachtel (CN=Susanne Bachtel/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 1-JUL-1997 11:06:47.00

SUBJECT: Re: Fireworks and cloning

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:

I'm already overbooked on my pass, but last year I think they would have let you in with a couple of extra people. (altho I don't want to be responsible if they don't make it!)

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Beverly K. Hartline (CN=Beverly K. Hartline/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 1-JUL-1997 11:22:54.00

SUBJECT: Re: Fireworks and cloning

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:

Thanks for trying to help Monisha. Unfortunately I won't be in town. Is there anything else I could do to earn a cloning report?

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: HughWach@aol.com (HughWach@aol.com [UNKNOWN])

CREATION DATE/TIME: 1-JUL-1997 13:21:31.00

SUBJECT: Re: RE: PCW September Event

TO: RMorgan%LMDC@mcimail.com (RMorgan%LMDC@mcimail.com [UNKNOWN])
READ:UNKNOWN

TO: hpyle@alumni.princeton.edu (hpyle@alumni.princeton.edu [UNKNOWN])
READ:UNKNOWN

CC: Peter.Reilly@usccr.sprint.com (Peter.Reilly@usccr.sprint.com [UNKNOWN])
READ:UNKNOWN

CC: Bruce W. MacDonald (CN=Bruce W. MacDonald/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

CC: HughWach@aol.com (HughWach@aol.com [UNKNOWN])
READ:UNKNOWN

TEXT:

Howard, Tiny, Bruce, Peter et al,
Got the note on the change in the kickoff event for September. I for one
am happier -- thought the other room a little too sterile.
Any other details, send 'em along.

Hugh

PS -- Howard, what about a triple cloning?

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Angela Phillips Diaz (CN=Angela Phillips Diaz/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 1-JUL-1997 11:25:03.00

SUBJECT: Re: Fireworks and cloning

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

wish I could help, but I wont be here; sorry.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 1-JUL-1997 16:46:14.00

SUBJECT: Cloning

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TO: Clifford J. Gabriel (CN=Clifford J. Gabriel/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

CC: Angela Phillips Diaz (CN=Angela Phillips Diaz/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:
Rachel, Cliff,

May we meet regarding a possible response from PCAST on the NBAC report?
I propose Tuesday afternoon, July 8 (since it looks okay on everyone's
calendar). However, instead of a meeting, you may want to give me
feedback on whether or not PCAST should respond with another letter to
POTUS, and if so, what you think the response should be. Thanks much.
Yolanda

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME: 2-JUL-1997 11:32:47.00

SUBJECT: Re: National Bioethics Advisory Commission

TO: Sltaylor33 (Sltaylor33 @ aol.com [UNKNOWN])
READ:UNKNOWN

TEXT:
Ms. Taylor,

I am sorry that your request was not answered. The most expedient way to get the report is to call or send a fax to the National Bioethics Advisory Commission, 301-402-4242 (phone) or 301-480-6900 (fax). The report is called Cloning Human Beings: Report and Recommendations of the National Bioethics Advisory Commission.

Yolanda L. Comedy
President's Committee of Advisors
on Science and Technology

Sltaylor33 @ aol.com
07/02/97 11:16:01 AM
Record Type: Record

To: ycomedy
cc:
Subject: Re: National Bioethics Advisory Commission

Dear Ms. Comedy

I thank you for your response to my request for Dr. Shapiro's report of June 9, 1997 regarding the subject of human cloning .
I have not received information from the individual that you indicated may reply.
I would appreciate your assistance or direction.
My genetics class is hoping to use this information to have a lively discussion on ethics.
Thank you for your time and guidance.

Susan L. Taylor
sltaylor@aol.com

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Sltaylor33@aol.com (Sltaylor33@aol.com [UNKNOWN])

CREATION DATE/TIME: 2-JUL-1997 11:17:05.00

SUBJECT: Re: National Bioethics Advisory Commission

TO: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP [OSTP])

READ:UNKNOWN

TEXT:

Dear Ms. Comedy

I thank you for your response to my request for Dr. Shapiro's report of June 9, 1997 regarding the subject of human cloning .

I have not received information from the individual that you indicated may reply.

I would appreciate your assistance or direction.

My genetics class is hoping to use this information to have a lively discussion on ethics.

Thank you for your time and guidance.

Susan L. Taylor
sltaylor@aol.com

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: racharo@facstaff.wisc.edu (racharo@facstaff.wisc.edu [UNKNOWN])

CREATION DATE/TIME: 3-JUL-1997 17:38:51.00

SUBJECT: ABAC Report - Introduction

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

> Ban Human Cloning: Report of the American Bioethics Advisory
> Commission

>
> (Click here for full text)

>
> Introductory letter:

>
> June 21, 1997

>
> William J. Clinton

>
> President, United States of America

>
> Washington, DC

>
> Dear Mr. President,

>
> The field of genetics is exciting and promising, but brings with
> it some serious challenges. The promises and challenges of the field
> were brought to public attention very dramatically in February this
> year, with the report from Scotland of successful cloning of a mammal.
> If the experiment at the Roslin Institute can be repeated, it would be
> an event of immense importance.

>
> The excitement and joy of this scientific breakthrough (if the
> experiment can be repeated) may be overshadowed by legitimate and
> grave concerns about the future, unless this nation and indeed all
> nations move quickly to protect legitimate science and to ban
> dangerous and irresponsible abuses. Fortunately, with regard to
> cloning, the line between the two is very clear: we should encourage
> responsible experiments in animal cloning, but ban all human cloning.
> The bright line dividing legitimate and exciting scientific research
> and development from dangerous and dehumanizing manipulation is easy
> to see: it is the line between animals and humans.

>
> To be sure, animal cloning has some hazards, and human cloning
> has some attractions. But the hazards of animal cloning (such as
> possible threats to biodiversity) can be handled responsibly, and the
> attractions of human cloning (human embryo research) can be foregone.
> Seeing the bright line, and ensuring that all scientists see it and
> respect it, will protect legitimate scientific endeavors while

> preventing assaults on human life and dignity.

>

> The American people and indeed all people everywhere have a right
> to the legitimate excitement and joy that accompanies scientific
> breakthroughs. But the report from Scotland raised grave concerns
> about the future of humanity. Many people have compared the promise
> and threat of cloning to the promise and threat of nuclear power. For
> the good of the nation and the world and science, we must embrace what
> is good and reject what is evil.

>

> Science and technology throughout the United States and the world
> will operate under a cloud of suspicion unless we can explain clearly
> how to distinguish real benefits from momentous harms. Scientists and
> bioethicists have a grave responsibility to understand the
> distinctions, to respect them, to articulate them fully, and to
> communicate them to the general public. Conversely, if any scientist
> or bioethicist should overlook or blur key distinctions, that person
> would be doing immense disservice to the nation, the world and to
> science.

>

> In February 1997, you asked the National Bioethics Advisory
> Commission to help you and the nation to think through an appropriate
> response to the report of sheep cloning and the prospect of human
> cloning. They have worked to respond to your request. At the same
> time, the American Bioethics Advisory Commission was established to
> ensure that the voices of grassroots Americans would also be
> represented in national debates, and we have also worked to understand
> how to separate the good from the evil. We are pleased to present this
> report to you and to all interested individuals. Our advice is very
> simple:

>

> 1. Encourage responsible animal cloning.

>

> 2. Ban human cloning immediately, completely and permanently.

>

> It is not often in the history of science that a breakthrough
> brings dramatic promise and grave dangers of the magnitude associated
> with mammalian cloning. It is the task of the leaders of this nation
> and of the world to embrace the benefits and avoid the calamities. The
> dividing line is obvious, and we urge you to protect that line
> scrupulously.

>

> Throughout the history of this nation, people have pondered the
> wisdom found in Scripture, including the sharp challenge in the words
> of Moses. He said that the command of God is not mysterious or remote,
> that it was not up in the sky or across the sea. Rather, it is very
> near to us, in our mouths and in our hearts; we have only to carry it
> out. Moses said (Deut 30: 19-20):

>

> "I call heaven and earth today to witness against you: I have set
> before you life and death, the blessing and the curse. Choose life,
> then, that you and your children may live, by loving the Lord, your
> God, heeding his voice, and holding fast to him."

>

> Mr. President, with regard to the promise and danger of cloning,
> there is a bright line between the blessing and the curse. Encourage
> animal cloning, but ban all human cloning immediately, completely and
> permanently. Hold the line.
>
> C. Ward Kischer, PhD, University of Arizona, Chairman, American
> Bioethics Advisory Commission
>
> Paul A. Byrne, MD, President-elect, Catholic Medical Association
>
> Ronda Chervin, PhD, Sedona, AZ
>
> William F. Colliton, MD, Bethesda, MD
>
> Donald J. DeMarco, PhD, St. Jerome's College
>
> Eugene F. Diamond, MD, Chicago, IL
>
> Rev. Joseph Howard, Shreveport, LA 71101
>
> Bernard Nathanson, MD, New York, NY
>
> Dr. Joseph Pastorek II, MD, Louisiana State University Medical Center
>
> Prof Charles Rice, Notre Dame Law School
>
> Dr. Jerome T.Y. Shen, MD, FAAP, University City, MO
<http://www.all.org/clon-rep.htm>
<BASE HREF="<http://www.all.org/clon-rep.htm>">

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<!-- Created by AOLpress/1.2 -->

<TITLE>ABAC Report - Introduction</TITLE>

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Ban Human Cloning: Report of the American Bioethics Advisory
Commission

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Introductory letter:

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<P>

June 21, 1997

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<P>

William J. Clinton

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President, United States of America

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Washington, DC

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To be sure, animal cloning has some hazards, and human cloning has some attractions. But the hazards of animal cloning (such as possible threats to biodiversity) can be handled responsibly, and the attractions of human cloning (human embryo research) can be foregone. Seeing the bright line, and ensuring that all scientists see it and respect it, will protect legitimate scientific endeavors while preventing assaults on human life and dignity.

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Science and technology throughout the United States and the world will operate under a cloud of suspicion unless we can explain clearly how to distinguish real benefits from momentous harms. Scientists and bioethicists have a grave responsibility to understand the distinctions, to respect them, to articulate them fully, and to communicate them to the general public. Conversely, if any scientist or bioethicist should overlook or blur key distinctions, that person would be doing immense disservice to the nation, the world and to science.

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In February 1997, you asked the National Bioethics Advisory Commission to help you and the nation to think through an

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<P>

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<P>

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"I call heaven and earth today to witness against you: I have set before you life and death, the blessing and the curse. Choose life, then, that you and your children may live, by loving the Lord, your God, heeding his voice, and holding fast to him."

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<P>

<P>

C. Ward Kischer, PhD, University of Arizona, Chairman, American Bioethics Advisory Commission

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<P>

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Eugene F. Diamond, MD, Chicago, IL

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Rev. Joseph Howard, Shreveport, LA 71101

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Bernard Nathanson, MD, New York, NY

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Dr. Joseph Pastorek II, MD, Louisiana State University Medical Center

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Prof Charles Rice, Notre Dame Law School

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Dr. Jerome T.Y. Shen, MD, FAAP, University City, MO

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RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Angela Phillips Diaz (CN=Angela Phillips Diaz/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:14-JUL-1997 11:41:15.00

SUBJECT: NBAC Report for PCAST

TO: Yolanda L. Comedy (CN=Yolanda L. Comedy/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

Angela Phillips Diaz (CN=Angela Phillips Diaz/OU=OSTP/O=EOP [OSTP])

READ:UNKNOWN

TEXT:

let's discuss @ our weekly

----- Forwarded by Angela Phillips Diaz/OSTP/EOP on
07/14/97 11:40 AM -----

Angela Phillips Diaz
06/25/97 09:43:40 AM
Record Type: Record

To: Yolanda L. Comedy/OSTP/EOP
cc:
Subject: NBAC Report for PCAST

Yolanda:

I would recommend that we get copies of "Cloning Human Beings" report & recommendations of the NBAC for PCAST. Prior to sending it to them, we should pull the PCAST letter to POTUS & POTUS response & meet w/ Gabriel, Gwin, & Levinson to determine what action if any we want to assign to PCAST in the cover transmittal letter. I would welcome your thoughts/proposals on how to proceed also.

Thanks.

Angela

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Mark.CANTLEY@oecd.org (Mark.CANTLEY@oecd.org [UNKNOWN])

CREATION DATE/TIME:15-JUL-1997 16:30:17.00

SUBJECT: US comments on dr doc, "Econ Aspects of Biot & Human Health"

TO: ronchi@oecd.org (ronchi@oecd.org [UNKNOWN])
READ:UNKNOWN

TO: 514@bmbf.bund400.de (514@bmbf.bund400.de [UNKNOWN])
READ:UNKNOWN

TO: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP [OSTP])
READ:UNKNOWN

TO: PETER.LANGE@bmbf.bund400.de (PETER.LANGE@bmbf.bund400.de [UNKNOWN])
READ:UNKNOWN

TO: martin.kueenzi@pharma.novartis.com (martin.kueenzi@pharma.novartis.com [UNKNOWN])
READ:UNKNOWN

TO: Laure.Benzing-Purdie@isdtcp3.hwc.ca (Laure.Benzing-Purdie@isdtcp3.hwc.ca [UNKNOWN])
READ:UNKNOWN

TO: karoline.dorsch@buwal.admin.ch (karoline.dorsch@buwal.admin.ch [UNKNOWN])
READ:UNKNOWN

TO: infounit@hefm.demon.co.uk (infounit@hefm.demon.co.uk [UNKNOWN])
READ:UNKNOWN

TO: yossy@m.u-tokyo.ac.jp (yossy@m.u-tokyo.ac.jp [UNKNOWN])
READ:UNKNOWN

TO: paulig@rki.de (paulig@rki.de [UNKNOWN])
READ:UNKNOWN

TO: david.harper@hesinfo.deamon.co.uk (david.harper@hesinfo.deamon.co.uk [UNKNOWN])
READ:UNKNOWN

TO: cantley@oecd.org (cantley@oecd.org [UNKNOWN])
READ:UNKNOWN

TO: tcueni@interpharma.ch (tcueni@interpharma.ch [UNKNOWN])
READ:UNKNOWN

TO: RADDY@doh.gov.uk (RADDY@doh.gov.uk [UNKNOWN])
READ:UNKNOWN

TO: maurice.LEX@DG12.cec.be (maurice.LEX@DG12.cec.be [UNKNOWN])
READ:UNKNOWN

TO: marion.gmach@bmg.gv.at (marion.gmach@bmg.gv.at [UNKNOWN])
READ:UNKNOWN

TO: marke@sbu.se (marke@sbu.se [UNKNOWN])
READ:UNKNOWN

TO: jamate@isciii.es (jamate@isciii.es [UNKNOWN])
READ:UNKNOWN

TO: isabella.beretta@bbw.admin.ch (isabella.beretta@bbw.admin.ch [UNKNOWN])
READ:UNKNOWN

TO: michaliszyn.george@ic.gc.ca (michaliszyn.george@ic.gc.ca [UNKNOWN])
READ:UNKNOWN

TO: 106150.3672@compuserve.com (106150.3672@compuserve.com [UNKNOWN])
READ:UNKNOWN

TO: frontali@vaxsan.iss.infn.it (frontali@vaxsan.iss.infn.it [UNKNOWN])
READ:UNKNOWN

CC: coleman.nee@oecd.org (coleman.nee@oecd.org [UNKNOWN])
READ:UNKNOWN

CC: Michael.OBORNE@oecd.org (Michael.OBORNE@oecd.org [UNKNOWN])
READ:UNKNOWN

TEXT:

Many thanks, Rachel, for transmitting to us the initial US comments on the draft document, "Economic Aspects of Biotechnologies related to Human Health". We note that further comments from FDA (via yourself) are to be expected shortly (18/21 July), but to maintain momentum we are immediately starting work on the matters raised in your communication of 10 July. (A week-end and "Bastille Day" have intervened since its arrival).

This covering note is to acknowledge receipt of your communication; to transmit it (as an attachment to this memo) to members of the Steering Group (with your agreement, as confirmed by 'phone to-day - thanks); to make some general comments in response to the points raised; and to indicate that we are starting on the revisions and additions through which we propose to meet the concerns expressed. We shall await the receipt of your remaining comments before dispatching (or placing on the Electronic Discussion Group) the proposed revised text.

For ease of reference, we have numbered the 25 paragraphs of your memo (excluding titles), i.e.

Introductory / covering memo: 1-4

Comments on Full Report: 5-7

Comments on Revised Exec, Summ. + Linkage Elements: 8-13

Brief Comments on Other Components of the Report:

- Outline of Outreach Policy Doc: 14-16
- Section I: 17
- Section II: 18
- Section III: 19-22
- Section IV: 23-26.

General comments

2) & 3): here and elsewhere, the general question of fulfilment of objectives requires us to examine the original agreed statement of objectives. These are summarised in para 13 of the Executive Summary of the Part I report:

"13. For the first phase of the project, reported in this volume, four specific objectives were formulated:

1. provide an up to date review of current and forthcoming developments of biotechnology in the health care sector, defining some of the key questions;
2. identify methods currently available to policy makers for the economic evaluation of new medical biotechnologies;
3. determine whether there are methodological inadequacies in the existing systems of economic evaluation of new biotechnologies, and consider their implications for the process of innovation;
4. determine whether the use of the various techniques of technology assessment and economic appraisal is effectively integrated into overall systems of health care planning and delivery."

The implication that biotech is inherently or inevitably more expensive is certainly not the intended message; rather, the papers make clear that in some cases (e.g. EPO), the cost may be more, but it also delivers more - e.g. in quality of life - for needs previously unmet or less than adequately treated. In other cases, costs in early stages of an innovation may be apparently high, but particularly at such stages are not an adequate basis for confident economic evaluation. (See chapters by Drummond & Mason, and by Kobelt).

- 4) As suggested here, we shall seek to met the US points by modifications to the Executive Summary and Linkage pages.

Full report

5)-7) The criticisms of excessive length, stylistic inconsistency and perhaps of disproportion, we hope to meet by the preparation of the two "Policy Reports" based on the full papers. Regarding disproportion, and later comments on the length devoted to genetic testing, a general problem of balance was presented by the impossibility of covering in depth all the many areas of potential application of biotechnology to health care. Our selection of case studies was considerably influenced by the prospect of availability of sufficient documentation. We acknowledge the importance of subjects such as cloning and fertility treatments, and xenotransplantation; however, evaluation did not yet seem possible. At the same time, the introductory paper on the science and technology was intended to give a broader "waterfront" coverage of the potential. This made it more difficult to link this chapter with the case studies selected for inclusion.

Executive Summary and Linkage Elements

9) We shall add some wording to bring out more clearly the rationale and focus of the report.

10) "Some of the roles described for industry seem unrealistic" - this criticism probably has more force in some OECD countries than others; we shall qualify the statements accordingly, using some of the language in the US comment.

11) We shall reduce the section of the Executive Summary referring to the genetic testing.

12) We shall bring forward to an earlier point in the Executive Summary some of the related points.

13) The points about greater riskiness are supported by material in the Kobelt paper, some elements of which could be inserted in the Executive summary. The increasing length of time, and cost, of developing and securing registration for a new product are widely documented, and create risks for small companies in terms of the greater "lumpiness" of the business. Recent volatility of stock prices of biotech companies in response to disappointing results of late-stage (Phase III) trials have illustrated this. These subjects are treated extensively in Part II (please see EDG pages).

Outline of Outreach Policy Document

14) Source and context will be clarified.

15) In drafting the full text of the Policy Document, the points about the various impacts of biotechnology products on costs will be clarified.

The Science and the Technology

16) It is true that this paper has been drafted separately from the other papers; it aims at a reasonably comprehensive overview, whereas the case studies are selected, and few in number. Also, a major criterion in the selection was the availability of sufficient historical data to make some evaluations and judgements; thus militating against the inclusion of leading edge areas such as gene therapy, for which it could not yet be realistic to carry out serious economic evaluation except in the broadest terms (e.g. of scale of unmet need). Some sentences to clarify the relation between the first and subsequent sections will be added in the Executive Summary.

Section I

17) Agreed - this section is fundamental to the whole report, and we shall examine whether this could be more clearly emphasised in the Executive Summary or first Linkage pages.

Section II

18) We feel that the comment is not entirely fair to Murray's paper. The section is not seeking to provide an overview and appraisal of the state of development of recombinant vaccines, but does address a number of other important economic / policy issues, where there is a large unmet need, predominantly in developing countries; and where the number of companies participating in development work is obviously greater than the likely number of "winners" in terms of successfully arriving at a commercially viable product. We shall seek in the linkage pages to clarify the rationale and relevance.

Section III

19) et seq: The length devoted to this topic may in part reflect the interests of the authors - but Dr Battista by background, present responsibilities, and his presidency of ISTAHC highly qualified to make these judgements, and as Secretariat we were therefore reluctant to fight strongly against them, the more so given the high public and political interests shown in these applications of modern biotechnology.

22) Historically and currently, most clinical applications of genotypic diagnosis have been applied for single-gene disorders which have high or 100% prognostic reliability. More recently, there has arrived a number of genes more associated with propensity, or forming only partial or contributory factors, e.g. in multi-factorial phenomena. It is indeed this shift from patterns of "inevitability" to a more complex and troubling proliferation of information relating to propensities which gives rise to harder problems of economics, ethics and clinical counselling practice, and hence of policy. These complexities of course partly explain the length of this chapter.

Section IV

23) See remarks above about selection of case studies for which documentation was available.

24) Biotechnology augmenting quality of life - we agree with this point, and will seek to augment the Executive Summary to strengthen this further.

25) IPR aspects are treated in Part II of the report; we shall consider incorporating a suitable cross-reference to this.

26) We acknowledge that there may be some redundancy with Drummond & Mason's short paragraph on GCSF; but here it facilitates the reading of the chapter as a coherent whole.

We await your further comments, which we shall seek to address also, and then distribute a revised (marked) text via the EDG.

Date: Tue, 15 Jul 1997 21:41:00 +0200 (MET)

From: "Mark CANTLEY, STI/BIO"@mr.oecd.org

Subject: Comments on Economic Aspects of Biotechnologies

MIME-version: 1.0

Content-type: TEXT/PLAIN; CHARSET=US-ASCII

Posting-date: Tue, 15 Jul 1997 00:00:00 +0200 (MET)

A1-type: DOCUMENT

E-mail from Rachel Levinson of US Office of Science and Technology Policy to M. Cantley and E. Ronchi of OECD, also to C. Nee of US Delegation to the OECD

Object: Comments on Economic Aspects of Biotechnologies

Message Creation Date was at 10-JUL-1997 16:00:00

1) The attached document represents our initial comments regarding the draft document, "Economic Aspects of Biotechnologies Related to Human Health." I will receive another set of comments but felt that it would be appropriate to forward these, given time constraints. The FDA expects to finish its comments by the end of next week. Their initial comments on the introduction are very positive.

2) I am most concerned that the current document does not accomplish the goal we originally set, that is, in an international context, how do human health products produced through biotechnology rate when compared to other, more traditional forms of therapy.

3) The current document, in some cases, perpetuates the notion that biotech is more expensive, without supporting documentation, or implies that safety concerns justify a more rigorous (and thus more expensive) regulatory review.

4) I believe that certain adjustments addressed in detail in the attached comments can help to improve the document and correct certain misperceptions or inaccuracies. As I have discussed with Elettra and David Harper, it is my understanding that such corrections would be accomplished via the Executive Summary and the linkage pages, rather than

editing the contract papers. I hope that it will be possible to take an intermediate approach that will improve the final document without taking such a long time that its usefulness is diminished. I realize that I have been tardy in delivering comments and apologize to you and the WPB.

U.S. Comments on the OECD Report on The Economic Aspects of Biotechnologies Related to Human Health

Comments on the Full Report

5) In its present state, the report is a compendium of papers developed by numerous contractors. As a consequence, it is much too long, gives disproportionate emphasis to some subjects, and provides insufficient discussion of others. It could greatly benefit from the attention of an editor with an understanding of the report's objectives and content, who can impart brevity, substantive balance, and stylistic consistency.

6) Implied in the stated objectives of the report is the notion that it will allow policy makers in OECD member countries to improve their own approaches to the assessment and economic appraisal of new technologies. Yet, the treatment of economic issues is actually quite superficial and the report contains little quantitative analysis, and thus may be of limited utility to those who must study these issues thoughtfully.

7) In addition, considering all of the products and activities that the new biotechnologies have yielded, the report focuses disproportionately on genetic testing. Genetic testing is a significant development fraught with ethical and scientific considerations, but it is certainly not the most important development from an economic point of view. Some attention is given to gene therapy, monoclonal antibodies, and vaccine development, but these discussions seem limited relative to the portion of the document devoted to genetic testing. Regarding these products, the emphasis of the report is on their economic impact relative to disease management and prevention, and almost no attention is given to the other ways in which these products benefit national economies, such as through the revenues associated with their patenting, licensing, and sale. Other products of biotechnology with important health and economic consequences and promise are virtually ignored, including reproductive technologies (e.g., cloning, fertility treatments), genetically-engineered tissues for transplantation, genetically-modified animal models for human disease, animals engineered to yield xenotransplantable tissues and organs, and so on.

Comments on the Revised Executive Summary and Linkage Elements (Dist. 02-May-1997, doc # 51579)

8) One goal of the Executive Summary should be to convey succinctly the content of the full report, which it does successfully for the most part. Although it mirrors some of the problems described above, it also corrects some of the imbalance within the individual papers, many of which provide excessive content on scientific and ethical considerations. The Executive

Summary gives the reader a stronger sense of the objectives of the project and its economic focus than does the sum of the individual papers.

9) It would be helpful if the summary could give more attention to the rationale for the focus of the report. In other words, it should explain, *Why biotechnology?* An underlying concern seems to be that the products of biotechnology are somehow more costly than other forms of technology used in health care, and therefore countries should give special attention to their costs when considering their approval or reimbursement for their use. One could argue, however, that the most expensive health care interventions generally have little to do with the *new* biotechnologies as defined in this report. The report does suggest that biotechnologies have a harder time getting approved due to concerns over safety, but this observation does not speak directly enough to relevant economic questions. Thus, some additional justification for the report's focus would be useful.

10) Drawing on the Drummond and Mason paper, the Executive Summary suggests some roles for government and individual companies in developing economic evaluations of biotechnology products. Some of the roles described for industry seem unrealistic. For example, one bullet in paragraph 55 states, *governments should ensure that biotechnology companies, particularly the smaller ones, are aware of the potential need for economic evaluations [of biotechnology products] and are well prepared.* In fact, many companies would argue instead that, in a free market, the only reasonable economic considerations relate to the demand for those products and whether they will recover their development costs and make a profit, given whatever prices the market will bear. It is probably not reasonable to expect companies to have macro-economic considerations in mind when developing new products. The reasons for the emphasis on *small companies* and the meaning of being *well prepared* as used in the sentence cited above are both completely unclear.

11) Because it reflects the imbalance of the full report, the Executive Summary focuses excessively on genetic testing, and delves further into issues of discrimination and privacy than is warranted for a paper on economic matters. Much attention is given to the conceptual framework for considering various types of genetic tests (and the diseases they identify), which might indeed be useful in a different sort of paper, but is once again too far removed from the supposed thrust of this piece. In addition, genetic testing takes place in both clinical and research settings, with different implications relevant to each. The lengthy classification scheme does not address this distinction.

12) The segment on genetic testing is then followed (beginning with paragraph 86) with a section titled, *Is the biotechnology industry under-estimating risks, and over-estimating success? Who pays for innovation?* This important and very globally-stated question seems like a non sequitur after the protracted and very specific discussion of genetic testing. The subsequent text then presents a very limited and unsatisfying discussion. A broader discussion of this question belongs somewhere earlier in this report.

13) The Executive Summary is followed by a series of linkage pages to other sections of the report. The purpose of these pages in terms of the overall organization of the report is not clear. The first linkage page asserts that the pharmaceutical business has become more risky, yet the report doesn't support this statement in any way. Do company financial statements or stock prices bear this out? Drug development has always been considered a process entailing a high degree of risk, but one could argue that new techniques (combinatory chemistry) and new strategies (developing new drugs) have increased the yield and lessened the risk of drug development somewhat. It is generally the new biotechnology pursuits of these companies, I believe, that inject an added element of risk, but this phenomenon is not explicitly addressed in this section.

Brief Comments on Other Components of the Report

Outline of an Outreach Policy Document (Dist. 29-Apr-1997, doc. # 51466) --

14) M Page 6, Figure 1 --This purports to show The total biotechnology industry by market segment, but the context is not clear. Does this chart portray the situation for the U.S. or the world?

15) M Page 10, paragraph 16 --The assertion made here (as is often made in other settings) is that new technologies increase the costs of medical care expenditures. While this is true of some technologies, particularly those associated with end-of-life or heroic treatments, the specific case of biotechnology is different and needs special consideration. One goal of biotechnology, for example, is to enable large-scale production (generally through genetically modified bacteria) of pharmaceutical products that otherwise would be produced synthetically in much smaller quantities, and thus more expensively.

Biotechnology and the New Revolution in Health Care and Pharmaceuticals: The Science and the Technology (Dist. 01-Apr-1997, doc. # 50237)

16) M This paper presumably is intended to provide the background on the scientific aspects of the new biotechnologies to allow lay readers to understand the types of technologies being discussed. Yet, it seems to have been drafted in isolation of the other papers, and thus the topics do not correlate well with those discussed in the rest of the report. For example, it describes much of the science behind somatic cell therapy, the economic consequences of which are barely discussed elsewhere. Somehow this paper need to be better integrated with the other papers (or vice-versa).

Section I: Economic Evaluation --The Challenge, the Need, and the Problems (Dist. 01-Apr-1997, doc. # 50239)

17) M This section seems to be reasonably well prepared and presents the thrust of what the paper as a whole should be about. Proportionately more attention should be given to this material than to the other sections of the report.

!&Section II: Economic Evaluations of Immunisation Programmes: The Case of Hepatitis B Recombinant Vaccine!8 (Dist. 03-Apr-1997, doc. # 50344)

18) M The report would be strengthened if recombinant vaccine development were addressed more generically, and less attention were devoted to this case example (or the case were placed in an appendix). It may simply be that the state of recombinant vaccine development is such that there just isn't enough generalizable knowledge in this area to discuss it at length. Nonetheless, this paper is longer than it needs to be.

!&Section III: Using Genetic Information: In Testing and Diagnosis!8 (Dist. 02-Apr-1997, doc. # 50290)

19) M As stated at length previously, disproportionate emphasis is given to this topic, and this paper should be much shorter. It also requires better organization and editing for accuracy and redundancy.

20) M Page 2, paragraph 5 states !&the issues surrounding genetic testing are rife with potential conflicts of interest!8 While this is an issue fraught with ethical considerations, !&conflicts of interest!8 are a minor consideration compared to issues of privacy and discrimination (all of which are tangential to the subject of this report).

21) M The Introduction (pages 5 to 7) does not provide very useful information.

22) M Page 8, paragraph 35 states, !&genotypic diagnosis is inherently prognostic!8 In fact, the opposite is true, and this is in part why genetic testing presents so many ethical dilemmas. There is concern that clinicians and patients will make treatment decisions and other important choices based on clinically equivocal genetic information. A case in point is the BRCA-1 gene, which was initially presumed to a fairly high degree of prognostic significance. Additional studies have shown, however, that the presence of BRCA-1 is much less predictive than originally believed, and thus its utility in clinical decision-making is in question.

!&Section IV: Lessons from the Process of Adoption of Two Biotechnology Breakthrough Drugs: EPO and GCSF!8 (Dist. 02-Apr-1997, doc. # 50291)

23) M As with other case examples, this one should be shorter and/or included in as an appendix item.

24) M This paper appropriately devotes attention to quality of life, which is difficult to measure, and yet one of the most vital considerations in determining the value of new technologies. Many technologies, particularly those that prolong the end of life, not only lead to tremendous cost, but add little in terms of quality of life. The promise of many biotechnology products is that they do augment quality of life, but insufficient attention is given to this in the Executive Summary and in the other cases.

25) M Page 9 gives attention to the important issue of intellectual

property. More attention could be devoted to this topic elsewhere.

26) M Pages 22 to 23 provide unnecessary and redundant information on the science behind CSF technology.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: TannerR@od6100m1.od.nih.gov (TannerR@od6100m1.od.nih.gov [UNKNOWN])

CREATION DATE/TIME:16-JUL-1997 20:12:33.00

SUBJECT:

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])

READ:UNKNOWN

TEXT:

Please be apprised that as of today all requests for the cloning report should be forwarded to

Robert Tanner

NBAC

6100 Executive Blvd * Suite 5B01A

Rockville, MD 20892

fax: 301.402.0906

email: rt69f@nih.gov.

Thank you for your cooperation.

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: acapron@law.usc.edu (acapron@law.usc.edu [UNKNOWN])

CREATION DATE/TIME:17-JUL-1997 18:24:09.00

SUBJECT: Re: your mail

TO: nbac-members@lists.Princeton.EDU (nbac-members@lists.Princeton.EDU [UNKNOWN])
READ:UNKNOWN

TEXT:

Rob:

What is the status of getting a "printed" (and bound) version of the report (and in smaller than 8.5 x 11" format)?? Is that still going to happen or just duplicate the "pre-print version" forever?

Alex

On Wed, 16 Jul 1997, Tanner, Rob wrote:

> Please be apprised that as of today all requests for the cloning report should be forwarded to

>

> Robert Tanner

> NBAC

> 6100 Executive Blvd * Suite 5B01A

> Rockville, MD 20892

> fax: 301.402.0906

> email: rt69f@nih.gov.

>

> Thank you for your cooperation.

>

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Skip.Stiles@mail.house.gov (Skip.Stiles@mail.house.gov [UNKNOWN])

CREATION DATE/TIME:18-JUL-1997 09:13:40.00

SUBJECT: Ehler's Bill Markup

TO: Jeffrey M. Smith (CN=Jeffrey M. Smith/OU=OSTP/O=EOP [OSTP])

READ:UNKNOWN

TEXT:

Jeff,

The Technology Subcommittee will be marking up the Ehlers bill to ban cloning using federal research (HR 922, "None of the funds made available in any Federal law may be expended to conduct or support any project of research that involves the use of a human somatic cell for the process of producing a human clone." - the active phrase in the bill) The legislation is referred to the Commerce Committee and the Science Committee, and the Commerce Committee apparently has no plans to move at this time.

We would like your input on what you would like to have done with this. Also, does this go beyond the EO already in force = what is the additionality of this legislation? Let me know.

Also, we are moving the computer security bill in the Technology Subcommittee as well that day - HR 1903.

Mike Quear is the contact on cloning and computer security (225-6917).

Hasta

Skip Stiles
Democratic Legislative Director
House Committee on Science
822 OHOB
Washington, DC 20515

(202) 225-8483
(202) 2260983 (fax)

committee home page - http://www.house.gov/science_democrats/

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Gerald J. Hane (CN=Gerald J. Hane/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:18-JUL-1997 11:10:38.00

SUBJECT: Dr. Mori's visit with JHG

TO: David Heyman (CN=David Heyman/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TO: Deanna M. Behring (CN=Deanna M. Behring/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TO: Laura L. Efros (CN=Laura L. Efros/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TO: Cathleen A. Campbell (CN=Cathleen A. Campbell/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TO: Kerri A. Jones (CN=Kerri A. Jones/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

CC: Gregg P. Cramer (CN=Gregg P. Cramer/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

CC: Gerald L. Epstein (CN=Gerald L. Epstein/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

CC: Rachel E. Levinson (CN=Rachel E. Levinson/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

CC: JoAnn Ward (CN=JoAnn Ward/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

CC: Bruce W. MacDonald (CN=Bruce W. MacDonald/OU=OSTP/O=EOP @ EOP [OSTP])
READ:UNKNOWN

TEXT:

From 8:30 -9:05 am Dr. Mori visited with Dr. Gibbons in room 424. Dr. Mori was accompanied by Japan's Science Counselor, Mr. Kuramochi.

Three subjects were discussed, 1) the Carnegie G7 meeting which Dr. Gibbons did not attend, 2) the timing of the JHLAP and JHLC meetings in 1998, and 3) Dr. Mori's desire to press certain medical science issues in Japan.

CARNEGIE G7

- CERN/LHC

Dr. Mori noted that CERN and the LHC was an "important" subject of discussion. European representatives expressed concern that they did not

have enough money to complete this project and were asking for Japan and the U.S. to increase their contributions.

Dr. Gibbons noted that we had just finished working with Congress to secure the funds that we had promised. He noted that Congress was keeping close scrutiny of U.S. participation and was particularly interested in ensuring some sort of a quid pro quo.

- ITER

Dr. Mori indicated that ITER was not a major topic of discussion. He noted that both Italy and Canada, which had expressed interest in being an ITER site earlier (?) were rather subdued. (Japan, as you know, as postponed any major increases in funding for about three years.)

Dr. Gibbons noted the importance of keeping fusion energy alive as an option for the future.

- Human Cloning

Dr. Mori noted that Ministers agreed that cloning a "human" was not acceptable science. They did feel, however, that cloning human cells was important for medical research. The French Minister raised the idea of all nations agreeing on a law to ban human cloning, but others responded that this would be best addressed within the context of each nation.

Dr. Mori noted that he has suggested to Prime Minister Hashimoto that Japan establish a Bioethics Commission to examine this and other issues. The Prime Minister was supportive, but the bureaucracy has been slow to move.

Dr. Gibbons noted that the selection of individuals on such a Commission was very important in the U.S. to ensure its credibility. He also noted that Harold Shapiro of Princeton might be a useful source of advice for Japan on this matter.

- Natural Disasters

Dr. Mori said that natural disasters were also discussed at some length, particularly earthquakes. Bob May of the UK was still optimistic about the future of earthquake prediction.

- Science Summit

Dr. Mori reported that they discussed the idea of a "Science Summit" to give the meeting more visibility and impact. He noted that the down side would be that this would formalize the meeting and participants would lose some ability to have free discussions.

Dr. Gibbons said that he was intrigued by this idea and that it deserved further discussion. He sensed value in increasing the visibility of this event. He also noted that we should work to more fully integrate science in the leaders meetings, such as G7, and pointed to the inclusion of emerging infectious diseases in the last G7 summit.

JOINT HIGH LEVEL COMMITTEE (JHLC) /JOINT HIGH LEVEL ADVISORY PANEL

Dr. Mori noted that although he had hoped to have the Advisory Panel meeting before the October JHLC meeting, the Ministry of Foreign affairs balked at this idea. He said that they are now hoping to convene the advisory panel early next year and conveyed the hope of the Ministry of Foreign Affairs that the U.S. would host the JHLC meeting next spring/summer.

Dr. Gibbons said that we would consider this.

EXPANSION OF COOPERATION IN HEALTH/DISEASE

Dr. Mori commented that he was in the U.S. now for the U.S.-Japan Medical Sciences Agreement, which has a 30 year history of promoting successful collaboration. He also noted that Prime Minister Hashimoto has a particular interest in the area of health and proposed a Human Caring Society activity in the G7 (this includes EIDs and aging at this time as well as consideration of how to ensure the welfare of the people.) Dr. Mori would like to build stronger cooperation with the U.S. in this area. He thinks that the activities of the U.S.-Japan Medical Sciences Agreement could be used as a core of this more highly visible initiative, and asked for Dr. Gibbons' support.

Dr. Gibbons expressed his support and agreed to help as needed.

END

RECORD TYPE: FEDERAL (NOTES MAIL)

CREATOR: Donna I. Coleman (CN=Donna I. Coleman/OU=OSTP/O=EOP [OSTP])

CREATION DATE/TIME:21-JUL-1997 12:15:31.00

SUBJECT: Re: Phone Message from Bill Raub

TO: Alicia McKay (CN=Alicia McKay/OU=OSTP/O=EOP @ EOP [OSTP])

READ:UNKNOWN

TEXT:

Alicia,

I am assuming this message is for Rachel. Am I correct?

dic

From: Alicia McKay on 07/21/97 11:39:12 AM

Record Type: Record

To: Donna I. Coleman/OSTP/EOP

cc: Rachel E. Levinson/OSTP/EOP

While You Were Out

While You Were Out

Contact:

of:

Phone:

FAX:

Bill Raub

DHHS

202/ 690-5874

Message:

Contact: Bill Raub

Company: DHHS

Phone: 202/ 690-5874

FAX:

Message: Would like to speak w/ you Re: the mark-up on Rep. Ailer's (sp) cloning bill.