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MEETING OF THE
NATIONAL BIOETHICS ADVISORY COMMISSION BOARD

Saturday, May 17, 1997
7:45 a.m.

Salons D and E
Crystal City Marriott
1999 Jefferson Davis Highway
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1

PROCEEDINGS

2

DR. SHAPIRO: Colleagues, I would like to call the meeting to

3

order. Thank you all very much for being here.

4

I have a number of preliminary issues to either announce or discuss

5

before we get started on our meeting business.

6

REPORT TO THE PRESIDENT - INTRODUCTION

7

First of all, I would like to quote from remarks from the President

8

yesterday around the issue of the apology for the Tuskegee Study--(Inaudible.)--

9

meeting before last.

10

In any case--(Inaudible.)--relevant to our--(Inaudible.)

11

And finally, by Executive Order, I am also extending the charges--

12

(Inaudible.) And we will worry about these issues, that issue--(Inaudible.)

13

And the President went on to say--(Inaudible.)--subject protections.

14

(Inaudible.)

15

And that is a subcommittee, as you all know, headed by Dr.

16

Childress, who has been working very diligently--(Inaudible.)

17

So I just pass that news on to you.

18

Second, it is quite clear to me that, although this is our last

19

scheduled meeting before the 90-day deadline, it is quite clear to me that we are going

20

to need another meeting.

21

I don't know, but we will have to work again with general counsel

22

and so on to find out what our notice requirements are. There are, of course, notice

1 requirements for us to have another meeting--(Inaudible.) And we have to obey those,
2 whatever they are. It is not clear to me right now just exactly what those are. It could
3 be there is a 15-day notice period. (Inaudible)--in the *Federal Register*.

4 There may be conditions under which that notice period can be
5 waived, or just a smaller number of days. We will have to investigate that tomorrow
6 and Monday and let you know.

7 As you know, we do have a meeting scheduled already, and notice
8 already given, for June 7th. That is beyond our 90-day deadline. We have to do that.
9 We will certainly be in contact with the White House to see if that is acceptable or not
10 acceptable.

11 So I don't have any more information than that today because we are
12 just not sure of what our-- (Inaudible.)--the way we have it here.

13 And, of course, I am not sure of everybody's calendar of everybody
14 sitting around the table. And that will be a difficult aspect, too.

15 (Inaudible.)--not tomorrow, but Monday or Tuesday, and let you
16 know where we come out on that depending on--(Inaudible.)--and what the actual
17 requirements--(Inaudible.)--and how the President and the White House feels about
18 this, and when they would like to be ready to receive this report.

19 So I think we will just spend today trying to move ourselves on to
20 get as close to our final report as we can, although I don't think-- It is quite clear to
21 me that we can't make it today.

22 We will, of course, be discussing almost immediately particular
23 recommendations, something we were doing just before at the end of our last meeting,

1 as--

2 I would like to get a sense of the committee, as we go through these
3 recommendations--(Inaudible.)--so that we can get a sense of the writing and define
4 these recommendations as to how we feel. I don't think that we are going to be able
5 today to come to any final resolutions--(Inaudible.)

6 RECOMMENDATIONS

7 DR. SHAPIRO: So what I propose is that we begin discussing
8 specific recommendations here before us and, while I don't want to get tied down in
9 too much detail, I would obviously, in some cases, find this extremely important and--
10 (Inaudible.)

11 And I want to thank Larry for having articulated through Liz's e-
12 mail a set of recommendations. Today, quite a few of us will focus on just what it was
13 that we were thinking.

14 I have, I wouldn't say "revised" them, because I don't know if Larry-
15 -(Inaudible.)--revisions or not, but they are before you in something that looks like
16 this. Proposed, revised recommendations. (Inaudible.) But that is this document
17 here, which everyone should have a copy of.

18 We also passed around a copy of some proposed conclusions and
19 recommendations--(Inaudible.)--articulated that is also-- Everyone should have a
20 copy of both of these. Does anyone not have a copy?

21 (No response.)

22 DR. SHAPIRO: I have some. I have only one of them. (Inaudible.)

23 Does anyone else need a copy?

1 (No response.)

2 DR. SHAPIRO: Everybody has a copy? (Inaudible.)

3 (Simultaneous discussion.)

4 DR. SHAPIRO: And let me, since we do have to start somewhere--

5 I think neither Alex or I have any pride of authorship here. That is, whatever works

6 best, works best.

7 It will be a little difficult to discuss them both simultaneously, so we

8 defer to--(Inaudible.)--any decisions on which kind of framework, or some better

9 framework, that might emerge we might want to use.

10 And I am going to start off, however, with the statement that I sent

11 around, which starts off with a simple statement you have before you saying that, "At

12 this time, it is morally unacceptable for anyone in the public or private sector, whether

13 in a research or clinical setting, to attempt to create a child using the adult nuclear

14 transfer technique."

15 It goes on to say, "We believe there is a widespread and moral

16 consensus on the issue because of the lack of--(Inaudible.)--safety and effectiveness of

17 this method in humans. Moreover, many additional and serious ethical concerns have

18 been identified which require a great deal more widespread careful and deliberation of

19 thought."

20 That is a statement you will find familiar because it is very similar--

21 (Inaudible.)

22 But then it comes to actual recommendations and suggestions. I will

23 just go through these. We may reformat them. We may adopt Alex's format. We will

1 try to get to the substance of some of these and see-- At least get a sense from the
2 committee. We don't have to-- I don't want to take a vote at this time, but I want to
3 get a sense for where we are.

4 And the-- And it proceeds therefore and says, "The commission
5 therefore recommends the following for immediate action."

6 And one is, "A continuation of the current federal moratorium of
7 cloning human beings in this fashion."

8 And that is something that can be discussed. Last time, there
9 seemed to be, by itself at least, no disagreement on the commission.

10 But let me just ask now, again not focusing on how we phrase it or
11 which format it goes in, but just make sure that we see what it is, what is the sense of
12 the commission?

13 Does anyone have any concerns about that?

14 (No response.)

15 DR. SHAPIRO: Okay. Again, it goes on and says a second thing.
16 "The immediate request to all firms, clinicians, investigators and professional societies
17 of the private sector to voluntarily comply with the intent of the federal moratorium."

18 Now, I don't mean this to be the last thing-- That is not meant to be
19 the last word on this subject. That is only the immediate action. We will come, in a
20 moment, to discuss amongst ourselves what, if any, kind of legislative action we might
21 require or ask for in that area.

22 But the question I have is just regarding immediate action that if the
23 President shows he could immediately, that day, ask, for that moment, ask for

1 voluntary compliance with the federal moratorium--(Inaudible.)--not only those who
2 are using federal funds for certain purposes.

3 Bernie?

4 DR. LO: Yes. I just want to emphasize sort of getting the sense of
5 the general--(Inaudible.)

6 DR. SHAPIRO: Yes.

7 DR. LO: (Inaudible.) The specific wording.

8 DR. SHAPIRO: Correct. I agree.

9 DR. LO: For example here, I want to make sure embryologists--
10 (Inaudible.)

11 DR. SHAPIRO: That is exactly right. We are just trying to get a
12 sense of things here. We are not trying to decide now on the language, but I do want
13 to encourage commissioners who have ideas about language, omissions, and so on, to
14 please write them down. Also bring it up, but write them down--the most important.

15 Because what I hope we can do today is people we will be taking a
16 number of recesses during the day, and just work on improving some of these things.
17 And anything you can write down will help us enormously. (Inaudible.)

18 (Simultaneous discussion.)

19 DR. LO: (Inaudible.)

20 DR. SHAPIRO: What I sense, at least in a general sense, is there is
21 no disagreement of that issue.

22 It then goes on to say that, "The commission further recommends"--
23 and here I think the wording is probably not as sufficient as the idea is here--"the

1 federal legislation extending human subject protections to all research settings within
2 the public and private sector."

3 Now here is an area where I think Alex made a very helpful
4 comment which I haven't really responded to yet in one of--(Inaudible.)--the fax.
5 Right? And you all have a copy of that, too. It is a fax to me from Alex on May 15th,
6 where one of the issues he brings up is what our intention is here, whether it will
7 expand the notion of research or just expand or reach this human subjects protection.

8 And that is something that we will have to address, particularly I
9 think-- I don't know if Steve has--(Inaudible.)--clinical or experimental situation,
10 clinical selection or experimental situation. And we will have to come back and think
11 about that carefully. It is a very good point.

12 But what this says for the moment is that--something that the
13 commissioners talked about a number of times in different settings--is wanting to
14 extend human subjects protection to all research settings. And we will come back to
15 what we mean by "research," and so on, but that-- This will undoubtedly need further
16 language, but--

17 What is the sense of the commissioners? Is there anyone on the
18 commission have, in a general way, reservations about that? Taking Alex's point that
19 we have to come back and say explicitly what we mean by "research."

20 MR. HOLTZMAN: I have a question.

21 DR. SHAPIRO: Yes, Steven?

22 MR. HOLTZMAN: I am fully supportive of that recommendation,
23 especially--(Inaudible.)

1 DR. SHAPIRO: That is exactly right. It is a good point. How do
2 other commissioners feel? Something like that? Basically something like that?

3 Alta?

4 PROF. CHARO: As you know, the Human Subjects Subcommittee
5 was fast getting to the point where we were going to ask the commissioners to make
6 some recommendations, and then the Dolly story hit and we kind of got derailed.

7 So I think it would be delightful if you chose to simply do two
8 things simultaneously, vote in favor of this recommendation, and I would like to say,
9 not without additional material about changes in actual research, keeping it simple,
10 extending existing notions of research to other--(Inaudible.)--persons, and then
11 tackling the much bigger, more complicated question of the gray zone separately
12 because, by keeping it simple, we could adopt it as a separate resolution, like have
13 been coming down the pike, and then--(Inaudible.)--the report.

14 MR. HOLTZMAN: If I could just state the argument again; that--
15 again, I fully support the recommendation--we do not have a report backing up that--
16 (Inaudible.)--recommendation.

17 PROF. CHARO: But we were asked-- The only thing that was
18 holding us up were a couple of people saying, "Well, what is the scoop? How do we--
19 What is going on out there?"

20 And the answer has always been, "We can't tell you what is going on
21 out there because the very absence of legislation means we don't have the data."

22 But we did ask--(Inaudible.)--to help us out by giving us more
23 evidence of what they do know about and they came back and gave us that evidence in

1 those letters we distributed, so I am not sure what more we could possibly give people,
2 pending a resolution on that.

3 DR. SHAPIRO: Okay. There are a number of people who want to
4 comment. Bernie?

5 DR. LO: Let me address the point of whether we should have a
6 simple recommendation or one that tries to address the difficulty of trying to define
7 what the clinical research is, in the clinical setting, and the dividing line between
8 research for protocols or unproven, innovative clinical practice.

9 It seems to me that where--(Inaudible.)--with regard to Dolly-type
10 cloning of human beings and--(Inaudible.)--research of doing this as a clinical,
11 innovative practice.

12 It is not research done with the intention of providing benefit to a
13 woman, a couple--(Inaudible.)--of infertility, and therefore, while I fully support
14 NBAC's recommendations about leading to subject research to federal guidelines in
15 the absence of federal funding, I am not sure research--(Inaudible.)

16 As we all know, that is a very common position that clinicians, I
17 think clinical investigators, take when they are doing innovative practices.

18 I think in the absence of addressing that issue head-on, a
19 recommendation, a simple recommendation, simply will not have any kind of--
20 (Inaudible.)--IVF clinicians--(Inaudible.)

21 DR. SHAPIRO: Alex?

22 PROF. CAPRON: I agree with Bernie.

23 And if we are going to end up with a recommendation about

1 legislation specifically on cloning, then I think I would agree with Steve that we
2 probably ought to defer until we are able to fully elaborate and support this other
3 recommendation precisely for the reason that Bernie says.

4 Because it doesn't seem to me that simply calling for an extension of
5 the human subjects regulations is going to do very much to address the very issue we
6 have, the very loophole, of the person who does the manipulation, then says, "I am
7 now not doing research; all I am doing is implanting the way I would do if I were
8 doing any other IVF procedure. That is not research."

9 And if we were not going to reach any conclusion on legislation
10 about cloning, then it would be reasonable to say, "Well, we ought at least to bring this
11 under the human subjects protection area."

12 But, Alta, I guess I initially was persuaded by you that this was a
13 good opportunity to point to the need to extend, but because I agree with Bernie I
14 would only be in favor of that extension, that endorsement, if we take the additional
15 step of saying we have got to make clear that this kind of innovative step is also
16 covered by these regulations.

17 DR. SHAPIRO: Larry?

18 DR. MIKE: I am for including a simple statement in the report. I
19 think we would be defective if we didn't address this area. However, it is quite simply
20 to make a very simple statement and reference that to a more reasoned and elaborate
21 discussion and recommendation coming out of the Human Subject Research
22 Committee, which I think we are all going to support anyway down the road.

23 DR. SHAPIRO: Rhetaugh?

1 DR. DUMAS: I am in favor of leaving the recommendation in. I
2 realize that it doesn't cover the issue of clinical work, but I think that it is important to
3 extend the protection of human subjects because we have two recommendations that
4 indicate, that recommends continuing a certain kind of research. And I think that we
5 need to make sure that we have appropriate extension of human subjects protection for
6 that.

7 I think we are dealing with two separate issues.

8 One is whether or not the current protection of human subjects is
9 adequate to cover the recommendations that we are making. And my assumption is
10 we want to make that recommendation to be sure that it is accurate.

11 The second one is the issue that Alex brings up, and I think we need
12 a separate statement to cover that.

13 DR. SHAPIRO: Thank you. Bette, and then David.

14 MS. KRAMER: (Inaudible.)

15 DR. SHAPIRO: Beg your pardon?

16 MS. KRAMER: Larry made it.

17 DR. SHAPIRO: Thank you. David?

18 DR. COX: I am in favor of a separate statement. I recognize the
19 loophole that may be the equivalent of the winds blowing through a crack in the door,
20 so you might as well just open the door. And I would like to shut the door, even
21 though the winds can blow underneath. We will deal with the cracks in the door later.

22 DR. SHAPIRO: Diane?

23 DR. SCOTT-JONES: I am in favor of the recommendation overall,

1 but I am concerned about how it is going to fit into this particular report. And I think
2 if we do include it we will have to provide a lot more background information, a lot
3 more justification for it.

4 I would just regret seeing this in here just in this form as it is
5 because it sticks out. In this listing, it sticks out like a sore thumb. There has not been
6 the proper background for it, and I think it is important enough that we really should
7 give attention to it if we are going to include it at all.

8 DR. SHAPIRO: Alta, Steve and Bernie.

9 PROF. CHARO: Whatever background is needed, I think an
10 attempt should be made to supply some of it and see if it is enough.

11 I would urge people to think of human subjects protection
12 legislation as a two-step process.

13 First, extending existing protection to everybody as a simple first
14 step, uncomplicated. We understand what research means. We cover the people that
15 are enrolled in where research currently is.

16 The second part; that we go and get at the loophole that Bernie has
17 identified, which is being addressed in other ways by other recommendations, was to
18 hear for the moment, is extremely complicated because everything in medicine is
19 innovative. Experimentation in medicine is the norm, not the exception.

20 What Alex has raised as a possible, or as a necessary part of this
21 endeavor, is advanced and complicated. And I would be distressed to find that this
22 simple, easy, no-brainer gets lost because it is now going to be tied to something way
23 too big and impossible to tackle at this moment.

1 Finally, legislation. All the recommendations are not usually
2 exclusive or interdependent. We don't know what is going to happen with them.
3 Some-- It may be that legislation passed specific to cloning, in which case this would
4 be kind of *duplus* in terms of being more than you need for the protection of people in
5 regard to cloning, but we don't know that there is going to be cloning legislation
6 passed. And this might well get passed because there is a bill pending.

7 I don't see why we have to give this one up because we have got
8 another piece that we are recommending.

9 DR. SHAPIRO: Steve?

10 MR. HOLTZMAN: With all due respect--(Inaudible.)--everybody
11 agrees. Let us give them two different things.

12 (Simultaneous discussion.)

13 MR. HOLTZMAN: I don't think anyone at this table disagrees with
14 what we want to do here, or argue it is so important that what you want to do here that
15 it not ought be jailed in as a little item here.

16 So one way we might do this is to take the--(Inaudible.)--

17 (Simultaneous discussion.)

18 MR. HOLTZMAN: --and insert the words in which it attempts to
19 create a child using adult nuclear transfer technique might be--(Inaudible.)--or
20 something along those lines.

21 PROF. CAPRON: I didn't hear--

22 MR. HOLTZMAN: Basically, I want to keep the sentiment, but
23 make it specific to, "Federal legislation extending to human subject protection to all

1 research settings, whether in the private or public sector, it says, in which attempts to
2 create, attempts to create a child using adult nuclear transfer technique may be
3 attempted." But--(Inaudible.)

4 DR. SHAPIRO: Okay. Bernie?

5 DR. LO: (Inaudible.) But I think what Steve is trying to say is let
6 us tie our recommendation for federal legislation to--

7 (Simultaneous discussion.)

8 DR. LO: --cloning situation to say that we regard any attempt to
9 cloning a human being to a nuclear transfer--(Inaudible.)--as experimentation and,
10 therefore, we want to put it expressly into a new category of meeting human subjects
11 protection as--(Inaudible.)

12 MR. HOLTZMAN: No. I actually wasn't saying that. I was
13 actually just saying I--

14 (Simultaneous discussion.)

15 DR. HOLTZMAN: --want you to take this recommendation that
16 research in this area, this research, as research as defined, should be subject to the
17 human subjects protection.

18 I would then go down, further down, and say the commission also
19 recommends to try to address Alex's point--(Inaudible.) And it is almost an
20 acknowledge-- You know, acknowledge there is a loophole and that that is a concern,
21 and that in effect it should be taken up. (Inaudible.)

22 DR. SHAPIRO: Bernie?

23 DR. LO: Rather than trying to tie into what Steve was saying, I will

1 try to rephrase what I was trying to say earlier.

2 It seems to me that we are concerned about trying to prohibit, stop,
3 the first attempts to alter a human being, or the first successful attempt, in that if
4 someone goes ahead and uses the Dolly technique in humans, then all the
5 considerations we are talking about I think are going to be thrown out the window.

6 So that it seems to me one of our concerns with a voluntary
7 moratorium is that if it was effective, would that be an acceptable outcome? And I
8 think we are saying I think, with my section--(Inaudible.)--that if we really don't
9 prevent the first IVF physician trying this, or doing it.

10 And it seems to me it is that concern that a voluntary moratorium
11 won't work that we could let us consider, for example, recommending legislation.

12 And it seems to me--(Inaudible.)--this is not a tiny loophole. This is
13 such a large loophole that it is not going to be any deterrent at all to an IVF physician.

14 I mean, we have seen this already in the IVF sphere. It is just an
15 argument that this is just not research; it is an innovative practice. And so it seems to
16 me that if we are trying to put another barrier in the way of physicians who would
17 otherwise say, "What is wrong with doing it?" then I think we need to specifically
18 make sure it is a barrier--(Inaudible.)

19 DR. SHAPIRO: Rhetaugh and Eric want to speak, and then Alex
20 again.

21 And then I am going to propose that we come back--(Inaudible.)
22 But, in any case, Rhetaugh--

23 DR. DUMAS: Well, Harriet raised a question about the

1 recommendation kind of hanging unrelated to things in the report. And may that
2 might just argue from where the recommendation is placed in the line-up, because I
3 think it is related.

4 We are recommending that cloned and DNA sequences or cell lines
5 continue, and that other work that is related to this area is continued. And wouldn't
6 that be sufficient justification to want to extend the human subjects protection?

7 PROF. CAPRON: Those aren't covered by those regulations.

8 DR. DUMAS: They are not?

9 PROF. CAPRON: No. That is the whole--

10 DR. SHAPIRO: Eric?

11 DR. CASSELL: I would like to see it remain in. I think that it
12 serves a purpose. It has a loophole, but it serves a purpose--(Inaudible)--and it is an
13 important next step that we want to go.

14 I also would like to point out that the report as it is going to come
15 out is so strongly against cloning because of the risks that it would make a major
16 malpractice--(Inaudible.)--coverage of both on the clinical and on the other side. It is
17 a very-- It makes it very--(Inaudible.)

18 (Simultaneous discussion.)

19 DR. CASSELL: (Inaudible.)

20 DR. SHAPIRO: Alex?

21 PROF. CAPRON: I want to endorse what Steve said. I think
22 strategically we have got to recognize that the potential--despite Alta's statement this
23 is a so-called no-brainer--the potential to have this report attacked because it went into

1 something without the full discussion, that I hope the Human Subjects Committee will
2 have, and the full elaboration, is substantial.

3 And if we are, as Bernie says, not actually pointing a loophole here
4 because the people who want to do it would say even if, like that, the Glenn bill
5 passed, and I am afraid that a bill from a minority member that still I gather is looking
6 for House sponsorship does not look to me like a sure thing, even if it passed, they--

7 And it takes X amount of time for regulations to be issued, and in
8 the case of past human subjects regulation that was six years for the common rule to
9 come out. It is not as though these things happen rapidly. When we got done with it,
10 we still wouldn't have anything that addressed the principal thing we are worried
11 about, which is the person who says, "This isn't research;" that, "What I am doing,
12 once I have the embryo, is implantation and that is just standard practice now."

13 I would therefore think that it much better that we have a report
14 coming out, sometime between now and October, when we would fully address that
15 issue, give all the argumentation that will be necessary to try to convince people that
16 that is the step that is justified.

17 In other words, here we wouldn't be achieving anything, and we
18 would be potentially miring this report in another debate, which I don't think is as
19 obviously going to be acceptable as Alta suggests.

20 DR. SHAPIRO: Jim?

21 DR. CHILDRESS: I very much support the ideal that is captured in
22 the stigma, but I think I agree with the position that I heard Steve heading toward, and
23 I would like to see us accept it.

1 That for the purposes of this particular report, it seems to be better to
2 make sure that in fact we close the loophole without defining the overall structure.
3 The overall structure will come later.

4 And by targeting human cloning here through the extension of
5 human subject protection, we are quite sure it is covered in the federal area as well as
6 on the private, and I think we may well accomplish something without perhaps raising
7 some of the larger questions which we will try to address fully later on.

8 DR. SHAPIRO: Okay. Can I ask the last comment you--

9 (Inaudible.)

10 (Simultaneous discussion.)

11 (Technical difficulties.)

12 DR. SHAPIRO: --which might even help us in how we feel about
13 this one.

14 DR. SCOTT-JONES: Okay. I was just wondering if we could state
15 in this report our intent to consider this more fully?

16 And I think it is really important not to tie this important issue,
17 which does not have all the controversial elements of cloning, to the issue of cloning.
18 I think it is really important to keep is separate.

19 DR. : That is a good point.

20 DR. SHAPIRO: Okay. Thank you. Those are very helpful
21 comments. Obviously--(Inaudible.)

22 (Simultaneous discussion.)

23 DR. SHAPIRO: We will come back to this later on today just to get

1 a more accurate sense of where people are coming down.

2 Let us go on to this next item here which, again, I ask you not to
3 focus too strictly on language; it is the idea that I am trying to get a sense of the
4 commission--(Inaudible.)

5 (Simultaneous discussion.)

6 DR. SHAPIRO: But this discussion has been very helpful on that
7 particular issue and--(Inaudible.)

8 (Simultaneous discussion.)

9 DR. SHAPIRO: The next item, which also comes under
10 commission recommendations, we have to recommend carefully and narrowly focused
11 federal legislation to prohibit, in both the public and private sector, the attempt to
12 create a child using adult nuclear transfer techniques.

13 We also believe that such legislation should contain some type of
14 sunset clause, or some other type of provision, that would require us to review and be
15 assessed the continued desirability to subject prohibition.

16 That is not very eloquently worded, I would have to say, but I think
17 the idea is pretty straightforward; namely that we would support federal legislation:

18 One, to prohibit this in the public and in the private sector;

19 Second, that such legislation should be narrowly focused on what
20 we are talking about and not inadvertently into other areas such as cloning DNA
21 molecules and something of that nature; and,

22 Third, that it have some provision--the sunset clause is something
23 that we have talked about, but maybe there is a better way to put that--that would

1 require us not to necessarily impact, but would require the country to review and
2 reassess the continued desirability of such a prohibition as two things happen.

3 One, as we get a better understanding of--(Inaudible.)--and, two, as
4 ongoing discussions of ethical and moral issues continue, the country may find itself
5 coming to some kind of consensus which is either the same or different from what it is
6 today.

7 Now, if you will recall, this is the subject that we discussed right at
8 the very end of our last meeting. And initially our discussions have been going in a
9 slightly different direction; namely that we have called for an extension of the
10 moratorium, we have called for voluntary adherence to the moratorium in the private
11 sector. If that failed, we would then ask that the legislation be specific.

12 Toward the end of the last meeting, I think it is fair to say that most
13 of the commissioners, as I understood it--and correct me if I am wrong--really thought
14 that legislation ought to come now, and not wait to see whether the voluntary
15 moratorium could take hold and, therefore, if that is the case, you would need some
16 kind of recommendation to call for legislation appropriately focused and with the
17 provision for reassessment some time.

18 That is the guts of the recommendation. Now, to let you know how
19 the commissioners feel about that or--(Inaudible.)

20 (Simultaneous discussion.)

21 DR. SHAPIRO: Yes, Alta?

22 PROF. CHARO: (Inaudible.)--children now, but I am generically
23 uncomfortable with federal legislation as a first-line approach in these areas.

1 And I wonder if it would be sufficient to say that we don't think
2 people should try to make babies this way right now, and that if legislation is
3 considered then it ought to be carefully and narrowly focused to the pivotal private
4 and public sectors, et cetera, et cetera. In other words, not necessarily endorse that
5 legislation be introduced, but recommend that if it is introduced it consider that it have
6 the following elements in it.

7 DR. SHAPIRO: Okay. This is the exact--and I appreciate you
8 articulating this--this is exactly the issue we were struggling with at the end of the
9 session last time. You have articulated it very well.

10 David?

11 DR. COX: Yes. I have, perhaps more than any other commissioner,
12 have been on the fence on this. (Inaudible.)--as I am still at the same place as I was at
13 the last meeting, which is in favor of the proposal you just made and--

14 DR. SHAPIRO: You are off the fence then.

15 DR. COX: I am off. (Inaudible.)--is suggesting federal legislation.
16 The reason why-- The dread of enforcement for me is to not have this quite artificial
17 distinction between federally funded research and the rest of the world and I hope I
18 come to believe that federal legislation is--(Inaudible.)

19 DR. SHAPIRO: Bernie?

20 DR. LO: I share Alta's skepticism about trying to legislate
21 everything, but I think again it goes back to if we are really so convinced that it would
22 be morally unacceptable at this point to try Dolly-making techniques for baby-making-
23 -(Inaudible.)--then I think we need to think about whether our recommendations

1 actually present sound feasible policies to making sure that that works.

2 I am just concerned that if we merely call for voluntary actions, that
3 we are ready to have discussion about whether we are going to try to bring research
4 protection in as well--(Inaudible.)

5 Maybe you could help us here. These people are impractical. That
6 is not going to be enough. If they really feel that strongly it is wrong, how come their
7 policy recommendations leave the door-- Again, to use David's words, if we are
8 perceived as leaving the door wide open, as opposed to, you know, just a narrow
9 crack, people are going to I think question our credibility and our practicality on other
10 issues as well.

11 So if we really believe, as I think we do, that it would be morally
12 unacceptable, it seems to me we have to crack their recommendations to give a very
13 high probability that that moral prohibition will be observed.

14 DR. SHAPIRO: Thank you. Let me just make a logistical
15 announcement I was supposed to make directly at the beginning of the session, and I
16 apologize. It is quite important that commissioners speak directly into the microphone
17 for purposes of creating a transcript and so on, so I apologize for not making that
18 announcement at first.

19 Jim?

20 DR. CHILDRESS: If we have a consensus, and I think we do, that
21 we should try to prevent this from occurring, at least for the time being, then it seems
22 to me that rather than viewing this, as Alta suggested, as a second step, I get that the
23 first steps was recommending--(Inaudible.)--and make this something that we strongly

1 recommend, but--

2 And the reason I can feel comfortable with that is--(Inaudible.)--as
3 you contested in the second part of your paragraph here, some way to review it, to
4 continue to review it, in light of what we are arguing is required; mainly continuing
5 assessment of the ethical arguments that are being offered for and against, since
6 beyond the safety one I am not sure that we have a consensus about some language--
7 (Inaudible.) And that is why I really disagree with Alex. It is morally unacceptable to
8 attempt, I mean, without the temporal of the patient there, I wouldn't be able to--
9 (Inaudible.)

10 DR. SHAPIRO: Eric?

11 DR. CASSELL: Well, first of all we are all agreed that we think it
12 shouldn't be done because it is risky. We have had trouble finding a really good
13 reason why you should do it in the first place, even if it wasn't risky.

14 And if you say I think we are going moratorium, it is like saying you
15 shouldn't have a law, then you have-- Then we-- Why should we have a law? If you
16 feel that strongly about it, you have got your sunset clauses, why shouldn't you have a
17 law? So that there are a number of degrees and you have got it from both sides to
18 make it a firm prohibition and I think--(Inaudible.)

19 But why is it we are prohibiting--

20 (Technical difficulties.)

21 DR. CASSELL--we all agree--(Inaudible.)--if we can't think of a
22 reason we should--(Inaudible.)

23 (Technical difficulties.)

1 DR. SHAPIRO: Steve?

2 MR. HOLTZMAN: I guess what I would ask Bernie is--

3 I actually support Alta's position here because I think we were
4 discussing whether or not it was moral, right, good reasons, whatever, between germ
5 line and gene therapy with the blue line gene. You all said that would be horrific.

6 And yet I am not sure this group sitting here would think it would be
7 a good idea to have federal legislation prohibiting--(Inaudible.)--set of gene therapy
8 with the blue line gene because of the nature of the legislative process and what can
9 happen in the context of the discussion of that kind of legislation.

10 It may be terminally pragmatic, but I think that what we could do
11 constructively is just say, if there is to be legislation, here is what it is it should
12 address, and here is what it ought not do. (Inaudible.)

13 DR. SHAPIRO: Thank you. Arturo?

14 DR. BRITO: I just wanted to respond to something that Jim said. I
15 agree with what Jim said and the way he said it because I am a little-- I definitely
16 think there should be legislation prohibiting this use in private or federally funded
17 endeavors.

18 I just want to express a sentiment about the term "morally
19 unacceptable." I don't agree that that is the reason. I don't think we can determine that
20 right now, that it is morally unacceptable. I think it is scientifically unacceptable.
21 And I just want to say that because I think it is too risky right now to be doing this.

22 DR. SHAPIRO: Arturo, let me just respond to that.

23 Alex is next on list of people who want to speak.

1 I have been-- I guess it is really a point that Jim made, but I found it
2 very helpful myself, that at the current time safety is an ethical reason and it is-- That
3 is where the term "morally unacceptable" comes from.

4 DR. BRITO: Okay.

5 DR. SHAPIRO: It is because safety itself is an ethical reason right
6 now. There are other ethical reasons. And I found that a helpful way to think about it.
7 I don't insist on it, but that was a point that Jim made. I don't know when you made it,
8 Jim, but you made it at one point, and so that is where that comes from.

9 DR. BRITO: I just wanted to clarify that. Yes.

10 DR. SHAPIRO: Okay. Thank you. Alex?

11 PROF. CAPRON: Two points. The first is a response to Eric's
12 point.

13 I take the term "moratorium" to refer to the notion that something is
14 being foregone for a time; that the emphasis on moratorium. The method of the
15 foregoing could vary. We certainly do recommend professional societies and others
16 saying this is not acceptable now.

17 If we were to have legislation with a sunset clause, that would be a
18 moratorium. There are, for example, many examples in legislation now that include a
19 moratorium; that are described as a moratorium that are legislative, so I don't-- That
20 is-- To me, that is not a distinction.

21 I came into the room agreeing with the position that Alta and Steve
22 have taken, and indeed the recommendations as I drafted them have that language in
23 them. They do not recommend legislation. I did that for a reason, partly what Alta

1 says, and partly the sense that there is legislation pending. There is a good deal of
2 interest in that legislation.

3 And what I thought we could do was to say, if you are moving ahead
4 with legislation, these are the considerations that are necessary. And we get ourselves
5 involved in that process through this report, and I hope influence it.

6 I think I have been persuaded in this discussion, by the position that
7 you started with and that Bernie and Jim stated, that if we think that this should not go
8 forward and we are worried that the *in vitro* clinics, in the absence of legislation, may
9 not adhere to any voluntary restraint, because they have not done so even in the face of
10 the American Fertility Society and other groups' restraints on other topics about *in*
11 *vitro*, that it makes sense not to leave ourselves in this awkward position of basically
12 saying there is a need to prevent it.

13 A careful examination of the history of IV would say that it doesn't
14 get stopped by voluntary restraints, so everyone would sort of wait for the other shoe
15 to drop. I would express-- I would expect the first question at the press conference to
16 you to be, "Are you in favor of federal legislation then?"

17 The other thing about saying something about federal legislation is
18 that what would be worse in this area would be a patchwork of state statues which
19 would probably be crafted much less carefully. And so a reason for endorsing federal
20 legislation is that we can expect it to be uniform, and I think we can expect it given the
21 difference between the state and federal legislatures to be preferable.

22 DR. SHAPIRO: Thank you. Let me just say for my colleagues that
23 are sitting up at this end of the "U," I mean, they can-- When they raise their hands--

1 (Inaudible.)--easier for you to see because you are not afraid I may ignore you. I
2 apologize. We use--(Inaudible.)

3 (Laughter.)

4 DR. SHAPIRO: Bette, then Tom and Carol.

5 MS. KRAMER: Yes. I think it is really incumbent upon us to call
6 for legislation. In the ethics chapter, we are basing the point that the primary ethical
7 objection to the cloning is a safety issue, but at some other point--I have forgotten
8 which chapter it is--we spell out various ways in which we see safety or potential harm
9 from the existing science to the people. And I think we are going to look lax on this if
10 we don't do that.

11 The other part of-- The other part of the language that I wonder
12 about is I think I would like to see us stronger on recommending legislation. This
13 legislation creates a sunset clause. I think that that ought to be a strong part of the
14 recommendation in the light of our continuing call for continued exposition of the
15 issue.

16 DR. SHAPIRO: Tom?

17 DR. MURRAY: First, let me just say that I abandoned, in this
18 report, of something very much of the spirit of this particular recommendation.

19 Listening to the comments, particularly Steve's comment--
20 (Inaudible.)--we have both the advantage of having been the active participants in this
21 conversation now--(Inaudible.)--two and a half years. People who we are
22 recommending will not have the--(Inaudible.) We should just be very mindful about
23 what we say, that will be read and interpreted by folks who may not be aware of--

1 (Inaudible.)--activity do a recommendation--(Inaudible.)--probably not terribly
2 lengthy, but clear explication at this point in time. And we must be particularly
3 careful to warn against the dangers of--

4 (Technical difficulties.)

5 DR. MURRAY: That is just a kind of reminder I think. If we can
6 bear that in mind, I am a little more--(Inaudible.)

7 DR. SHAPIRO: Thank you. Carol?

8 DR. GREIDER: (Inaudible.)

9 (Technical difficulties.)

10 (Laughter.)

11 (Technical difficulties.)

12 DR. GREIDER: I have just a question for some of the people that
13 don't want a practical line drawn--(Inaudible.) I know that there is a certain-- There
14 are legislation that has been proposed in this area already. If we come out and say
15 that we want to recommend legislation, does that somehow endorse some of the things
16 that are already ongoing, even though we know there are problems with the language
17 in those areas?

18 PROF. CAPRON: No.

19 DR. SHAPIRO: I think that is the right answer and we will have to,
20 if we do come out that way, we will have to articulate it in a way that is pretty clear.
21 And I don't want to defend this particular language right now, but I don't think that is
22 something we need concerns us.

23 PROF. CAPRON: Carol, if I might, the only thing, it seems to me,

1 that an endorsement of legislation might call on us to do, which we are not going to be
2 able to do in the time, is to propose our own statute.

3 And actually that was another reason why I originally agreed with
4 Alta's and Steve's position here because I was afraid, if we called for legislation and
5 didn't have a bill to propose, someone would say, well, what is it--

6 And I think if we call for legislation, give our reasons for it, and say
7 it must distinguish between the work that is prohibited and other work and it must
8 have a sunset provision, or some other condition that allows it to be reviewed, we have
9 set forth what we think are the important parts. We are also--

10 DR. GREIDER: We couldn't control it.

11 PROF. CAPRON: Well, we wouldn't have any control even if we
12 drafted something. It is just that, in ordinary course, it seems to me, a commission in
13 this position ought, if it wants legislation, ought to give you the language of the
14 legislation. I don't think we have the time to do that, but we give all the elements
15 which should be in it.

16 DR. SHAPIRO: Larry?

17 DR. MIIKE: I will just start off with saying that this discussion sort
18 of reminds me of what we are talking about on the ethical side about cloning being
19 people not wanting to give up their babies. It sounds to me like that is the kind of
20 discussion we are having here. We want to issue a report and we want to control the
21 use of it. If we issue a report it is out there.

22 The sense that I had from the last meeting and for which I tried to
23 put in my set of recommendations was the moratorium was a temporary hold while we

1 did something more encompassing and there was a legislative side.

2 I will put out an idea that I think legislation with a sunset clause at
3 least forces a reassessment. If we have a moratorium, a long-term moratorium, what is
4 the impetus to try to end it? It just goes on forever.

5 The other part is that, even with sunset clause, the momentum of
6 legislation would be that every three or five years you look at it again and you
7 reauthorize it. I think that that will come. At least it will force a re-look.

8 And in my draft of the recommendations I looked at a moratorium--I
9 mean, a legislation--with or without a sunset clause, as merely shifting more of the
10 burden for those who would want to end the ban so that, you know, just in terms of--
11 At least the sunset clause forces a reassessment, but the momentum still is to keep it
12 going. Without a sunset clause it is a very difficult hurdle to overcome, to try to end
13 that.

14 DR. SHAPIRO: Thank you. Any other comments? (No
15 response.)

16 DR. SHAPIRO: Obviously, there is some disagree here, but I think
17 it is fair to say that the majority of the commissioners feel at least we should be
18 working on a recommendation like this, although some may disagree when we come
19 down to it.

20 DR. DUMAS: Well, hearing Bette and Larry, I would suggest that
21 that recommendation be crafted such that it is not just a belief but a part of the
22 recommendation that the sunset clause be--(Inaudible.)

23 DR. SHAPIRO: Yes. Well, we will do it. And all these things are

1 going to be drafted probably this morning as we take the recess and try to settle some
2 of these things into better shape.

3 Let me go on right now to look at two other recommendations that
4 are laid out here which, while we I think all would agreed to, in fact I think we haven't
5 spent-- I want to just stop now and make sure that I have captured people's views
6 properly.

7 And they are first that, "Research and cloning via adult nuclear
8 transfer using animals should continue to be permitted subject to existing regulations
9 regarding the humane use of animals and subject to existing regulation." That is
10 somewhat redundant. We will have to clean that up, and review the procedures.

11 Let me just read the second one and we will talk about both of them
12 together.

13 The second one is "Cloning of DNA sequences and cell lines should
14 continue subject to existing regulations and standards."

15 So I think it is clear what we mean there. We will have to clean up
16 some language here. And let us just see how the commission feels.

17 Larry?

18 DR. MIIKE: I have stated this before. I don't think we should take
19 these on directly as recommendations. We are looking at the subject of cloning for
20 human beings, so I would steer clear of the animal research area. It is just sort of the
21 underlying assumption that that goes on. So I would not even mention it in the report.

22 The second part is also I would rather have it as a statement rather
23 than a recommendation saying that these other areas are not effected simply by stating

1 that "Cloning is used in many ways by the scientific community and clearly these uses
2 of cloning are not at issue." And just simply to make that as a statement rather than a
3 recommendation.

4 PROF. CAPRON: That is a good idea.

5 DR. SHAPIRO: Alex?

6 PROF. CAPRON: I agree with the recommendation as you put it.

7 And it seems to me that, beyond the statement, Larry, we have
8 reached a conclusion here, which is that these forms of research do not implicate the
9 same ethical concerns that lead us to our recommendations on the prohibition. And it
10 is important to tie a factual description with an ethical conclusion.

11 DR. SHAPIRO: Steve?

12 MR. HOLTZMAN: It seems to me there is a difference between
13 saying we believe this kind of research is important and it should go on, which we
14 could choose to say, and then the other approach which is more reflected in Alex's
15 draft, which is to say whatever it is we may be saying about baby-making, cloning, we
16 don't for a minute want this other stuff to be impugned.

17 So I think it will be--(Inaudible.)--and I think even if we take Larry's
18 position, when we are already asked to comment on these other forms of research, I
19 think we would have some responsibility, particularly, you know, if we recommend a
20 legislation to make sure that these other forms of research are--

21 (Simultaneous discussion.)

22 DR. MIKE: I am in agreement. I am just saying that I don't think
23 we should elevate it to the level of a recommendation.

1 PROF. CAPRON: It is a conclusion, isn't it?

2 DR. MIKE: No. It is a recommendation that we are stating right
3 now.

4 MR. HOLTZMAN: Well, that is my question. Does-- Which are
5 we saying? Which of those two? I mean, we can frame it that way.

6 DR. SHAPIRO: Well, let me just-- I know there are others who
7 maybe want to say a word.

8 It is my sense-- I don't have a strong feeling about this way of
9 formulating versus the way Alex wanted it, but I think that I agree with what Alex
10 said. There is a lot of confusion on this issue. And it seems to me that these are
11 extremely--(Inaudible.)--areas of a certain knowledge. (Inaudible.) I am not trying to
12 preach to somebody. We all agree on that.

13 And I think however we do it, maybe that we ought to highlight
14 somewhere that this is a very important foundation--(Inaudible.)--medicine and it is
15 critical to continue. And that maybe there is a better way to do it than just
16 recommending this. And somehow we have to highlight that, you know. (Inaudible.)

17 MS. KRAMER: Harold, maybe what we need to do is to take away
18 that phraseology of "recommends," because if putting it in recommends it kind of puts
19 it into consideration of the foregoing bullets where we are inviting people to consider
20 what we are saying and agree or disagree or whatever. So just to take it out and
21 rephrase it.

22 MR. SHAPIRO: That is a possibility.

23 PROF. CHARO: The start the rephrasing might be "The

1 commission also notes that research da da da, using animals, will continue to be
2 permitted." It doesn't change anything except the endorsement. It simply
3 acknowledges that is reality. And we could even say on the moratorium--

4 DR. DUMAS: I don't consider that an endorsement.

5 PROF. CHARO: Right. And say-- People are saying that they are
6 upset about the notion of endorsing it, but they also want to highlight the fact that
7 there is a regime doing animal research. You can just say right up there, "We know
8 that this exists and will continue to exist."

9 DR. SHAPIRO: Alex and David.

10 PROF. CAPRON: I will pass for the moment.

11 DR. SHAPIRO: David?

12 DR. COX: Yes. I think that from the scientific point of view, and
13 certainly I would like to personalize what we heard from a variety of people testifying
14 with respect to the science, is that the biggest thing the scientists don't want to see
15 happen is, due to a misunderstanding of the facts, ongoing important research is
16 screwed up.

17 And I think that I am very in favor of stating explicitly what we
18 don't want to see the legislation involving, but I quite agree that I don't think there
19 should be a recommendation, but I would like to see a statement either tied, you know,
20 to the legislation of basically saying that we are not talking about--(Inaudible.)

21 DR. SHAPIRO: Jim?

22 DR. CHILDRESS: I know this might be too weak to recommend,
23 may not be expressly what we are after, but someone used the language of "conclude,"

1 and something that really does indicate, as we need a connection with what we are
2 saying in the legislation, the kind of narrow focus we think that legislation should
3 pass.

4 So I do think we need a very strong statement. I think the only issue
5 is to how we now structure that?

6 DR. SHAPIRO: Alex?

7 PROF. CAPRON: I guess, precisely then responsive to Jim's point
8 and David's point, I would invite you to look at Section V in my recommendations
9 because I try to do exactly that.

10 There is a recommendation, but the recommendation is that any
11 regulation or legislation be carefully drawn so as not to interfere with this work. And
12 then we don't endorse the work, but we simply say it is a separate issue; it doesn't raise
13 the same ethical issues and it shouldn't be swept up.

14 DR. SHAPIRO: I think, in fact, I am very glad that Alex pointed to
15 that.

16 (Simultaneous discussion.)

17 DR. : But we support it.

18 DR. SHAPIRO: If you could look at Roman V, it is on page 2 of--
19 (Inaudible.)--Alex's folder, and I think he has just characterized it very well. I am not
20 going to repeat that. But it is helpful to look at to see how he--

21 (Simultaneous discussion.)

22 PROF. CAPRON: And obviously the language here may also need
23 a lot of tinkering--

1 DR. SHAPIRO: (Inaudible.)

2 PROF. CAPRON: --but that is the intent.

3 DR. SHAPIRO: And that certainly is another way--maybe way--in
4 which we find more easy agreement for all of us.

5 Well, why don't people take some time to make sure you look at that
6 and we will come back to this issue because--(Inaudible.)

7 But that is a very helpful suggestion and I think Alex's language
8 may in fact bring us closer than something that I have got down here.

9 Let us go on then and-- Excuse me. Steve, I think did you want to--

10 MR. HOLTZMAN: (Inaudible.)

11 DR. SHAPIRO: Okay. Let us go on and deal with some of the
12 other issues here. And we will be circling back on all the other issues during the day.

13 This particular set of recommendations will go on to say the
14 following. "The commission also notes, since different ethical and religious
15 perspectives and traditions are divided on many of the important ethical issues, and
16 support any attempt to create a child--(Inaudible.)--techniques, and we recommend
17 that."

18 And then there are I guess one bullet here and I will hold on that.

19 "The federal government--(Inaudible.)--very widespread in its
20 continuing deliberation and incompleteness upon these issues." That just comes--

21 Again, I don't want to--(Inaudible.)--of our discussions and our draft
22 documents that we believe that continued serious deliberation on these issues is really
23 essential, as we go forward.

1 And let me just go to what is the final one here and that is the
2 language, which is really adopted from--for those of you who have read carefully--
3 really adopted from Alex's memo to me, that he faxed to me, and it says, "Finally, in a
4 technological age a democracy requires that all citizens are actually equipped to
5 participate in the process of evaluating the effects, the effects of new scientific
6 developments in helping to shape--(Inaudible.)"

7 And this is the bullet. "The federal government seek other
8 appropriate opportunities like information and education to the public on--it should be--
9 -science and cloning and on other developments in bioethical science and practice.
10 These developments appear to have an impact on important cultural practices and
11 commitments."

12 Now these, at one level, are not I don't believe controversial ones.
13 The commission has talked about this many times. There really are two aspects to
14 this--(Inaudible.)

15 One is that we think continued serious deliberations are very
16 important.

17 And, two, is it called for the federal government to find appropriate
18 opportunities for education, and so on, in this area.

19 Now, on the former I really don't think there is any differences
20 between this.

21 On the latter, that is the issue where we are asking the federal
22 government to find opportunities to provide information and education in these areas, I
23 think we do have--(Inaudible.)

1 At least I have sensed some differences between us regarding how
2 general versus how specific a call we want to make here. And so I will leave both
3 these issues up for discussion. I don't have any intense views on the issue myself.

4 Anybody have any comments?

5 Excuse me. Eric?

6 DR. CASSELL: My only concern-- This is fine, even with a little
7 bit of change. My concern is that sometimes a call for education is a motherhood
8 thing, you know. And how can you knock it?

9 I mean, it is-- Then people say, "Well, if we are already educating
10 everything--(Inaudible.) And if that were a little stronger then we--(Inaudible.) And I
11 would like us to be a little stronger. I don't think we have to recommend exactly how
12 it be done, but we should point--(Inaudible.)

13 DR. SHAPIRO: Diane?

14 DR. SCOTT-JONES: I agree with Eric that it should be stronger.
15 And I think the language of it is a bit soft and tentative because it says "when these
16 developments appear to have an impact on..." I think we could state more-- At least
17 state "because these developments have an impact on," instead of softening it to say
18 that only in some instances would we really want people to be educated. We should
19 always want that.

20 DR. SHAPIRO: David?

21 (Simultaneous discussion.)

22 DR. COX: Yes. Part of the--

23 Although this is tricky to get the balance right, I guess for me one of

1 the ways to strengthen that is to emphasize that you want-- It is education, yes, but
2 you want people to be--(Inaudible.)--with respect to the facts, you know. You want
3 them to have the correct facts of the discussion. And I think that perhaps one way to
4 strengthen this is that we are saying what it is we want to educate people with, you
5 know, to have the correct facts.

6 DR. SCOTT-JONES: Could I just--

7 DR. SHAPIRO: Diane?

8 DR. SCOTT-JONES: I just want to add to that. I think what David
9 has said also places some of the burden of this education back on scientists and the
10 science community because the scientific community should make sure that people
11 have access to the facts, so the burden isn't just on the people who we are considering
12 uneducated but it is on the scientific community as well.

13 DR. SHAPIRO: Other comments? Bette?

14 MS. KRAMER: I believe I had suggested in an e-mail on this
15 subject that perhaps we could strengthen it further by asking that a specific agency, or
16 a specific body, have the obligation to oversee this education so it is not dispersed and
17 its effectiveness is attended to both in addition to cost effectiveness as well.

18 DR. SHAPIRO: Other comments or questions on this? Steve?

19 MR. HOLTZMAN: While agreeing with the sentiment, Bette, I
20 don't think that this one piece of hard biomedical technology deserves a special
21 organization to be responsible for the education.

22 And I think it was suggested that, as a recommendation, that an
23 existing body, for example, the NIH--(Inaudible.)--or whatever, and we might get into

1 that kind of recommendation. So--(Inaudible.)--clarify it. Do you mean--(Inaudible.)

2 MS. KRAMER: Well, somebody-- Either somebody had pointed
3 out or something that we read said that the National Academy of Science had an
4 education program going on, the ELSI people have a program going on, and I think
5 that one of the things that we have seen in the Genetics Committee is that there are lots
6 of things going on out there. There is no central registry. There is no way of
7 knowing.

8 And I have not-- I have the feeling that whatever educational efforts
9 are ongoing are also widely dispersed and I think that this cuts into the effectiveness of
10 it and also makes it a lot more costly.

11 I guess what I am trying to say is I recognize we are not-- This isn't
12 the proper place to try to be proactive, which was an earlier call that I had made, but I
13 beg us to do something more than just say "amen."

14 PROF. CAPRON: Well--

15 DR. SHAPIRO: Larry? Just a second. Well, Larry wanted to say
16 something.

17 DR. MIIKE: Well, also--

18 DR. SHAPIRO: He also pointed out that if you look at Alex's draft,
19 item Roman VI--is that right, Alex, Roman VI?--it really is, one, probably a better
20 articulation for what--(Inaudible.)--down here and is-- You might also look at that as
21 we are talking about it--(Inaudible.)--closer to what you have in mind and very much
22 more terse. And that will be--(Inaudible.)

23 DR. MIIKE: I guess-- I guess I am a cynic on these issues. These

1 are to me like whenever we do policy studies we always call for more research. It is
2 sort of like the one thing you always include as a generic recommendation.

3 It is the execution and the impact that is important and I always-- I
4 just never know whether, you know-- You either have a totally comprehensive
5 approach that is totally and realistic in applying, or you try to be so specific that it
6 hasn't much impact so--

7 DR. SHAPIRO: Eric?

8 DR. CASSELL: Well, one of the things that has brought many of us
9 to the side of a strong change of statement is the ignorance that greeted Dolly. Now, if
10 that is-- Now, if that is what came about with all the educational efforts--(Inaudible.)
11 And so I have a feeling that we ought to make that quite clear. We ought to-- One
12 way of saying that is that ignorance--(Inaudible.) I mean, that, the announcement of
13 Dolly and that is not a powerful statement.

14 DR. SHAPIRO: All right. I think that, again, I do recommend and
15 we will try to--

16 PROF. CHARO: Oh, I am sorry. (Inaudible.) Are you going to
17 offer comments that aren't related to education?

18 DR. SHAPIRO: I am going to come back to this.

19 PROF. CHARO: Okay.

20 DR. SHAPIRO: To additional issues in a moment.

21 PROF. CHARO: Thanks.

22 DR. SHAPIRO: I just wanted to repeat what I said a moment ago;
23 that it might be very helpful to--(Inaudible.)--education, and look at Alex's Roman VI.

1 (Inaudible.)

2 Let me also-- Yes. Education? All right.

3 MS. LEVINSON: Well, while not necessarily proposing--

4 (Inaudible.)--point out that the charter contains a phrase that allows the commission,

5 or authorizes the commission, to make recommendations--(Inaudible.)--specific

6 agencies and that those agencies--(Inaudible.)--back on their response to those

7 recommendations--(Inaudible.)

8 DR. SHAPIRO: That is a good reminder. Thank you very much for

9 that.

10 PROF. CAPRON: Could I have a point of information on that?

11 This issue has been out on the table a little while.

12 Have we had--because I haven't seen it--a listing of the present

13 science education efforts by NSF, NIH, including ELSI, et cetera? I mean, it would

14 certainly--

15 If we were going to take up your recommendation, Rachel, which is

16 in many ways a way of being much more focused instead of saying federal

17 departments and agencies but listing the ones that are relevant. I just wonder if that is

18 readily available to us?

19 I mean, for all I know, the Defense Department, in its science side,

20 sponsors a certain amount of education on science issues, et cetera, et cetera. I just-- I

21 would be-- Well--

22 DR. SHAPIRO: Well, in answer to that question in part, one, we

23 haven't got a listing, or at least I don't see one. If we have one, I haven't seen it.

1 Second, I know of no agency in the federal government that does not
2 have a, that sponsors research that does not have an educational element in it. It may
3 be good, bad, indifferent, large, small, but they all have it.

4 PROF. CAPRON: And Princeton is the recipient of funds from all
5 of them.

6 DR. SHAPIRO: And Princeton is the recipient of all of them.

7 (Laughter.)

8 DR. SHAPIRO: Unfortunately--(Inaudible.)

9 PROF. CAPRON: But you are working on it?

10 DR. SHAPIRO: Yes. Always.

11 (Laughter.)

12 MR. HOLTZMAN: This isn't-- This is something I would ask
13 people ought to think about as we go into a recess, triggered by Eric's statement, and
14 that is are we calling for more education or education to include this new issue where
15 we will be saying the fact that people respond--(Inaudible.)--should give us pause to
16 reflect on what kind of job we are doing.

17 And the recommendation is more along the lines of stop, ask
18 yourself, "Is this working?" How can we reformulate this education so that it does
19 work?

20 DR. SHAPIRO: I will just say something about education and the
21 point that Eric made regarding the response, initial response, to this.

22 In some sense the initial response was uncorollated with, in some
23 sense, how well educated you were. Some of the silliest responses came from the best

1 educated--(Inaudible.)

2 (Simultaneous discussion.)

3 DR. SHAPIRO: And that itself was actually the most striking
4 aspect of this as far as I am concerned. People just responded very quickly. Often
5 people who should have known better, and did know better, two weeks later when
6 they stopped to think about it, it was one of those cases where people talked before
7 they thought. One of those many cases.

8 (Laughter.)

9 DR. SHAPIRO: And so that was really the most striking aspect of
10 it, to me. I wouldn't expect a lot of people, even very well educated people, to
11 understand just what science has been accumulating regarding cell differentiation, and
12 stable-state, and so on. That is a fairly sophisticated literature of its own, which most
13 people would not even--scientists would not--normally be following.

14 And so there are some limits to that. And so I think we have got to
15 be careful about where we are talking about education here. It is not just to those
16 people, some unwatched group who don't know anything. It is a reflection of-- Well,
17 it is the broader question and-- Well--

18 DR. CASSELL: Well, it is like--(Inaudible.) The depth of the
19 belief in genetic determinism seems to be unassailable, and yet it is a fundamental lack
20 of understanding which becomes an education--(Inaudible.)

21 DR. SHAPIRO: Alta, Bernie.

22 PROF. CHARO: Yes. I mean, Rachel, thank you for the invitation,
23 but I would like to urge us not to take you up on it and to return to where we started

1 which was a much more general statement, not only because of the complexities of
2 who needs to be educated but, number one, I don't think, even though we have spent a
3 lot of time on it, that cloning is really the most important thing in the world of science
4 today, or in the world of things to be learned today. It is really kind of a small thing.
5 And we are just kind of overly focused temporarily on it.

6 And, second, if we were trying to identify the things that you would
7 love to have educational efforts focused on, that are related to cloning, I think that you
8 probably would start looking at areas that are not cloning-specific but are more
9 generally important, like biological determinism and the dilemmas faced by more and
10 more information about genetic influence coming out without it necessarily leading to
11 genetic determinism in people's minds.

12 And that is a very complicated empirically-based discussion. It is
13 more than just what agencies are doing; it is who knows what, where, how, when?
14 And we talked earlier today about wanting a stronger empirical base before we go
15 forth with recommendations that have legislative impact across the board. I think this
16 makes a much stronger case for restraint.

17 And so we would like to just say thank you very much, but no
18 thanks.

19 DR. SHAPIRO: Bernie?

20 MS. LEVINSON: I didn't-- I didn't make a recommendation. I
21 just--

22 PROF. CHARO: I know. I know.

23 DR. SHAPIRO: Bernie?

1 DR. LO: Yes. I think this is an area where we all have very strong
2 feelings that we would like to see better understanding of the science and also I think
3 better understanding of the social ethical policy implication for science.

4 How to say that in a way that avoids Larry's trap of making sort--
5 (Inaudible.)--is very tough.

6 And I also want to say that I think a lot of people devoted a
7 considerable amount of time--(Inaudible.) I know Bruce Alberts(?), who is now
8 president of the National Academy of Science, I think Harold Varmus, the director of
9 the NIH, have both thought a lot about public, increasing public understanding of
10 science and awareness of the social implications.

11 Again, we need to say something strong but also say something that
12 is sensible and doesn't sort of fit, that acknowledges the efforts that have been made
13 and builds on that rather than sort of appearing I think that we know how to do it.

14 (Simultaneous discussion.)

15 DR. LO: (Inaudible.)--try very hard and obviously--(Inaudible.)

16 DR. SHAPIRO: Carol?

17 DR. GREIDER: I want to disagree a little bit with something that
18 Alta said, and not disagree with what you meant.

19 (Laughter.)

20 DR. GREIDER: (Inaudible.) Well, you said a couple of things.
21 And that was that, in the area of education, cloning is a very minor issue. Although
22 the actual production of Dolly might be a minor issue, I think it actually brings out an
23 extremely major issue, which is what you ended up saying, and that is the area of

1 genetic determinism.

2 PROF. CHARO: Right.

3 DR. GREIDER: And this is something that we are going to be
4 dealing with in the Genetics Subcommittee at least for the rest of the stuff that we are
5 going to be doing.

6 And agreeing with the idea that there was an initial response to
7 cloning that pointed out to me a great misunderstanding among the public and among
8 scientists in terms of, you know, what genes can do and can't do.

9 And I think that this is, although it is a minor thing now with
10 cloning, it is going to be a very major component, and so we are talking about
11 education as a major thing we need to educate about that was the problem with
12 cloning.

13 DR. SHAPIRO: David?

14 DR. COX: That was my point.

15 DR. SHAPIRO: Yes. Alex?

16 PROF. CAPRON: I very much agree with Carol's remark and with
17 yours. I can see in our chapter somewhere, when we talk about the need for education,
18 using, for example, the genetic determinism misunderstandings.

19 I would not be in favor of our highlighting, in the conclusion itself
20 and the recommendation for greater efforts in this area, disparaging comments about
21 the ignorance that was displayed by other people because a certain amount of that, it
22 seems to me, is a way of saying they disagree with what we think is right.

23 And these are points about which there will be arguments, and the

1 arguments are not simply other people should learn the facts. The facts themselves are
2 part of something about which people can disagree, and what a fact means, and what is
3 evidence of that fact, and so forth. So science isn't something that a scientist can tell
4 you and then you accept it and there is no argument about it.

5 So I just want to be cautious that we not set sort of, with the back of
6 our hand, in a very prominent way in our conclusions, say the reason we are
7 concluding this was, "My, God, were people stupid when they talked about this
8 subject."

9 DR. COX: That is why Carol's point is so important because it ties
10 together what you want to apply the facts to.

11 DR. SHAPIRO: Steve?

12 MR. HOLTZMAN: Let's see if I can get this right. Maybe there is
13 something though that belongs up front which isn't an impugning of this or that group,
14 and that is something to the effect of the reaction to Dolly, the spoke of one spread,
15 misunderstanding of the roles of genes, or a misunderstanding of a widespread belief
16 in genetic determinism.

17 (Inaudible.)--and then, therefore, we even wanted to address is the
18 need for educational efforts of whatever kind to redress that problem because of its
19 potentially profound implications way beyond Dolly in terms of issues like--

20 (Simultaneous discussion.)

21 PROF. CAPRON: Yes. I guess I were prefer that in a discussion
22 because I am also not comfortable with saying that the only area of education that
23 needs attention is genetic determinism, or that that is the only important ethical

1 problem.

2 I agree with you; that is one of the ways this connects to a broader
3 project, Carol.

4 But in terms of saying that that was the problem or putting,
5 highlighting that too much, Steve, as opposed to having it in the discussion, I would be
6 a little concerned that we--

7 DR. SHAPIRO: I think it is true that this kind of extreme version of
8 genetic determinism, if we can call it that, will come in, in a number of spots of the
9 report, for discussion and in content of saying, you know, we--(Inaudible.)--and cause
10 us some trouble. That will be an important area of thought.

11 And I agree that it would be very difficult for us to pick a subject,
12 even one as big as this, to highlight here because, you know, we could argue all day.
13 "Well, instead of dealing with this, we will deal with number two." (Inaudible.)

14 (Simultaneous discussion.)

15 DR. SHAPIRO: You know, it is just not-- We can't really do it
16 here. But it will-- That is a critically important issue in this discussion and it will be,
17 certainly be, in the report.

18 Let me just go on now to-- Let me also direct your attention right
19 now to an item which, in fact, I had meant to include in our recommendations. I did,
20 but it-- It is Item VII--Alex's--which I think is not controversial. And let me just draw
21 your attention to it. And that is the United States Government should cooperate
22 with its foreign counterparts to enforce any common aspects of the respective policies
23 with respect to the cloning of human beings. That is-- I had meant to have something

1 like that. I just didn't--

2 (Simultaneous discussion.)

3 PROF. CAPRON: It is drawn from Larry and Alta's previous--

4 DR. SHAPIRO: So that, in my judgement, should be part of that
5 statement, or something very close to it, should be part of the things that we
6 recommend.

7 Are there any comments, questions, concerns, et cetera?

8 DR. MIIKE: Only in that--

9 DR. SHAPIRO: Larry?

10 DR. MIIKE: Would we take this on as our, as one of our,
11 responsibilities if we leave it open?

12 Alta?

13 PROF. CHARO: Can somebody-- In one of the comments on the
14 last, on the third, drafted policy draft, it asks what does this mean in terms of gene
15 analysis? And I threw in a few examples. It is diffuse and would not involve us. Is it
16 a matter of when there are--

17 You know, it depends on what happens here, through legislation or
18 actually criminal penalties in another country. Will we have legislation for criminal
19 penalties? If both countries have similar policies, similar penalties, do you have the
20 basis for a mutual enforcement of one another's laws in a way that takes place
21 routinely and is not involved in checking with the commission? I mean, there are
22 routine channels of cooperation that would be invoked.

23 DR. MIIKE: I only meant whether, in Alta's recommendation of

1 that, whether we would take on the issue, take on the responsibility of seeing what
2 similar bodies in other countries are doing because they would be following the issue
3 in their particular country, as I would guess we would.

4 PROF. CHARO: The distinct--

5 DR. SHAPIRO: My expectation--

6 PROF. CHARO: I am sorry.

7 DR. SHAPIRO: Excuse me, Alta. My expectation is that we will
8 indeed follow that, but I don't think that we should anoint ourselves right now as--

9 This is a government responsibility to be taken, and the government
10 should decide how it wants to deal with it. It may give it to us; it may not. So we
11 have got plenty on our agenda in the next year and so that I don't want us to take on
12 anything that would require a whole new effort. But we could get assigned to it, or
13 asked to do it, and so on, and we would have to reassess it, as well as--(Inaudible.)

14 Okay. Let me make a-- Are there any--

15 PROF. CAPRON: There is one other matter.

16 DR. SHAPIRO: Excuse me, Alex. Yes?

17 PROF. CAPRON: We had discussed, and I had therefore included
18 in my attempt to put together a consensus statement, something that appears under III-
19 D, on page 2, and that is the notion that there might be established a continuing
20 oversight function.

21 And I thought in our discussion we had not come to the conclusion
22 that we should say thus, or come to the conclusion that it should be something separate
23 from the Recombinant DNA Advisory Committee--I mean, some people have said this

1 is just a gross form of genetic therapy, just all the genes instead of selected genes--or
2 some new body that would have responsibility to keep track of what is happening in
3 mammalian cloning and what the implications of that are for our primary
4 recommendation, which is that this is unsafe at this time.

5 And I think that we need, at some point, to--

6 DR. SHAPIRO: I think you are right. I am very glad that you
7 pointed that out.

8 As Alex said, this is Item B, the top of page 2. This is what Alex
9 has.

10 And Alex is right to have pointed out that we haven't had any
11 thorough discussion of that but it did come up--(Inaudible.)--and the issue here, as I
12 understand it, is that we need a recommendation, but that we consider assigning the
13 responsibility for monitoring ongoing development in science, either with an existing
14 body or a new body, as I understand the recommendation. And I think we need to see
15 how people feel about it.

16 David, then Bette.

17 DR. COX: I am in favor of such a recommendation, although I want
18 to be careful about being too specific. Having a whole bunch of independent boards
19 for each separate thing is not necessarily a good-- I am very in favor of it because it is
20 timely.

21 There is an overriding independent recommendation coming down
22 for this kind of a body, particularly with respect to genetic information. Primarily they
23 are being focused-- Most of those arrows are pointing towards the Secretary of Health

1 and Human Services to figure out a way to put this together. So I think that, in
2 conjunction with all of those recommendations, for a variety of other sources, this
3 would be very timely, particularly coming from this commission.

4 (Simultaneous discussion.)

5 DR. SHAPIRO: Bette?

6 MS. KRAMER: I was just going to put in the context of our past
7 discussions. And I think it really came up primarily at the law bucket, at the law and
8 policy bucket meeting, and it was in the context of do we want to consider making this
9 kind of a suggestion or--or--do we want to consider making a suggestion for a sunset
10 provision? Not that we couldn't do both, but that was the major discussion at that
11 time. And I don't think we ever resolved it; we just talked about it.

12 DR. SHAPIRO: Tom?

13 DR. MURRAY: I would be reluctant to vote for such a
14 recommendation unless I had a clearer sense of just what the mandate--(Inaudible.)--or
15 a precise picture of what is supposed to be--(Inaudible.)

16 DR. SHAPIRO: Alta?

17 PROF. CHARO: I am also not inclined to vote in favor of such a
18 body. As drafted in this particular example, it doesn't say that. It says that it should
19 be-- The government should consider making such a thing. I do agree that it could be
20 tied back, as it always has been, to the question of sunset clauses.

21 And the way it has come up, and the way that they combine--

22 (Inaudible.)--is going to recommend legislation with a sunset clause. The question is
23 what triggers the sunset?

1 And the two choices are automatically based on time or based on
2 some substantive criteria that has been met, and somebody has got to decide what the
3 criteria are and whether they have been met, which implies the existence of some
4 group of people, or an existing body--(Inaudible.)

5 And so if the recommendation on legislation were written to say we
6 think it is important that there be a--(Inaudible.)--visiting this and that the government
7 should consider the actions of automatic sunseting or the use of some kind of body
8 that will have attention to criteria.

9 We do not have to endorse the body. We don't have to get into the
10 details of it which, I agree with you, is where we would get into a lot of very
11 complicated discussions that will lead to a lot of disagreements--(Inaudible.)

12 Did that-- I mean, I know--(Inaudible.) And I wonder if that would
13 satisfy you?

14 DR. SHAPIRO: Tom, then Alex.

15 DR. MURRAY: Yes. The language here is much more broad than
16 that, than--(Inaudible.) Look at things but--(Inaudible.)

17 PROF. CHARO: That is true.

18 DR. MURRAY: (Inaudible.)

19 PROF. CHARO: That is true. I have outlined something much
20 narrower.

21 DR. MURRAY: Yes.

22 PROF. CHARO: Yes.

23 DR. MURRAY: But that is actually to be highlighted--(Inaudible.)-

1 -we expect them to do, and what functions. And I have a sense that this is very, very--

2 (Simultaneous discussion.)

3 PROF. CHARO: Right. This is--(Inaudible.)

4 DR. SHAPIRO: Alex?

5 PROF. CAPRON: Well, clearly the way this was intended is
6 responsive to what Bette said and also Alta; that this body could be the one that meets
7 the language under point C, where it says a sunset clause or a set of specific conditions
8 to be met.

9 But I would suggest that, even if you have a temporal sunset clause,
10 it would be very valuable to have this group, which would be--

11 Tom, I think these are quite specific and valuable functions; both
12 keeping abreast of developments in the field, engaging in further deliberation on the
13 ethical issues, and engaging the public in that process.

14 So that when the sunset is up we don't have a legislature suddenly
15 saying, "Whoops, we have got the cloning issue to think about again." You instead
16 have them expecting that a report will be forthcoming from this body a year before the
17 sunset clause expires updating the commission's initial work in that field. Because I
18 expect that some of these issues could be further refined, that there would be thought
19 about them, the public's views would be better understood, et cetera, et cetera. So it
20 could relate to both forms of a temporal or a conditions-met moratorium.

21 DR. SHAPIRO: Let me make a few comments on this set of issues.

22 First of all, with the option of either having what people call a
23 temporal sunset; that is time--two years, five years, eight. You live with the number

1 you pick--vis-a-vis having conditions that are met, I am not at all in favor of the latter.

2 I think that of the five, our greatest wisdom is to describe those
3 conditions myself in a way that maybe will be meaningful and will, in fact, generate
4 pretty reliably a reassessment. We just don't know enough about how this is all going
5 to progress and so on.

6 So I myself--trying to think this thing through--really always get
7 back to some kind of temporal number. I understand it is arbitrary. That is we don't
8 know whether three, two, seven. I think that all sunsets are arbitrary. But at least you
9 know it happens.

10 Whereas a set of conditions which are very, very difficult to draw
11 properly, I think--

12 PROF. CAPRON: What if it simply said prove that the procedure is
13 safe. Let the-- The procedure goes ahead in India and they create 100 babies this way
14 and there are no birth defects and you have to say, "Well, we can't argue on the safety
15 ground anymore. We have to have other reasons."

16 DR. SHAPIRO: Well, that is right, except that other issues may
17 come up which have us look, or have some people--not us necessarily--look at the
18 safety issue in a somewhat different framework, somewhat different light. I just think
19 these are very hard things to anticipate.

20 But, in any case, that is just my sense of it.

21 What if-- Would it make any sense at all to think of a temporal
22 sunset clause and ask not for an ongoing body necessarily, but you could also-- You
23 know, an N-1. You could trigger a study, for example, from NBAC, or some other

1 appropriately designated body.

2 This would get us away from setting up a new body and really not
3 necessarily carry something on all the time. That may or may not be necessary. The
4 science will-- Science and policy will look at this issue. But an N-1, whatever--

5 PROF. CAPRON: You can say to a standing or *ad hoc* board.

6 DR. SHAPIRO: Right. Right.

7 PROF. CAPRON: You could phrase--

8 DR. SHAPIRO: (Inaudible.)

9 PROF. CAPRON: If you were concerned that we not seem to
10 endorse the creation of a new federal bureaucracy.

11 DR. SHAPIRO: Right. That is-- And I am concerned about that.
12 Carol?

13 DR. GREIDER: I agree with that. I would like to endorse a motion
14 of a sunset clause as temporal and--(Inaudible.)--and I want to point out that the sun
15 usually does set on a temporal--

16 (Laughter.)

17 DR. GREIDER: Usually not based on some set of conditions.

18 DR. SHAPIRO: Bernie?

19 DR. LO: I also want to second Carol's idea for a sunset provision
20 and an N-1 review. And review it for N-1 years.

21 I think one of the problems we face is that we have so many good
22 ideas we try to do them all at once. I think that we should make sure we get, we focus
23 on sort of a narrow goal of trying to achieve it, which is--(Inaudible.)--a way of

1 reviewing the issues again before the sunset, before the sun actually sets, so there can
2 be a forum for discussion.

3 And I would like to sort of make sure we state the purpose and the
4 need for that kind of recess without specifying the structure under which that, or the
5 process by which that is taking place because then we get dragged into all sorts of
6 questions of permanent bodies, *ad hoc* bodies--(Inaudible.)--so I think that--

7 It is more important we establish, in principle, that there has got to
8 be a responsible review mechanism, a year or two years, or whatever, before the
9 sunset clause sets.

10 PROF. CAPRON: Ninety days.

11 DR. LO: Whatever.

12 (Laughter.)

13 DR. LO: (Inaudible.) Be careful not to sort of tack on too many
14 things to one function. I mean, again, it would be nice if one body did all the things
15 indeed, but it is not clear to me that the body that reviews a year before the
16 moratorium, before the sunset, is the same body that should be engaged in--
17 (Inaudible.)

18 (Simultaneous discussion.)

19 DR. LO: We need to not find-- Have that body read too much,
20 make sure it--(Inaudible.)

21 DR. SHAPIRO: Larry?

22 DR. MIIKE: Yes. I was going to suggest that actual legislation--
23 Say Bernie Lo will discuss ethical issues and Alta will discuss policy issues.

1 (Laughter.)

2 DR. MIKE: But just in terms of-- I think any legislation, with or
3 without a sunset clause, it is essential that within that legislation there is set up a
4 review so that there is a reasoned body of evidence before the discussion goes on in a
5 legislative session.

6 I also think, from the educational side or just for the continuation of
7 this issue, we do need to have a periodic review. So it is essential within either set of
8 circumstances.

9 DR. SHAPIRO: Bette?

10 MS. KRAMER: Yes. And to go further perhaps I will make a
11 motion that we volunteer Carol and David as the reviewing committee.

12 PROF. CHARO: I will review sunset--

13 MS. KRAMER: An N-1, right?

14 (Laughter.)

15 MS. KRAMER: You know, to get back to the education issue for a
16 second, I was wondering, since I know when the Genetics Committee reconvenes and
17 gets back to its initial agenda, or to its original agenda, that as we issue reports we are
18 going to, I am sure, going to have a need to call for education and maybe, maybe in a
19 broader timeframe, we will have more of an opportunity to investigate what is going
20 on out there and to maybe do some thinking about it.

21 So perhaps, for the purposes of this report, if we just make a strong
22 endorsement of the attempts that are being made and add our voices, we will have an
23 opportunity to speak to it further somewhere down the road when we can do it with a

1 little more time.

2 DR. SHAPIRO: I am sure this 90 days will not be the last time
3 NBAC looks at these issues--(Inaudible.)

4 Any other comments right now?

5 What I am going to propose is that we recess for a while and I, and
6 perhaps one or two others, will struggle a little bit with trying to improve this language
7 and incorporating some of the suggestions that have been made and talked about with
8 Alex and see about which of these frameworks would--(Inaudible.) And I just need
9 some time to struggle with some of the suggestions that were made.

10 (Simultaneous discussion.)

11 DR. SHAPIRO: So just one announcement before the recess. I
12 don't know how--(Inaudible.)--struggle along with this, so I will ask people to really
13 stay in the area, at least if that is possible.

14 I would also like to say that there are some press people from Japan
15 who are here that would like to interview members of the commission. Anybody who
16 is interested, they are in the back over there. I am sure they would like to speak to
17 some of you, if you have an interest in doing so.

18 So let us recess. I am going to ask Alex to speak to you so we can
19 work on it. And all right. We will probably need at least a half an hour.

20 (Whereupon, at 9:25 a.m., there was a recess.)

21 DR. SHAPIRO: Let us start on the next aspect for discussion--
22 (Inaudible.)

23 I really want to turn now to Dr. Lo, who will bring us up to date on

1 the work he and his colleagues have been doing on what we called the ethics chapter,
2 ethics bucket, the ethics area, in which we are trying to articulate what are the most
3 difficult sub-parts of this report.

4 So let me now turn to Bernie just to bring us up to date on where
5 that effort is.

6 ETHICS CHAPTER

7 DR. LO: Well, the ethics bucket and ethics chapter are a long way
8 from achieving the goals that we want to achieve.

9 I will try to, first, articulate the moral/ethical considerations that are
10 pertinent to the Dolly-type cloning, and secondly describe the framework for what we
11 hope will be a future discussion of--(Inaudible.)

12 Last night we had a-- We always seem to have these sessions where
13 we sort of look at what we have done and say, "We haven't really accomplished what
14 we are trying to accomplish."

15 And I think we are going to need some widespread reworking of the
16 chapter. And Jim Childress and Tom Murray and--(Inaudible.)--and Tricia Backlar
17 and I tried to, in a way, to start to work on it.

18 Let me just say that the changes that will be made from what you
19 have in the e-mail I sent--I guess it was Thursday--first, there is agreement that the
20 introduction needs to be changed.

21 Our current thinking is to make the introduction much, much briefer
22 and to start with four or five representative quotes from people from reports we have
23 had, quotes people made and used sort of exemplifying the range of responses. And

1 then very quickly to transition into the arguments, the ethical considerations, both with
2 regard to individual acts of cloning and with regard to the practice of cloning and
3 social policies relating to cloning.

4 I think we do want to start with individual situations first because,
5 first I think it is what people think of. It is easier to think about specific situations and
6 often individual cases to bring up sort of points that otherwise would--(Inaudible.)

7 But I think we want to get-- We are going to have to move a lot of
8 material somewhere else in the report that--material that, for instance--deals with the
9 differences between ethical consideration of individual acts and cases versus practices.
10 I think it is very nicely done.

11 You know, I say that because I think, you know, it is really true--
12 (Inaudible.) But it appears, sorts of get in the way, of sort of getting to the sort of the
13 meat of the issues.

14 What we have done is also realized that the current way of sort of
15 listing things out doesn't hang together. It is sort of a lot of sort of arguments that
16 don't sort of--(Inaudible.)--what the relationship is. And we are now thinking of sort
17 of rearranging things in a more structured and a little bit more coherent way. And that
18 is what you have here.

19 I guess what we would like to do is sort of try and think through the
20 outline because I think without a sort of coherent outline sort of the text is not going to
21 stand alone either.

22 And so what we want to do is, first, start with the con arguments and
23 then the pro arguments, because I think that is most of what we hear and this is really

1 sort of driving the public concerns. And then separate that into con arguments that
2 really relate to consequences of cloning, from the ones that are wrong in and of
3 themselves, sort of regardless of whether they lead to other undesirable consequences.

4 And another consequence is you want to separate out harms and
5 risks to individuals, start with that, and then go to harms and risks to important social
6 cultural moral values.

7 And then we sort of listed, within the harms to individuals, the
8 various types of harms that might befall the child who results from cloning, if that
9 were ever to be acceptable, as well as to the women sort of undergoing your oocyte
10 definition of gestation.

11 And then under social values--that really has been the most difficult
12 section to write--taken with a lot of input from various people who are really
13 concerned about social relationships of justice, control, human dignity and
14 modification.

15 And then separate from the consequences, we want to have a section
16 that really groups together the arguments that really are arguments that cloning is
17 wrong in and of itself, whether or not an individual is harmed--

18 (Simultaneous discussion.)

19 DR. LO: --in a sort of specific way.

20 And there I think we are really talking about it violating people's
21 dignity, including, you know, boundaries of treating, you know, treating children as
22 clones, as objects, rather than as full, whole persons.

23 So that is sort of-- We are trying to find structures where the

1 individual arguments, individual argument framework, which I think is pointed out.
2 We are not-- This is really a sort of an opening for discussion. It is really a way of
3 suggesting how further discussion might proceed.

4 Other than the concerns at the present time now, the risks being
5 unethical, which was the risk from acceptable, there is not agreement on a lot of these-
6 -(Inaudible.)

7 The--(Inaudible.)--con and in terms of the pros and then, and get
8 separate out the arguments in favor of cloning, and real consequential arguments that
9 argue that cloning might provide benefits, and we sort of separate out benefits, and
10 what kind of benefits.

11 And then we have another big section on the arguments in favor,
12 arguments that were not based on--(Inaudible.)--but a rights-based argument that have
13 to do with--(Inaudible.)--rights to procreation or--(Inaudible.)--children.

14 So that is how the thinking really radically restructured the sort of
15 what the meat of the ethics chapter.

16 I am reminded of a--(Inaudible.)--of one of our intensive care units
17 in our hospital who said, "None of us is as smart as all of us." And I really think that
18 what we need now is a lot of input, a lot of thought from all of you as to how to sort of
19 structure this part of the report to make it as clear and as helpful as possible.

20 So I encourage you, on your trip home, or within the next couple of
21 days, to take a look at this and send in, let me know what you think are ways to
22 strengthen the structure.

23 I think once we do that, sort of moving things around to the places

1 they now appear is a very possible aspect, a hard conceptualization, sort of building
2 the scaffolding framework that is important, we are going to try and get this to the
3 point as well as possible, as strong as possible.

4 Because really what we are calling for is a framework in a sense, a--
5 (Inaudible.)--by which people can continue the discussion. We are not trying to settle
6 the arguments, other than a recommendation--(Inaudible.)--framework, which will,
7 you know--

8 DR. SHAPIRO: Okay. Thank you very much. And let me, if I
9 could, just make one or two comments right now. Of course, there will be others.

10 And perhaps before I comment I should turn to other members who
11 have been thinking about this. So let me see if Jim or Tom or Eric would like to
12 comment. Yes?

13 DR. MURRAY: Yes. A couple of quick things. One, I think I like
14 Bernie's--(Inaudible.)--but I think there should be another barrier. No one has been
15 called to be as--(Inaudible.)--rather difficult group of people at times and--(Inaudible.)

16 (Simultaneous discussion.)

17 DR. MURRAY: (Inaudible.)--thank you, for myself--(Inaudible.)

18 DR. : Yes.

19 DR. MURRAY: A couple of things. And one is very minor, a that
20 is just that, in this outline, you probably want to move the rights out to the--

21 (Inaudible.)

22 Secondly, I think there has been-- This is really a very constructive
23 move forward. And I think we have many of the elements, but I think you should

1 know that much of the text will remain, but there will be a lot of shifting around as--
2 (Inaudible.)

3 And thirdly, there actually is already a new text for some of these
4 things that we think of as simply an improvement over what was in the last version
5 you saw. And I would--(Inaudible.)

6 I think you have to be very careful--(Inaudible.)--here about making
7 sure that none of the-- You have asked the group to explain the arguments that people
8 have made--(Inaudible.) You do not in any way--(Inaudible.)--oversell the importance
9 of genetics--(Inaudible.)

10 DR. LO: But that is an important point that Diane and others have
11 made and is crucial. (Inaudible.)

12 DR. SHAPIRO: Carol?

13 DR. GREIDER: I just want to make one comment. Although we
14 have been discussing issues of how it is that things are worded to avoid the issue of
15 genetic determinism, and I am happy to work very hard on the wording of things--
16 (Inaudible.)--there are also though are issues about keeping exact, the content of this
17 list--(Inaudible.)--that gets to the issue of genetic determinism.

18 For example, pulling out, under harms, control. Reading from the
19 text that is currently here, cloning allows a new kind of control, no longer just--
20 (Inaudible.)--but positive eugenics, selecting the traits, the current--(Inaudible.)--
21 although such efforts to control the child are only--(Inaudible.)--important for
22 environments of even stating that somehow you can control a child because you have
23 determined the genetics of that child, that-- Just that concept in and of itself is steeped

1 with ideas of genetic determinism. And so it is not just the wording, but some of the
2 major issues that are here that really need to be carefully thought out. And perhaps
3 control is an issue that has been raised in the public. There needs to be an element of
4 that here.

5 But to just state it that directly, as if there is some inherent way to
6 control a child because you know what the genetics is, is inappropriate.

7 And so it is not just moving around and restructuring how these
8 things are ordered, or somehow changing the wording, but some pretty fundamental
9 issues about what have come out of this that I have concern with.

10 DR. MURRAY: May I make a quick follow-up?

11 DR. SHAPIRO: Yes. Go ahead.

12 DR. MURRAY: Carol, let me see if this would help. Really some
13 people think this is what is going to happen. And I think maybe we need to just be
14 very careful when we write this and say, "Look, this isn't a view that may be out
15 there." Some people may believe it. It is in fact an erroneous view. It is a wrongful
16 view. I mean, a dangerous view.

17 But if we were to make a clear distinction between what we sort of
18 heard people say and then treat each statement very expressly so that the people may
19 say, who read this, and say--(Inaudible.)

20 Would that help?

21 DR. GREIDER: That would help to some degree. Although the
22 way that these things are listed--that these are the benefits and these are the harms--
23 just stating it in that way, from the outset, even if, at the very beginning, one has to be

1 very careful.

2 DR. LO: (Inaudible.)--benefits and harms?

3 DR. GREIDER: Right. So we can work with the individual--

4 DR. LO: No. I--(Inaudible.)

5 (Simultaneous discussion.)

6 DR. GREIDER: I just wanted to point out that it--

7 DR. LO: No. I think that is very important.

8 DR. GREIDER: --is somewhat the language, but it also is the meat
9 of what is there.

10 DR. SHAPIRO: Well, in terms of what the issue is that Carol is
11 raising now, that same issue is true-- It also applies to some of the other things listed
12 here. That is, harms are not things that we claim together unanimously are harms.
13 These are just important considerations raised by others, some of which we may think
14 of as wrong, some of which we may have no judgement on. And we, in fact, we just
15 try to make that clear.

16 On genetic determinism, we all agree on what is inappropriate. On
17 others, we may just have to say that--(Inaudible.)

18 Alta, then Jim?

19 PROF. CHARO: I think though-- I agree with what you said, but I
20 think that there is going to be a subset--

21 DR. GREIDER: Yes, but there is--

22 PROF. CHARO: (Inaudible.) I think there is going to be a subset of
23 things where we actually go one step further to address Carol's concern.

1 A long time ago, I think I remember Kathi saying something about
2 the benefits of perhaps having a single page that describes what cloning is not. It is
3 almost like cloning myths. Here is a myth.

4 And some of the things that have been alleged as harms, that we
5 have felt compelled to write about in the text, no matter how ludicrous, grow out of
6 the myths. The idea that you do cloning and suddenly the resulting person is of the
7 same age as the person from whom you obtained the cell, or the idea that this person is
8 now going to be used as a mine for vital organs. We are going to take their heart out
9 and kill them.

10 These are the kinds of things that are so ludicrous that to even
11 discuss them in the part that calls them harms is to in fact continue to reapply them in
12 a way that I think is a disturbing parallel.

13 We can identify the subset, pull them out for this kind of high
14 profile cloning fears and myths, and then not have to treat them in the harms section,
15 and in the harms section discuss only those things that are arguably harms.

16 And we don't all have to agree with each one of those, with each one
17 of those, but at least let us limit it to the ones that are at least arguably harms, not
18 things that are clearly silly, but that are out there because of the science fiction, out
19 there because of--(Inaudible.)--out there because of occasional gross
20 misunderstandings, even by the best educated people.

21 DR. LO: I would like to follow-up and say this is very helpful. It
22 seems to me there are very different kinds of things we want to, we might want to pull
23 out.

1 One of the things that are inaccurate scientifically, that people are
2 claiming this will be what cloning is about--(Inaudible.)

3 There are another set of things which are really examples of cloning
4 that are so outrageous and repugnant that everyone would agree that they would be--
5 (Inaudible.)--and those include buying and selling, killing of clones and using the
6 organs for some other purpose, probably cloning an adult without his or her consent.

7 And it seems to me we should be able to elevate those to the status
8 of what we can now single out the risks, unacceptability of risks at the present time as
9 being absolutely--(Inaudible.)--may get lost in the context of some people saying that.

10 It would be helpful to get some feedback from the people about
11 whether conceptually, and sort of have a presentation separating out those things from
12 the rest of the outline--(Inaudible.)--as you go through this discussion.

13 I have heard-- I think a lot of you have sort of voiced similar
14 concerns to what Carol was saying and this may be-- I mean, I think one strategy is to
15 make sure we always bracket, "It is claimed that," or, "It is argued that," so that it is
16 really clear we are not describing--(Inaudible.)

17 But another is to really pull out the things where we really are--
18 (Inaudible.) Part of the chapter; that is some say but others disagree; some say but--
19 (Inaudible.)

20 DR. SHAPIRO: Okay. It looks like you do want to speak. Eric,
21 Jim and Diane?

22 DR. CASSELL: Well, in the emergency ward in which I trained--
23 (Inaudible.)--Bernie, it said, "It is better to be rich and healthy than poor and sick."

1 Are you going to leave in--it is not in this outline--but are you going
2 to leave in, at the end, what you have here, and the only one about, "In rebuttal to
3 ethical concerns," and the general comments that you have at the end of your chapter?

4 DR. LO: Well--

5 DR. CASSELL: The differences between ethical analysis and
6 individual acts of ethical analysis for the public, and so forth?

7 DR. LO: Yes. I think it needs to be in there somewhere.

8 DR. CASSELL: Yes. I do, too.

9 DR. LO: (Inaudible.)

10 DR. CASSELL: That is just what I wanted to say because just
11 because it is not on the outline it is still--

12 DR. LO: (Inaudible.) This is just part of the chapter with a very,
13 very shorter introduction, and then a transition section that leads to the ethics of the
14 policy and law section which is the difference between actual and ethical
15 considerations regarding actions versus ethical--(Inaudible.)

16 DR. CASSELL: Right.

17 DR. LO: So that--(Inaudible.)

18 DR. SHAPIRO: Jim?

19 DR. CHILDRESS: I am just following up--(Inaudible.)--working
20 on it today. I understood that we could get this better. I understood this to be just
21 simply focusing on that central part of the chapter, and that the other things would be
22 there in terms of the introduction and some conclusion.

23 One way to perhaps address part of the concern that Carol and Alta

1 and others have mentioned, on the control part, part of what is at issue there is the
2 effort to control, not to control, but the effort to control, and whether that effort to
3 control, as expressed just in cloning, but also didn't have various measures--
4 (Inaudible.)

5 So some of what is at issue there, I think in this discussion, could
6 fall under other headings without actual--(Inaudible.)--because it is really the effort
7 that--(Inaudible.)--some of the difficulties.

8 One last observation, one I had before. I hope that other things,
9 something about the ethics section now, but that we will keep in mind the language, all
10 the sections can relate to each other.

11 And later when we come to the religious perspectives section I have
12 tried, in the most recent revision, to highlight some of those connections and I would
13 hope--and Bill Freedman reminded me of this in a conversation--that some of the
14 comments we have in the science section, and in the religious perspectives section,
15 and in the other section are all closely related so we shouldn't simply, for instance,
16 quote those who are working in ethics in this section, and so forth, but there are ways
17 in which these do relate together.

18 DR. SHAPIRO: Thank you. Diane?

19 DR. SCOTT-JONES: I just--

20 DR. SHAPIRO: Excuse me. (Inaudible.)

21 DR. LO: Jim, I liked what you said about control made up of the
22 key concept. Would "intention to control" be better than "effort to control?" I mean, I
23 think you are right, there is another concept you get at--(Inaudible.)

1 DR. CHILDRESS: (Inaudible.)

2 DR. SHAPIRO: Okay. Diane? Sorry.

3 DR. SCOTT-JONES: In reading through the various drafts of this,
4 it seems that some of the examples that are given as possible benefits, as well as some
5 that are given as possible harms, really rely on a misunderstanding of the relation of
6 genetics and environment in human development, and maybe they could be put
7 together in a section instead of being placed as they are.

8 And I think Jim's suggestion that, instead of control, put either the
9 effort to control or intent to control, because that is based on a misunderstanding of
10 what one could do by replicating the genes of an adult.

11 So it seems to me that the chapter needs to do more than it does to
12 clearly state that some of the proposed benefits, as well as some of the proposed
13 harms, are based on misunderstandings.

14 And I would place the idea, which is III-E in the draft that I have,
15 reproducing an exemplary individual, that belongs in the same category as the intent to
16 control because they are both extremely misguided.

17 And I think they shouldn't-- They shouldn't be separated here
18 because they are part of the same phenomenon, and that is the assumption that you
19 will control a person by replicating the genes of an adult.

20 And I have a further comment.

21 I think that we should really avoid creating a social category,
22 "clone." And I think our society has lots of social categories that we put people in that
23 have an alleged biological basis but are really social categories. And I would hate to

1 see us add "clone" to the list of those that already are damaging in our society.

2 So, for example, under "reproducing an exemplary individual," III-
3 E, there are statements, "Providing only the genes of a famous person would not
4 ensure that the clone will replicate the accomplishments. Indeed a clone would be
5 unlikely to match such achievements unless the environment were also conducive."

6 You have already created a social category. And I think we should
7 avoid doing it, even though it might be unwieldy to say, "The person created by
8 cloning." I think we should force ourselves to do that.

9 And then, finally, I think that there are various versions of genetic
10 determinism, and almost any genetic determinist will allow that there is some role of
11 environment, but after allowing that they dismiss it.

12 And I tried to write a little bit. I really didn't have time to do this. I
13 just brought with me some of the things off my shelf that discuss these issues.

14 And I had circulated a statement summarizing some of
15 Lawonten's(?) work, where he talks about that we are not buckets, we are not empty
16 buckets at birth. And I think, since we use the bucket metaphor to describe our
17 working groups, maybe we could use it to illustrate that we don't begin life as empty
18 buckets with environment being just water that fills the bucket.

19 But that is one version of genetic determinism. And it is inherent in
20 some of the ideas in this chapter, but it is wrong, and I think we should get rid of it.

21 End of speech.

22 DR. SHAPIRO: That is a very helpful comment. And I myself am
23 trying to work through some of this. It is very uncomfortable every time I have used

1 that word clone, but didn't have the imagination to come up with something better.

2 But some of your remarks have helped a lot in that regard.

3 So I think we should be very conscious of that. Sometimes a little
4 language is a little-- It seems more difficult but, in fact, serves us better in the long
5 term. It is a very helpful remark.

6 David?

7 DR. COX: I would like to continue where Diane left off with
8 respect to this issue of genetic determinism.

9 And I think, as difficult as it is for me personally to accept, it is that
10 there is a large number of people, and many of them are my scientific colleagues, who
11 actually believe strongly that genes determine everything. And I think that for us to
12 pretend that that is not the case--

13 DR. MURRAY: It is just our genes making us say that.

14 (Laughter.)

15 DR. COX: --is a real mistake.

16 And so I think that it is a strategic mistake to get into this argument here in the
17 ethics section because some people will strongly disagree with us when we say that genetic determinism
18 is wrong, factually wrong. They will say that we are factually wrong.

19 So I would have the following suggestion is that, if we point out,
20 that whether you happen to be a genetic determinist or not, that, in either case, cloning
21 human beings is not an ethically good idea and that it is not an ethically good idea for
22 some of the reasons that Jim Childress laid out, which have to do with the
23 considerations of the person. Being a person, being an individual, and not being an

1 object and not being a clone, as Diane said, but being a person who evolved from
2 being cloned.

3 I think that what this does then, it puts our efforts on showing not
4 that you are a bad person, or you are intellectually wrong if you are a genetic
5 determinist, but that, even if you believe that, then that that is not the issue. The issue
6 is that there are other reasons why, you know, these things are benefits and risks.

7 So I think I quite agree with what Diane said. The commissioners
8 should be careful not to endorse the position of genetic determinism. I believe that
9 myself. On the other hand, I think we have to be cautious not to dismiss it because
10 there is a significant fraction of people who, in my personal view, are quite naive in
11 how they use it, but it exists nevertheless.

12 DR. SHAPIRO: Okay. There are a quite a number of people who
13 want to talk. Tom, and Carol, and Eric. Tom?

14 DR. MURRAY: Yes. Diane, thanks for the reminder about the
15 importance of not making, of redefining clones as sort of another category. That was
16 very-- That was extremely well put. And she is right.

17 And I think we could simply say in the outline we recognize it only
18 as chore in the end, although I think we will still leave in the text of the thing--
19 (Inaudible.) We just have to-- I hope you will help us. We will all try to be mindful
20 of that.

21 I do want to disagree with you about the organization of the ethics
22 section. I think genetic determinism is such a big idea, and it is so pervasive, that if
23 we organize the section around that, that it would-- It would sort of lump--

1 (Inaudible.)--all the other categories. What I would-- I just feel like it would work
2 better if we had a separate section--now, I don't know where it goes--(Inaudible.)

3 (Simultaneous discussion.)

4 DR. MURRAY: Maybe it goes somewhere in the science section.
5 Maybe it just-- We feature it as something in the introduction.

6 (Simultaneous discussion.)

7 DR. MURRAY: Something there. And then we refer, in each of the
8 times where it comes up in the ethics argument, we refer explicitly back to it and not
9 evade it. Just say, "Look, this really depends on the view of genetic determinism,
10 which we find scientifically not credible, or scientifically false." Whatever. Whatever
11 language you want to use.

12 But I would not turn the ethics-- I would not organize the ethics
13 section around it.

14 DR. SHAPIRO: Carol?

15 DR. GREIDER: So this issue about where genetic determinism
16 goes is a major thought in the report. I think it comes down to that, if it has to be
17 throughout, and along the way people have made suggestions about maybe putting it
18 in a section, a science section, having to do with this, and as it is constructed so far,
19 the science section has been mostly just the details of how Dolly was made.

20 But now let us look to this, and thinking about it, and Diane
21 suggested it to me earlier today, and Kathi just suggested it again, I think it would be a
22 good idea to have an explicit section in the science section dealing with it, partly in
23 response to what David just said, which is there are a number of scientists that would

1 call it genetic determinism.

2 DR. COX: They will raise their hands. We were just at a scientific
3 meeting and I asked how many people were scientific, genetic determinists, and
4 people raised their hands.

5 DR. MURRAY: We won't ask you where you were.

6 (Laughter.)

7 DR. COX: (Inaudible.)

8 DR. GREIDER: So because of that, to have it in the science section.

9 But also, a point, to follow-up on what Tom just said, to have
10 something in the introduction--there is some language like that right now--to make it
11 even more explicit in the introduction, that we can then refer back to each time. I
12 think we would go a long way for doing, you know, to dealing with the concerns we
13 have.

14 DR. SHAPIRO: Okay. That is helpful, Carol. Are you going to--

15 DR. GREIDER: And I will write that summary.

16 DR. SHAPIRO: (Inaudible.) That is right.

17 (Laughter.)

18 DR. SHAPIRO: If you will get that to Kathi so we can review it.

19 Okay.

20 Eric is next.

21 DR. CASSELL: I am sort of struck as I listen to this about the
22 history of determinism. I mean, it goes back to the idea of innate ideas. It was
23 attacked by Descartes and swept away by the *tabula rasa* of the enlightenment. And

1 in our own century we have had psychic determinism once again that came up. I
2 mean, the classical--(Inaudible.)--on the freedom of individuals to be themselves, or
3 free will if you wish, makes it clear that when you go after it, you have to go after it
4 very strong.

5 It is not simply somebody's mistaken fact. It is an inherent concept
6 and innate idea about where freedom and liberty lie.

7 DR. SHAPIRO: Bernie?

8 DR. LO: Yes. I think this is very helpful.

9 (Simultaneous discussion.)

10 DR. LO: And I would feel much more comfortable having the
11 section of genetic determinism in the science chapter as opposed to the ethics chapter
12 and we can just refer back to it.

13 DR. GREIDER: I think it should be both. I wasn't saying take it
14 out.

15 (Simultaneous discussion.)

16 DR. LO: (Inaudible.)

17 DR. MURRAY: May I ask--(Inaudible.)

18 DR. GREIDER: Yes.

19 DR. MURRAY: In the ethics chapter we might actually want to add
20 a small section which talks about some of the sort of social uses that genetic
21 determinists' ideas--(Inaudible.)--for example, and that might be--(Inaudible.)

22 DR. LO: Yes. I see that we need to think this through. Some of
23 this clearly is scientific. I mean, what would it mean to have Dollys in different

1 environments and--(Inaudible.) What would indications be for human--(Inaudible.)

2 I would like to sort of--(Inaudible.)--what mean by genetic
3 determinism because I think people, you know, mean a whole lot of different things.
4 And I think we should sort of lay that out.

5 I think Eric was getting to an important point about putting ethics--
6 (Inaudible.)--notion of restrictions over free will; that you really are determining the
7 way; that you cannot choose to go down a certain path. It seems to me that is what the
8 ethics needs to be about.

9 I think Diane has raised some very important issues having to do
10 with sort of a cultural historical context in America where ideas of determinism have a
11 particularly--(Inaudible.)--history of--

12 It seems to me that is another issue we need to put in which is not
13 now in the report. I am not sure where it should go, but I think we are talking about a
14 lot of different things that we are wanting to insert. And I just think we need to spend
15 a little more time thinking through where it is going to go and who is going to write it.

16 DR. SHAPIRO: Let me just make one suggestion and we can come
17 back in a second.

18 Diane is next.

19 There is, right now, the way the introduction is drafted, that there is
20 a kind of free statement there that says something about--(Inaudible.)

21 (Simultaneous discussion.)

22 DR. SHAPIRO: (Inaudible.) And we could certainly work in the
23 introductory section on saying that so we will have something. And I will work with

1 others. I will certainly get that in the introduction in some hopefully helpful way.

2 And then I think Carol--you obviously feel very strongly about it--if
3 you could draft something for the science chapter. And we could share all this and it
4 will help those who are doing the ethics chapter to decide just how they might want to--
5 -(Inaudible.)-- and take their own special view of it.

6 DR. GREIDER: A lot of it though is rewriting what we already
7 have.

8 DR. SHAPIRO: Right.

9 DR. GREIDER: It is not adding a section.

10 DR. SCOTT-JONES: I--

11 DR. SHAPIRO: Diane. Excuse me.

12 DR. SCOTT-JONES: I just wanted to make sure that I say it so all
13 the commissioners can hear it. Carol and I discussed this during the break.

14 We are not saying that we should supplant genetic determinism with
15 environmental determinism. We are not saying that this report should endorse a
16 *tabula rasa* view or anything like that. It is determinism in itself that is the issue here.
17 It is neither one nor the other, but that human development is propelled by the
18 interaction of those two and they can never be separated throughout development.

19 DR. BACKLAR: I want to say that I think it would be exceedingly
20 dangerous for us to start to address free will.

21 I think the issue here is environment, the effects of the environment
22 and circumstances, how, where one is brought up, where one is born. I-- I-- I am
23 very nervous that you are going to address free will. I don't think that any of us meant

1 that. I hope.

2 DR. SHAPIRO: Well, I don't know if any of us meant it or not, but
3 what are you so frightened about?

4 (Laughter.)

5 DR. BACKLAR: Because I think it will derail much of the
6 discussion.

7 DR. CHILDRESS: If I could tag onto that. Yes. I think it would be
8 a mistake to try to think of it only, as Eric's comments already suggested, it is a long
9 and complex history based in--(Inaudible.) There is nothing we could say without
10 getting into--(Inaudible.)

11 DR. SHAPIRO: Bette?

12 MS. KRAMER: I want to pick up on Carol's comments because I
13 hope that if we put in a discussion of genetic determinism in the science chapter that,
14 again, that we are not going to let some of the language, as it currently stands in some
15 of these sections, go forward because I think that by elevating some of the arguments,
16 that I think are so deterministic, to the same level of others will minimize the
17 importance of the really significant issues.

18 I mean, for instance, some of the section of the right to rear children-

19 -

20 (Simultaneous discussion.)

21 MS. KRAMER: --where it talks about making, creating a child that
22 is going to musically proficient is something--

23 I mean that is so deterministic that, by including it at the same level

1 as some of the more significant arguments, it minimizes the latter.

2 So I think, again, it really has got to be-- You can put it where you
3 want--I mean, the language of genetic determinism--but it does have to be tied in.

4 DR. LO: Okay. Let me try to say something here.

5 DR. SHAPIRO: Bernie?

6 DR. LO: Some of these actually come out of very specific
7 arguments that were made by certain members of the commission, actually people
8 who aren't here. I think at some point--(Inaudible.)

9 (Laughter.)

10 DR. LO: But--

11 DR. : (Inaudible.)

12 (Laughter.)

13 DR. LO: I tried to get--(Inaudible.) But I think though is this the
14 sense of the committee as a whole; that some of these things that--

15 (Simultaneous discussion.)

16 DR. LO: --individual people have felt fairly strongly about detract
17 from--

18 (Simultaneous discussion.)

19 DR. LO: And I think I need to be able to say that there is going to
20 be some judgements made as to what this--(Inaudible.)

21 (Simultaneous discussion.)

22 DR. LO: And I felt sorry for some of the people who have spoken--
23 (Inaudible.)

1 (Technical difficulties.)

2 DR. LO: --maybe we are finding unacceptable aren't here to sort of
3 give their side of it. But I think I would like to be able to interpret this to say that
4 people have advanced these very examples to saying, "We are sorry. We don't think
5 we can improve those."

6 Is that the sense of the group? I just want to be able to--

7 DR. SHAPIRO: Well, let me say on that--(Inaudible.)--true in this
8 report; that lots of ideas are not going to be included.

9 DR. LO: These are people, these are people--(Inaudible.)

10 (Simultaneous discussion.)

11 DR. LO: Some people felt, I mean, very strongly about an advance-
12 -(Inaudible.)

13 (Simultaneous discussion.)

14 DR. LO: --saying, "I am not convinced by what you all are saying."
15 (Inaudible.) So, okay.

16 (Simultaneous discussion.)

17 DR. LO: I think that is very helpful because I believe he works
18 quite well.

19 DR. SHAPIRO: Okay. Let me just say on the-- While I think a lot
20 of the comments that have been made have been extremely helpful and informative, I
21 think that the reorganization that you have suggested helps an awful lot. That it is
22 really a major step forward in my view, and should enable us to go-- I think will
23 enable you, Bernie, and his colleagues to see, in a pretty straightforward fashion, and

1 kind of accommodates various comments here that are appropriate. So I think it is
2 very helpful.

3 DR. LO: I thought this has been extremely helpful.

4 If I could just make one other suggestion. Diane, I thought you
5 very, very wisely brought in points of sort of an historical context--(Inaudible.) Can
6 we ask you to draft a paragraph or two on that? Because I think it is not in here and it
7 is important.

8 DR. SCOTT-JONES: Could I respond to that?

9 DR. SHAPIRO: Yes.

10 DR. SCOTT-JONES: Bernie is such a clever person.

11 (Laughter.)

12 DR. SCOTT-JONES: He asked me that privately during the break
13 and so he wants to get it on the record.

14 DR. LO: Right.

15 DR. SCOTT-JONES: Okay, Bernie. I will try.

16 (Laughter.)

17 (Simultaneous discussion.)

18 DR. LO: (Inaudible.)

19 DR. SCOTT-JONES: Thank you.

20 DR. SHAPIRO: (Inaudible.)--few minutes because 11:45 a.m. is the
21 time for public comment from those people who have come, and I want to be able to
22 accommodate them as quickly as possible.

23 We are, of course, running into very serious and important time

1 constraints and it is quite important that very soon that Bernie and colleagues not sign
2 off, but let us try to take whatever we have gotten and put it into a form that we can
3 then circulation to everybody for their comments.

4 So for those of you that said you would provide something, and so
5 on, that needs to be in the next day or two. It doesn't mean next week, or the week
6 after. It really means the next day or two if we are going to be able to use the material.
7 There is just no other way we can get this done. So please, for those of you who are
8 taking on these obligations--

9 DR. : (Inaudible.)

10 DR. SHAPIRO: --please do so quickly.

11 Yes, Tricia?

12 PROF. BACKLAR: I just want to make sure, Bernie. Are you
13 going to, as you have these sort of cataloging of harms and social values and wrong
14 acts and so forth, are you going to differentiate between what is a real harm that we
15 have at this time and what are possible harms? That may be another way of looking at
16 some of the sort of more science fiction issues.

17 DR. LO: No. That is a good point. I think we do need to clearly
18 distinguish the harms that we think are compelling reasons for social policy and public
19 policy at this point, from ones which are more harms we need to think about. I think
20 we need to deliberate.

21 It is still a question, it seems to me, of whether we separate out the
22 reasons we find compelling for our policy recommendations right now in a separate
23 section or just, within this outline, move them up to the top of the list and come back

1 to it and say, as we have said in all of this, it seems to me, "This, this and this are
2 compelling reasons for the recommendations." (Inaudible.)

3 But I think the other argument is so drowned out, that we need to be
4 sure we pull them out separately. I am torn because I think conceptually this works
5 better but, as you point out, there is the risk that a lot of things get listed and they
6 apparently take on equal weight just because of their expansive outlines.

7 DR. SHAPIRO: Arturo?

8 DR. BRITO: Yes. One of the things I am bothered with, when I
9 have read the ethics drafts so far and even moreso the way this outline reads is, to use
10 Tricia's word "cataloging," it gives me a feeling of some underlying subjectivity, or a
11 lot of underlying subjectivity here. And I think that is the problem with it.

12 I think all the points made are very important, but I think the way
13 this is divided, the pros and cons and the harms and benefits, et cetera, lends itself to
14 being a very subjective work. And it is very hard to distinguish what is being more
15 objective than subjective.

16 In other words, we are allowing our personal feelings to filter
17 through here.

18 DR. CASSELL: Right. But--

19 DR. BRITO: Well--

20 DR. CASSELL: Oh, go on.

21 DR. BRITO: I mean, let me finish and then I will-- What I am
22 suggesting--

23 What I suggest is, is maybe if we discuss it at each point

1 individually and not define it as pros and cons, but define it as potential harms and
2 benefits, as we go through it-- I don't know. I have just gotten that feeling whenever I
3 read the drafts, but--

4 Eric, go ahead and say what you were going to say because I have
5 got the feeling I have to respond to it.

6 DR. CASSELL: Well, it is the full conception of what is harm and
7 what is benefit without reference to persons. If you can give that, then you have an
8 objective measure of harm and benefit. Otherwise you are left with persons' views of
9 these things. Considered persons' views. There is no other way.

10 DR. BRITO: Well, my point is--

11 DR. CASSELL: There is no objective measure.

12 DR. BRITO: Okay. My point here is-- Well, no. You can look at
13 it objectively.

14 DR. CASSELL: How?

15 DR. BRITO: For instance, there is the definition of social
16 relationships that is going to be discussed and it is only listed under the cons, social
17 values, social relationships. Whose social values? Whose social relationships? Why
18 is that necessarily a harmful event or a risk?

19 We already discussed the issue of control and we changed it to
20 intention of control. I think it is a big help.

21 So I guess it comes back down to wording. I think you can be
22 objective in the way you look at it and say, "Okay, it is possible. It could be harmful
23 in this situation, but it possibly could be beneficial in this situation."

1 DR. CASSELL: Well, that--

2 DR. BRITO: So, I don't--

3 DR. CASSELL: I don't think there is any--

4 (Simultaneous discussion.)

5 DR. BRITO: And then--

6 DR. DUMAS: No. I agree.

7 DR. BRITO: What? No. No. My point is that the way this is
8 catalogued, the way this is described, I think it-- The structure itself needs to be
9 changed a little bit. I don't think the content necessarily needs to be changed, but I
10 think the structure.

11 DR. SHAPIRO: Now, let me-- Jim wants to make a comment in a
12 second. But I think a great number of-- A great many suggested harms and suggested
13 benefits have been raised and brought before us. A very, very large number.

14 DR. BRITO: Right.

15 DR. SHAPIRO: The most important ones of which are in here
16 somewhere. Not all of them, by any means, but the most important ones of which are
17 in here.

18 And I think it is quite important, from the point of the view of the
19 reader, to categorize them in some way, otherwise it will really look like a laundry list
20 in there with no-- I mean, it is our responsibility to enlarge and refine what we have
21 heard in some way that is just more than a laundry list.

22 Now, I am not married to this particular one more than any other I
23 can think about.

1 DR. BRITO: Okay.

2 DR. SHAPIRO: I think your point is well taken that we ought to try
3 and, you know, very subjectively say so when we are not the--

4 DR. BRITO: I guess the subjectivity here comes from the cons.

5 DR. SHAPIRO: Yes.

6 DR. BRITO: I don't know. I have to think about it a little bit more
7 and I will do it through e-mail and write my views. But I am just seeing that there is a
8 lot of-- There are too many cons here and not enough pros.

9 (Laughter.)

10 DR. BRITO: Or potential.

11 DR. SHAPIRO: (Inaudible.)

12 (Simultaneous discussion.)

13 DR. SHAPIRO: But then you have--

14 (Simultaneous discussion.)

15 DR. SHAPIRO: But, anyhow-- But I do think it is--

16 DR. : You can't find the pros.

17 DR. SHAPIRO: I really do think-- I take your point and accept it
18 and I am sure that Bernie will--(Inaudible.) I do like the idea of categorizing these in
19 some way. I think it helps a lot.

20 Jim?

21 DR. CHILDRESS: I appreciate the point that you are raising and I
22 hope that you will, wherever you see language--a statement of arguments and so forth--
23 - distorting positions or merely reflecting our own biases, in that regard, that you will

1 direct that to our attention.

2 But it seems to me that this is an effort to be objective in the sense
3 that it is an effort to take account of both the concerns and the arguments that have
4 been offered by a variety of people, including several who have testified before us,
5 about human cloning.

6 If the cons outnumber the pros, that is in part because that is the way
7 much of the public discussion has gone. And part of our task is to look at what has
8 been offered and then to indicate where there are counter-arguments.

9 So I see this as-- I don't think objective means totally value-free,
10 and I don't think we could ever aspire to that, but it seems to me there is a form of
11 objectivity that tries to be fair in the presentation of the arguments--attend to what is
12 critical arguments--and look at both sides and see things. (Inaudible.)

13 (Technical difficulties.)

14 DR. CHILDRESS: And that in some ways this chapter is, to a great
15 extent, as is the one--the religion chapter--descriptive and that it is trying to lay out
16 what is there and make some sense of what is there.

17 The structure that is provided, again, is an effort to pull together
18 what would appear to be just a string of arguments in ways that you can see, "Well,
19 this is really focused primarily on the outcomes or effects or consequences," and so we
20 need sort of to group those together and let it--

21 You are right. Any structure is going to, in some ways, distort but
22 what we are trying to do is find one that will enable us to come up with a report that
23 hangs together and that is fair to the positions we are trying to represent.

1 DR. SHAPIRO: I know there are others that want to speak. I will
2 just call Rhetaugh as the last person right now because then we have to go to the
3 public statements.

4 DR. DUMAS: Okay. In considering that structure, I think it is very
5 important that it really is able to distinguish between descriptions of what people have
6 told us--the input that we have collected--and the positions that we have arrived at
7 within our body.

8 And I had problems with the outline under the wrong acts, under the
9 rubric of wrong acts, because it wasn't clear to me whether or not these are wrongs
10 that we have defined or whether there is some effort here to categorize the input that
11 we have had from other sources. So I think it is going to be very important to make
12 that distinction.

13 When I read earlier drafts, I couldn't make the distinction between
14 reporting and claiming.

15 (Simultaneous discussion.)

16 DR. LO: If I could say something. I think it is important. And I
17 guess first I would like some clarification as to what we all agree on. I think it is
18 actually rather limited and, as I said, but I think we need to know this.

19 I think what we agree on at the present time is that we think the
20 current risks, physical risks of cloning, through nuclear transplantation of adult cells,
21 to the child produced--(Inaudible.)--is unacceptable; that the risk is unacceptable.

22 DR. DUMAS: As best we can access it.

23 DR. LO: As best we can access it.

1 few minutes late and I apologize to those who have come to speak to the
2 commissioners.

3 (Simultaneous discussion.)

4 DR. SHAPIRO: We are sorry to be a few minutes late. So let us
5 begin that right now. I just want to remind everybody when you address the
6 commission--(Inaudible.)--that any address should take no longer than five minutes.

7 (Simultaneous discussion.)

8 DR. SHAPIRO: Anyone addressing us running longer I will try to
9 remind you to bring your remarks to a close. I don't mean to be impolite, but I think
10 that I will ask everyone to try to abide by the rules. (Inaudible.)

11 (Simultaneous discussion.)

12 DR. SHAPIRO: The person with us right now is Gail Youness. She
13 would like to address us. There is a microphone right over here. This might be easier
14 for you if you don't mind using it. If you could just pull it down. Is that better?

15 MS. GAIL YOUNESS

16 MS. YOUNESS: Yes. Can you hear me?

17 DR. SHAPIRO: I can hear you.

18 (Simultaneous discussion.)

19 MS. YOUNESS: Is that better?

20 DR. SHAPIRO: That is better. I am sorry. It is a little inconvenient
21 for you.

22 MS. YOUNESS: Okay. That is all right. I appreciate the
23 opportunity to be here today and I am going to keep my comments really brief because

1 I was very pleased to see that so many of my concerns have already been discussed
2 here today.

3 So I am just going to-- My concern-- I guess my main thrust of my-
4 -

5 DR. : (Inaudible.)

6 MS. YOUNESS: Excuse me?

7 DR. SHAPIRO: I am very sorry to interrupt. Some members of the
8 commission would like to know if you are simply representing yourself or--

9 MS. YOUNESS: Oh, I am sorry. Yes. I guess I do just represent
10 myself. I had sent some material in to be disseminated. You may have read it. I
11 guess I should just say-- Let us just do this real brief. I will do it this way.

12 I was adopted and I didn't find out until I was 46. And when I found
13 this out I started to do some research and I started looking back into my own life and I
14 came to some conclusions. And one of them was that I felt that reproductive
15 technology really paralleled adoption. And so as such I drew some parallels.

16 And one of the things that I wanted to be here to say today is that
17 when you talk about cloning a human being, I guess, from my standpoint, we would
18 just be--I would be--looking at it as very narrowly as a reproductive technology.

19 And I guess my biggest-- There is probably just two or three
20 concerns.

21 One of them is that, with any of these technologies, and I haven't
22 heard it here today so much but we hear a lot about the child, and we are concerned
23 about the welfare of the child. And I think that people forget sometimes that we grow

1 up. And all of these children will grow up some day.

2 And the effects of what we do when they are children remain I think
3 your whole lifetime. Those things don't go away. So that was one of the most
4 important, you know, issues.

5 And another issue that I really believe, and this is my opinion just
6 from my own experience, is that our biology is really inherently connected to our
7 psychology. And I think we need to realize that we should be raised as much as
8 possible. We shouldn't remove people from their genetic backgrounds.

9 And I say that because I think with this new-- With the newer
10 reproductive technologies, people are-- People can be created and implanted into a
11 host mother and brought to, into this world, and never be told and never understand,
12 you know, where they came from.

13 And my concerns about things like this are things like whose
14 medical-- Whose medical history do these people get if they don't know? They are
15 not going to inherit anything from this host mother.

16 And what about, you know, what about keeping up with the medical
17 backgrounds of the donors, of the tissue, or the egg, or the sperm that are-- These are
18 really important issues, I think.

19 And I guess that all-- And I see it happening here, and I am very
20 pleased that the committee is concerned. And you are looking ahead and you are
21 trying to make sure that we don't make mistakes today and we don't move ahead too
22 quickly with these new technologies. And they are wonderful. And I think they can
23 do a lot of good for mankind.

1 But I would just like to make one remark. I, you know, I think that
2 we need to be very careful about creating a human being and relegating them to
3 secrecy, not knowing where they came from, and allowing them to go through their
4 lives, as I did, with a very distorted perception of who they were, and never really
5 being adequately able to understand or express to someone else what it is they are
6 feeling.

7 And so I also want to say that, as far as I am concerned, I am fine. I
8 mean, from my standpoint, my birth parents had no choice. It was a good choice.
9 They-- I had a wonderful home.

10 But I am not so certain that I would be-- I don't know how I could
11 accept necessarily having been created specifically for the purpose of being
12 systematically disconnected from my biological ancestry to gratify the desire of
13 another person.

14 And I really-- That is the question that I really can't answer. And
15 basically that is all I wanted to tell you.

16 And I am really pleased to see so many other concerns that I have,
17 have been already addressed here today.

18 DR. SHAPIRO: Well, thank you very much. Those were very
19 thoughtful comments. We appreciate you coming here today.

20 MS. YOUNESS: Thank you.

21 DR. SHAPIRO: Is there anyone else who would like to address the
22 commission at this time?

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MR. CAVANAUGH O'KEEFE

MR. O'KEEFE: Good afternoon, Doctor. Dr. Shapiro, I just-- I want to take a--

DR. SHAPIRO: For the record please, your name?

MR. O'KEEFE: I am John Cavanaugh-- Thank you. I am John Cavanaugh O'Keefe with the American Bioethics Advisory Commission.

In looking to recommendations on legislation, I did think that it was worthwhile carefully making a distinction between a ban on the implantation of cloned embryos, on the one hand, and the banning of cloning itself on the other.

And in the discussion through the morning there was, it seems to me, a confusion between the two. And I think it is worthwhile. I think it is tremendously important to separate the two out.

If you ban only the baby-making so-called cloning aspect, or the baby-making aspect of cloning, you leave open, I think, permanently all cloning eventually. A ban on the cloning of-- I am sorry.

The implantation of cloned embryos will certainly be ruptured in the not-too-distant future if 10 or 15 or 20 years down the line we have hundreds or thousands or tens of thousands of embryos that have been created with the Dolly technology, or whose lives have started in that way. It will-- It is not possible to defend the idea that they should all be discarded.

The people who are currently most opposed to cloning would lead the way in fighting for the implantation of those cloned embryos.

I think that it is important to keep these two issues apart. A ban on

1 cloning by nuclear transfer is one thing, and a ban on implantation of cloned embryos
2 is worlds apart. They are not close and should not be confused.

3 Thank you.

4 DR. SHAPIRO: Thank you very much for your comments. Any
5 questions or comments?

6 (No response.)

7 DR. SHAPIRO: Thank you very much. Are there any others?
8 Anyone else who would like to address the commission at this time?

9 (No response.)

10 DR. SHAPIRO: Okay. Let me make a suggestion. It is 12:00
11 o'clock. It is the time we had scheduled for lunch so we will adjourn now for an hour.
12 We really cannot take more than an hour. We are running up against time constraints.
13 I know a lot of you, including myself, have transportation arrangements, so that we
14 really must be back by 1:00 p.m.

15 Thank you very much.

16 (Whereupon, at 12:01 p.m., there was a luncheon recess.)

17 DR. SHAPIRO: I would like to call our meeting to order. We have
18 quite a lot to get accomplished this afternoon and I appreciate everybody's attention.

19 Let me turn it now to an issue which Alta would like to present to
20 us, which comes from a discussion he had this morning.

21 Alta?

22 ADOPTION OF RESOLUTION

23 PROF. CHARO: Gee, I had--

1 DR. SHAPIRO: (Inaudible.)

2 PROF. CHARO: No, no, no, no, no, no, no.

3 DR. SHAPIRO: How many hours do we need to find the pages--
4 (Inaudible.)

5 PROF. CHARO: No. It is not that. I am sorry. There was a copy
6 of the President's statement yesterday sitting here--

7 DR. DUMAS: I have it. Do you have it? I have a copy.

8 PROF. CHARO: No. Never mind. Some--(Inaudible.)

9 DR. : (Inaudible.)

10 PROF. CHARO: Yes. I will do my best.

11 DR. : (Inaudible.)

12 PROF. CHARO: Let me-- No. I had one that I had marked up for
13 this purpose which has vanished.

14 DR. SHAPIRO: Stop harassing Alta and let her speak.

15 (Laughter.)

16 PROF. CHARO: (Inaudible.) We started this morning talking
17 about the possibility of putting in a recommendation; something that said that we
18 were--

19 PROF. CAPRON: Alta, your mike please? A little closer. I am
20 advised by--

21 PROF. CHARO: That we were recommending federal legislation to
22 extend universally, to extend to all people in the United States human subjects
23 protection.

1 Objections were raised about the placement of that in the cloning
2 report because it was a larger issue than just cloning.

3 Reference was made to earlier discussions about the concerns that
4 anything that talks about specific ways to implement the principle of protection to
5 human subjects necessarily raises empirical questions having to do with how we ought
6 to begin to go about--(Inaudible.) costs might be and what the gains might be.

7 In an effort to find a way around these, what I am proposing is the
8 following. You have, on the second page, behind the revised outline for the ethics
9 chapter, a short two-line resolution, which I am proposing we adopt totally separate
10 from the cloning report.

11 And you will notice that it does not make any effort to speculate
12 about how one would implement this. But it did seem to me that it is a day that is
13 particularly appropriate for this because I want to just use three sentences from the
14 President's statement. You know, yesterday, finally having apologized to the
15 Tuskegee survivors, that he made reference to the point of that exercise in an apology.

16 He said very specifically that what he was trying to do was
17 remember the men who were used in research without their knowledge and consent
18 and he characterized that as an example of them having been betrayed, called it
19 shameful, and specifically said that the point of this exercise would not only be to
20 apologize, and I can't find the exact language here--(Inaudible.)

21 DR. DUMAS: It is on page 2.

22 PROF. CHARO: No, no, no, no. Where I had it, it was underlined,
23 Rhetaugh.

1 He said that the point of this was now to build on this in order to
2 make sure that it never happens again. And he called for very specific action.

3 So I am offering up to you for your consideration a resolution that
4 simply says, "No person in the United States should be enrolled in research without
5 the twin protections of informed consent by an authorized person and independent
6 review of the risks and benefits of the research."

7 If we agree with this, that informed consent and some kind of
8 independent review to make sure that the research is not unreasonably dangerous, then
9 I urge you to say yes to this as a matter of principle.

10 What this means, in terms of how it plays out in the context of
11 cloning, or the specific language of the recommendations, I don't know yet. I haven't
12 even read them because I just came down and found them. But this would fill, at least
13 in principle, I think a critical gap in protection that now exist for anybody enrolled in
14 medical research, whether in a cloning context or otherwise.

15 And since we don't have any actions that have been taken so far in
16 regard to cloning, I would just love to see us do this. I think it would be entirely
17 appropriate to do it this weekend.

18 DR. : (Inaudible.)

19 (Laughter.)

20 (Simultaneous discussion.)

21 DR. : It was a joke.

22 PROF. CAPRON: The twin protections. Now, that is protection of
23 twins.

1 DR. SHAPIRO: All right. I think everyone has a copy--
2 (Inaudible.)--everybody's attention.

3 DR. DUMAS: No.

4 DR. SHAPIRO: Does anybody have a copy of this? It is behind the
5 outline and was handed out at the same time as the new section--(Inaudible.)

6 (Simultaneous discussion.)

7 PROF. CAPRON: Alta, were you referring to the statement on page
8 2 beginning with the phrase, "The legacy?"

9 PROF. CHARO: (Inaudible.)

10 PROF. CAPRON: On page 2 of the President's statement?

11 PROF. CHARO: I don't know what anymore, Alex. I can't find it
12 because I only have the one outline.

13 PROF. CAPRON: I am just trying to help, Alta.

14 DR. SHAPIRO: (Inaudible.) Question.

15 (Technical difficulties.)

16 DR. SHAPIRO: We have discussed this many times as a
17 commission, one way or another. Probably--I don't know how everybody feels--but
18 probably there isn't a need for any extensive discussion. Of course, that is--
19 (Inaudible.) If there are questions or concerns, we certainly ought to air them now.

20 Alex?

21 PROF. CAPRON: Is it understood that we are doing this in the
22 context of our full report on human subjects protections?

23 PROF. CHARO: I expect that there is going to be more work on

1 this, yes.

2 PROF. CAPRON: Okay.

3 DR. CHILDRESS: As I understood it--

4 DR. SHAPIRO: Jim?

5 DR. CHILDRESS: --from the earlier discussion, there would be a
6 fully development on the context for this.

7 PROF. CHARO: I sure hope so.

8 DR. MIKE: Is this a resolution that stands apart from our report or-

9 -

10 PROF. CHARO: Yes.

11 DR. MIKE: --is to be included--

12 Well, I still want the discussion to go on about whether we should
13 have some reference in our specific report on recommendations.

14 DR. SHAPIRO: Absolutely.

15 PROF. CHARO: As I said, yes. This is not to decide one way or
16 the other how this would be used or not used in the recommendations themselves, but
17 if one of the problems has been--(Inaudible.)--how can we start dealing with all the--
18 (Inaudible.) reports. Here is a chance to deal with it separately first.

19 DR. SHAPIRO: Rhetaugh?

20 DR. DUMAS: (Inaudible.)

21 (Laughter.)

22 DR. DUMAS: I think that the resolution is straightforward. I think
23 it is entirely appropriate for us and the timing is just right. And I would like to

1 recommend that we adopt it.

2 DR. SHAPIRO: Thank you. Other comments, questions? Yes,
3 Tom?

4 DR. MURRAY: I think the language, which is very carefully
5 crafted, escapes--(Inaudible.) There are forms--(Inaudible.)--no formal informed
6 consent--(Inaudible.)

7 (Technical difficulties.)

8 DR. MURRAY: (Inaudible.)--arguably we deal with that. I just
9 want to point out that that is a subtly in there. I just want to have people come back
10 and say--(Inaudible.)

11 DR. SHAPIRO: Any other comments?

12 (No response.)

13 DR. SHAPIRO: All right. Let us see how we feel about this. All in
14 favor, please say aye.

15 (Whereupon, there was a chorus of "ayes.")

16 DR. SHAPIRO: Opposed?

17 (No response.)

18 DR. SHAPIRO: That is unanimous. Thank you very much.

19 (Applause and laughter.)

20 NEW DRAFT RECOMMENDATION FROM MR. ALEX CAPRON

21 DR. SHAPIRO: Let me-- We may not-- I want to make some
22 comments on a draft that has been distributed to everyone during the lunch hour. It is
23 called--(Inaudible.)--draft that includes recommendations. It is an attempt to

1 incorporate some of those ideas that came out this morning into various conclusions
2 and recommendations we have before us.

3 (Inaudible.)--is Alex, who drafted this on my request, may have
4 something he wants to say.

5 I don't think it is necessary for us to have a discussion again now.
6 What is necessary is that in the next day, two or three, that if you have any comments,
7 suggestions, objections, we want to hear from them, and let us hear from them in the
8 form of amendments to this document--not new documents, not editorial comments,
9 but actual amendments to the language you see on these pages. There is also-- The
10 last page here, which Alex may want to comment on further, just deals with some
11 additional comments which we will see how this will relate to other things that go on
12 in the report, and so on, and so forth.

13 So, Alex, do you want to add anything?

14 PROF. CAPRON: Well, I just wanted to reassure people, and I am
15 sure I didn't note all the things, but at various points this morning, where there was a
16 discussion of a potential recommendation and the view was, "Well, we ought to deal
17 with that but perhaps not in the recommendations," and I set forth three of those
18 points.

19 The third one is obviously related to the motion, the resolution, that
20 was just adopted, and it is point three. And the parenthetical, "If that has occurred, it
21 has now occurred." We have made a recommendation that the present federal
22 regulations be extended.

23 DR. SHAPIRO: All right. So we won't-- I don't want to-- Excuse

1 me. Carol?

2 DR. GREIDER: I just wanted to ask for a clarification. So this
3 conclusion and recommendation is updated from what we discussed this morning?

4 PROF. CAPRON: It is in a--

5 DR. GREIDER: Even though we discussed it in the context of your
6 draft and--

7 DR. SHAPIRO: That is right. We tried to put together into points,
8 and substance where we think we have all the points here, so I don't think there is any
9 change. But, I mean, read it over, see how it feels to you.

10 And the most important thing is to get feedback from--(Inaudible.)

11 And I think, in terms of the feedback, I would give it to either to Kathi or myself.

12 Either way. And you can sort of use e-mail if you want to.

13 But on all these matters we are going to maintain electronic control
14 of these materials in one place. We are no longer--(Inaudible.)--disk because every
15 time we do the disk comes back changed with new errors and--(Inaudible.)--so we
16 really have to start controlling the text.

17 DR. GREIDER: Mutations to your--(Inaudible.)

18 DR. SHAPIRO: Mutations to your--(Inaudible.) Cyberspace
19 cloning of electronic signals and so on.

20 So that is just so that we can keep appropriate control over the--
21 control in the right sense of the word--over the text.

22 So this-- Yes, Larry?

23 DR. MIKE: Just a point of clarification. Then on III of the latest

1 draft, we are going to reference about human subject experimentation?

2 DR. SHAPIRO: Yes.

3 DR. MIIKE: Another comment is on IV. IV, the way it is written,
4 would satisfy my concerns about actually elevating to a recommendation level,
5 however I still would not-- I don't see us having to put IV-B in there.

6 DR. SHAPIRO: IV-B?

7 DR. MIIKE: Which is about the use of animals.

8 DR. SHAPIRO: Yes.

9 DR. MIIKE: I think-- Yes. All I think we need to do is to say that
10 cloning encompasses a whole lot of other areas which are not at issue here, and so I
11 would-- IV-A is fine with me, but I would still like to see IV-B just disappear.

12 DR. SHAPIRO: Okay. We will certainly make note of that and
13 other--(Inaudible.) Let us know about your feelings so we have a sense of the
14 commission as a whole. Of course, we will bringing all this together one further time
15 so that, for any kind of final decision.

16 Yes, Jim?

17 DR. CHILDRESS: Excellent work I think in pulling it together
18 especially this morning, the drafts, so I think this is excellent.

19 DR. MIIKE: One other thing, Harold?

20 DR. SHAPIRO: Yes, Larry.

21 DR. MIIKE: The way that III is now written, it is-- How shall I
22 phrase it? The issue about legislation now has gone even further underground than
23 before. It has sort of been included as one of the kinds of things over in an overall

1 moratorium. And I am not sure that that is where we were heading.

2 I thought that if one looks on the opposite side, I thought we were
3 looking at it--as a moratorium--as we do what we can now without legislation, but the
4 aim was to tighten things a lot more by legislation.

5 And the way that this one is currently put together, it sort of just puts
6 them all under this moratorium rubric and so it is a question more of how much
7 emphasis we are putting about a straight legislative ban with, you know, obviously
8 with the other kinds of things about study bodies and sunset clauses.

9 DR. SHAPIRO: Well, I agree. It was not certainly my intention to,
10 as you put it, drive it underground, so any suggestions you have--really, these are
11 important ideas--let us know. Let us take a look at them. But I just want people to
12 have the discipline to write it. If you don't want it, write it down.

13 Yes, Rhetaugh?

14 DR. DUMAS: I think if we move C to the front, right up under--
15 (Inaudible.)--it would solve the problem for me.

16 DR. MURRAY: How about-- Rhetaugh, would it solve it if you
17 took--(Inaudible.) It would just make it the one before and then--(Inaudible.)

18 PROF. CAPRON: May I just make one comment because Harold
19 and I spent some time talking about this?

20 The notion is, if we are using the phrase moratorium to mean a time-
21 limited prohibition or ban on something, it has in our previous discussions had three
22 legs:

23 The first is that which is already in place, which we say should be

1 continued, is the federal prohibition on the use of federal funds;

2 The second, which we originally were fastening more weight on, is
3 the scientific societies and professional societies, making clear that it is unprofessional
4 behavior; and,

5 The third, which emerged more from this morning's discussion--as I
6 say, I crossed the fence on that to say that we, recognizing as we will in the discussion
7 in the chapter, the potential incompleteness of the federal and the ineffectiveness of
8 the purely voluntary--says that there should be federal legislation on that.

9 Those three points then become natural parts of an explanation of
10 what we mean by a moratorium that would extend to the private sector.

11 DR. MURRAY: Except that I would think a moratorium to be more
12 quasi voluntary, et cetera, and have the legislation be separate.

13 PROF. CAPRON: There is-- What I--

14 DR. MURRAY: It is-- It may be just a matter of emphasis, Alex. I
15 would like to see it--(Inaudible.)

16 (Simultaneous discussion.)

17 PROF. CAPRON: Well, let me tell you that a lot of legislation is
18 described as a moratorium when it has a time limitation on it.

19 DR. SHAPIRO: Larry, then Eric, and then we are going to have to
20 get off this topic.

21 So, Larry?

22 DR. MIKE: Well, three actually presents it backwards to me. My
23 emphasis would be that we want a stronger prohibition and that is to be legislation. In

1 the meantime, we do what we can through the voluntary extension and tighter controls
2 over the current mechanisms around. So I would switch-- If we are going to combine
3 them together, I would switch the way that it is stated.

4 DR. SHAPIRO: Well, I certainly understand the recommendation.
5 We will certainly would consider that.

6 Eric?

7 DR. CASSELL: I feel that way, too, but that is--

8 My comment is do we want to suggest how long the sunset is? Is
9 that part of our charge?

10 DR. SHAPIRO: That is the one issue that I wanted to raise; whether
11 we had--anybody here had any--(Inaudible.) We all know we are now in arbitrary
12 territory, so that we shouldn't spend too long discussing this particular subject, but
13 anybody have any lucky numbers?

14 DR. CASSELL: Well, doesn't it depend on what our scientific
15 colleagues think of the--

16 (Simultaneous discussion.)

17 (Laughter.)

18 PROF. CHARO: Until you see the green light.

19 DR. SHAPIRO: (Inaudible.)--decided whether it should be-- Until
20 it is decided I would get a 12-person jury. Somebody said 16, somebody said eight,
21 but let us have 12. Isn't that right, Alex?

22 PROF. CAPRON: No. Actually, in those years the King had 12.

23 DR. MIIKE: I would-- I would-- In an alternative to when is the

1 science more firm, I would propose when does the smoke clear a bit? There is so
2 much emotion involved around the issue, so I mean I would feel comfortable with a
3 three-year, but most people have talked about a five-year.

4 DR. DUMAS: Five.

5 PROF. CAPRON: Well, that indicates that four is correct.

6 (Laughter.)

7 DR. SHAPIRO: Let us not--

8 (Simultaneous discussion.)

9 DR. SHAPIRO: Whoa. Let us not worry about it right now. We
10 will come back to that issue.

11 PROF. CAPRON: Do you have a random number generator,
12 Christian?

13 (Simultaneous discussion.)

14 DR. MIKE: Well, it can't be greater than seven.

15 DR. SHAPIRO: Okay. Any other-- Please, let us hear from you in
16 writing on this.

17 (Simultaneous discussion.)

18 DR. SHAPIRO: (Inaudible.) I am sure there are amendments that
19 will be useful.

20 So I don't mean--in a way by having that ticket up there you have to
21 write something down--to discourage you because I am sure this can be improved on,
22 just like it has already been improved upon before we started today.

23 DR. DUMAS: (Inaudible.)

1 DR. SHAPIRO: That is right. That is right.

2 DR. DUMAS: And are you going to call us?

3 DR. SHAPIRO: Yes, I will. As I said before, I feel certain we are
4 going to have to have another meeting. I am not sure at this time exactly when it is
5 going to be. We will have to check on what our options are.

6 DR. DUMAS: Okay.

7 DR. SHAPIRO: But we will have to have another meeting before
8 we can make all these decisions final.

9 PROF. BACKLAR: On the West Coast.

10 DR. SHAPIRO: On the West Coast. Not likely, but we will see.

11 Okay. (Inaudible.) And again, Alex, thank you for putting this
12 together over the lunch period.

13

14

15 LAW/POLICY CHAPTER

16 DR. SHAPIRO: Let us go to the chapter, the draft now we have on
17 legal and policy considerations. I spoke to Alta before--(Inaudible.) I think most of
18 the first draft, of course, comes from the law and policy bucket, which Alex and Alta--
19 (Inaudible.)

20 (Technical difficulties.)

21 DR. SHAPIRO: (Inaudible.)--legal policy considerations--

22 (Inaudible.)

23 You don't have that?

1 PROF. CHARO: Don't have that.

2 DR. DUMAS: It was--

3 PROF. CHARO: But I will not say that it is--(Inaudible.)

4 (Simultaneous discussion.)

5 DR. SHAPIRO: Maybe it is time to adjourn this meeting.

6 (Laughter.)

7 PROF. CHARO: You all have four drafts of this now. It is gone
8 from--

9 DR. : (Inaudible.)

10 (Laughter.)

11 PROF. CHARO: This draft is much shorter than drafts two and
12 three, which were much longer than draft number one, so it--(Inaudible.)--process.

13 (Technical difficulties.)

14 PROF. CHARO: I am still not clear we have the exact electronic
15 control now. Last--(Inaudible.)

16 (Laughter.)

17 PROF. CHARO: --had it she was in electronic control. So
18 wordsmithing definitely gets set that way. I don't know--(Inaudible.)--the issues with
19 what is here now that you should know about just to get this thing finished.

20 DR. SHAPIRO: Again, we certainly want to provide some time
21 now, if there are any issues that are on people's minds right now that would be helpful
22 to pass on to Kathi, Alta and Alex, and so on.

23 But, again, if there are other issues that occur to you as you look

1 through this draft, we certainly need you to continue to comment on them.

2 Larry?

3 DR. MIIKE: It is a comment that I transmitted to Alta before, but
4 there is a fairly lengthy contracted piece on legal issues. I wonder how that is going to
5 be referenced, or if at all, within the report?

6 Because our original outline talked about a legal chapter in our
7 policy chapter I believe. And, granted, the legal issues get much more closely related
8 to the policy implementation because so many of those actions are related.

9 So I do get a little worried when the legal and the policy chapters get
10 intermingled and end up-- policies that are discussed in the legal policy chapter-- end
11 up in our recommendations. And I am a little worried about a more explicit linkage to
12 the other chapters in the report.

13 The way that this is framed right now, I don't have much of a
14 problem, but that is an issue I think I still needed to raise about how much-- Because
15 we were asked for our legal and ethical considerations on this issue, and so I wonder
16 how much of the straight legal kinds of expositions that one would have expected
17 would be in the actual body of the report?

18 PROF. CHARO: Larry, it turns out that much of the
19 recommendations are going in the direction they are. They vast majority of the
20 material in the legal contract is not relevant because we are not touching on topics that
21 it discussed, or because we are recommending that you not make children this way so
22 that the link, the expositions, on family law that might be relevant, if you were to have
23 this social practice, becomes less relevant.

1 And so what I have done for the moment--(Inaudible.)--is I have
2 taken all of the individual areas of thought that are directly implicated--(Inaudible.)--
3 divided them up, broken them out, and divided them up and tried to start segregating
4 the stuff that is factual from the stuff that was subjective, analytical, in the contract
5 material.

6 And I have now--(Inaudible.)--have 13 appendices waiting to be
7 used or not used at some time in the future, which would document all this stuff at
8 great depth. And I am just waiting to get some direction after you get the whole other
9 part of the report.

10 So all of it can appear.

11 DR. MIIKE: I am not necessarily saying that--

12 (Technical difficulties.)

13 DR. MIIKE: As a matter of fact, you know, probably most of that
14 will go into NTIS(?) and anybody who is interested will get that. But I just raise the
15 issue because I had raised it with you before.

16 DR. SHAPIRO: Well, it is an important issue. We have not made
17 any promises, you know, on just what, if any, appendices we will have. In part, it
18 depends on our time and so on because--(Inaudible.) And we have not decided either
19 whether at some time we will issue a supplementary report or complimentary
20 document which contains the papers we have contracted for, and so on, and so forth.

21 And frankly we just haven't had time to look at it carefully, thinking
22 of it as, at the current time, a bit of a distraction. Although you make a very good
23 point--(Inaudible.)

1 Yes?

2 MS. KRAMER: Alta, do you-- Do we need to have some kind of
3 an exposition in there that the legal--to the extent of what you just said--that the legal
4 issues--(Inaudible.)--in the direction policy-wise?

5 PROF. CHARO: It might be possible to put something in that
6 explains what certain legal issues kind of drop away. Sure.

7 MS. KRAMER: And then it makes a natural reference to the
8 appendix, or whatever you are going to put it.

9 DR. SHAPIRO: It sounds like a good suggestion. Thank you very
10 much.

11 Alex?

12 PROF. CAPRON: Do you think that, as redrafted here--and I have
13 not gotten through Kathi's redraft but the one we have in front of us--it adequately
14 explains why existing state laws, which were originally cited by some people as
15 prohibitory, are in fact, with one possible exception, depending on how the statute is
16 read, not preclusive of--

17 PROF. CHARO: What kind-- I am not sure. What kind of state
18 statues are you talking about?

19 PROF. CAPRON: On research, embryo research, and so forth.

20 PROF. CHARO: And why would that not-- What? I am just not
21 following your question.

22 PROF. CAPRON: I am asking you whether, since you have
23 obviously studied this draft more, whether it contains a discussion of those statues and

1 their limitations?

2 PROF. CHARO: Well, I don't even remember anymore what is in
3 this one, as opposed to the other three--

4 PROF. CAPRON: Well, that is--

5 PROF. CHARO: --but there is going to be very little there about
6 real research statutes because they are not perfect to--

7 PROF. CAPRON: Well, it depends-- Again, it--

8 (Simultaneous discussion.)

9 PROF. CHARO: --in most settings.

10 PROF. CAPRON: There were two things which in our first policy
11 law bucket meeting we discussed.

12 One was the effect of the federal prohibitions on driving research
13 into clinical settings very prematurely in this area with the result that there has been a
14 history--ironic, of the paradoxical effect--that there has been a history of
15 experimentation in effect without any oversight.

16 And the other thing that we were going to discuss was the way in
17 which those statutes might effect this area. If you saw any attempt to create the
18 embryo that would then go on and be implanted as research, do existing state statutes
19 address this? And, again--

20 PROF. CHARO: There are-- There are only a couple of state
21 statutes.

22 PROF. CAPRON: I know. I know.

23 PROF. CHARO: So--

1 PROF. CAPRON: So the point would be a discussion which says
2 exactly that; that although a number of states have had statues in this area, the way
3 they are written you have, on the one hand, New Hampshire which, as I recall,
4 basically parallels the federal in saying you can't do this but apparently says you could
5 implant, and then you have Louisiana--or is it the other way around? I can't
6 remember--

7 DR. : (Inaudible.)

8 PROF. CAPRON: Yes. And, I mean--

9 PROF. CHARO: I don't know. I mean, we would have to go back--
10 If you want to draft something for it, please do.

11 PROF. CAPRON: I will if there wasn't some reason for omitting it.
12 This is responsive--

13 PROF. CHARO: It might have been in there already and taken out
14 because we took out two-thirds of what we put in.

15 PROF. CAPRON: Well, Kathi-- Maybe I should ask Kathi because
16 you said you are not familiar with everything that is in here either.

17 Kathi, is that discussed in here? Can you point me to something as a
18 starting point?

19 DR. HANNA: It is mostly a discussion-- I mean, it has been
20 abbreviated into a short--(Inaudible.)

21 DR. : Your mike.

22 PROF. CAPRON: Your microphone, please. Footnote number--
23 (Simultaneous discussion.)

1 PROF. CAPRON: Okay. Thank you.

2 PROF. CHARO: No. Thank you.

3 PROF. CAPRON: Okay. This is in relationship to the question that
4 was put to Alta about what ends up in the appendices. But it does seem to me that a
5 reader, without having to find an appendix and wade through it, might expect our
6 summary on that. And I will look at this now. Thank you very much.

7 DR. SHAPIRO: Other comments regarding this? And I recognize
8 that this current version was just handed out today so I can't expect you to have read it
9 carefully.

10 (Simultaneous discussion.)

11 PROF. CAPRON: Some of you did. Some of us did.

12 DR. : There we go again.

13 DR. SHAPIRO: Anyhow--

14 MS. KRAMER: I would like to commend Alta and Harold, Kathi,
15 all those who have had a hand in the redrafting of this because I think it is so tight. It
16 is just--(Inaudible.)--complained in a previous draft lacked cogency, and this is exactly
17 that. It is cogent and it is clear and it is really detailed.

18 DR. SHAPIRO: Thank you very much.

19 MS. KRAMER: I think you should just adopt it with--(Inaudible.)

20 (Laughter.)

21 DR. SHAPIRO: Thank you. Other questions, comments?

22 Alta, anything further that you want to say?

23 PROF. CHARO: No. (Inaudible.)

1 DR. SHAPIRO: Well, I hope you are going to get some suggestions
2 as we go ahead in the next few days. And remember-- Now, I know I have said this
3 many times today, but we really do have to hear in the next few days. After that, it is
4 probably going to be too late to make changes.

5 Any other questions?

6 DR. CASSELL: (Inaudible.)

7 DR. SHAPIRO: That is right. Not editorial comments,
8 amendments, text.

9 DR. MIKE: Do I get six extra hours since I am six hours behind?
10 When I get up in the morning, half the day is gone already.

11 (Laughter.)

12 DR. SHAPIRO: (Inaudible.) Okay.

13 (Simultaneous discussion.)

14 RELIGION CHAPTER

15 DR. SHAPIRO: Okay. Let us now see if people have any reaction,
16 if you have any comments you want to make, on the latest draft we have of the chapter
17 on religious issues.

18 Jim?

19 DR. CHILDRESS: If I could make just a few comments. There is
20 no abstract yet. I will have that to you e-mailed I hope on Monday.

21 A few words about the chapter and process. This is a descriptive
22 chapter but as I commented earlier--(Inaudible.)--but I would like to be as objective,
23 even-handed and fair as I can in this. And I hope that you will go over it very

1 carefully to make sure that the positions we heard or read are fairly and accurately
2 represented.

3 It builds--(Inaudible.)--on the first part of that working capital
4 contract paper and on the testimony presented by the religious thinkers who appeared
5 before us, those who were invited, and those who participated in the public testimony
6 period.

7 The first draft was done and then Kathi, Tom, Zeke, Harold and Bill
8 Freeman all offered comments and suggestions and a thorough revision that included
9 restructuring some portions, reformulation of certain things, condition of the section
10 on particular cases and public policy toward the end, application of the conclusion
11 section, and an effort to connect this chapter with some of the other discussion,
12 particularly in the ethics section.

13 Further comment is definitely needed and I hope it will be thorough
14 and as detailed as you would like.

15 We would like to have that by Wednesday afternoon and that can go
16 to me by e-mail. I will work on it and get the--(Inaudible.)--to Kathi in the next day,
17 on Thursday.

18 Harold has already gone over it last night after the meeting. He
19 apparently doesn't need as much sleep as some of the rest of us. And he presented a
20 very thorough set of comments. And I hope that others will do the same.

21 One of the notes is mine in the version you have here. Kathi already
22 had notes from most of what was here; I have added several others and we will work
23 on those.

1 I do hope that the-- And I hope we could actually make a decision
2 about this fairly soon; that the contract papers can be made available in some form.
3 Carol--(Inaudible.)--of the President's Commission and National Commission because
4 I think they deserve--(Inaudible.)

5 Let me just give one example here.

6 I don't think we would want in this chapter the kind of detail that
7 Carol provided in analysis of--(Inaudible.) I think that is a risky thing to do; sort of
8 take that, rather than focusing on certain kinds of themes.

9 On the other hand, I think it would be very useful to have that
10 available in an independent or separate volume that gives the contract papers.

11 So I would recommend that the contract papers and the other written
12 testimony submitted be made available, if at all possible, because there are a lot in the
13 public who would like to read that. I think it has actually contributed to the overall
14 discussion.

15 (Simultaneous discussion.)

16 DR. CHILDRESS: But let me stop there and see if there are any
17 concrete suggestions now or--(Inaudible.)--materials for revision.

18 (Simultaneous discussion.)

19 DR. SHAPIRO: Thank you, Jim. Any comments for Jim at this
20 time?

21 (No response.)

22 DR. SHAPIRO: We are going to have a lot of reading to do on the
23 plane and the train, I guess, on the way back.

1 PROF. CHARO: Harold?

2 DR. SHAPIRO: Yes?

3 PROF. CHARO: Do we have a drop-dead date for comments from
4 one another so that we can make sure there is time for these changes to be finalized
5 and everything printed out?

6 DR. SHAPIRO: I think that--

7 (Simultaneous discussion.)

8 DR. SHAPIRO: Jim has just suggested that, for the religion chapter,
9 to be Wednesday. I don't think it can be any later than that. I am hoping it will be
10 earlier than that for most of the comments because we really need to work-- We are
11 working on a minute-by-minute basis now.

12 And so I am hoping that most of you who have comments will read
13 the material this weekend and Monday, and get your comments to us. I understand
14 people have other commitments so Tuesday will be really fine. Wednesday is really
15 the outside because, as you all appreciate--(Inaudible.)--if we can't have them by then,
16 it is very hard to pull together.

17 Some of the material we have to write will depend on the shape--
18 (Inaudible.)--present the recommendation. All of this needs to be worked out.

19 Actually we have all of this together, including some--(Inaudible.)--
20 material because the analogy stuff--(Inaudible.)

21 And so Wednesday, I would say, is the drop-dead date.

22 Any further comments on this?

23 (No response.)

1 DR. SHAPIRO: Okay. Well--

2 PROF. CAPRON: One question to Jim.

3 DR. SHAPIRO: Yes, sir.

4 PROF. CAPRON: You are in-- I wanted to know about your
5 intention in describing the material on pages 22 to 24, under the heading "particular
6 cases in public policies."

7 That is an issue which is discussed in the ethics chapter as well, and
8 it didn't-- It seemed to me there was a lot of content here about how religious thinkers
9 go about their thinking, but it didn't seem to me it quite was summed up by that title.
10 Do you have a comment on that?

11 DR. CHILDRESS: Perhaps that is true, though the intention was to
12 suggest--and much of this does focus on the public policy side and perhaps more
13 should be done on the particular case side--but toward the end I think in particular it
14 comes into play and I was actually going to include--(Inaudible.)--as well. But it
15 perhaps has not the best wording for it. It might just be the public policy--

16 (Simultaneous discussion.)

17 DR. CHILDRESS: --with some reference to any technical cases,
18 particular cases, in particular the--(Inaudible.)

19 (Simultaneous discussion.)

20 PROF. CAPRON: Yes. I mean, it seemed to me that more of what
21 was at work here was the question of whether one was absolutely against it or saw
22 particular possible justifications for its use. I mean, killing people is wrong but self-
23 defense is all right, and that there was a similar thinking that went on here.

1 DR. CHILDRESS: I think that is fair. I think--(Inaudible.)

2 PROF. CAPRON: Okay. I just-- Okay.

3 DR. SHAPIRO: Other comments? (Inaudible.)

4 (No response.)

5 SCIENCE CHAPTER

6 DR. SHAPIRO: Okay. Thank you. Let us turn now to the science
7 chapter. (Inaudible.) Carol?

8 DR. GREIDER: I guess my question for the commissioners would
9 be do they feel that the science chapter is done from this point on?

10 This one was handed out earlier than a lot of the other ones.

11 (Inaudible.) There hasn't been--(Inaudible.) In terms of clarifying language, there
12 hasn't been--(Inaudible.)--content change since the initial draft, although there has
13 been--(Inaudible.)--

14 (Simultaneous discussion.)

15 DR. GREIDER: --language changes and clarifications.

16 One of the issues that was raised was that it wasn't--(Inaudible.)

17 (Simultaneous discussion.)

18 DR. GREIDER: --try to change a lot of the language to make it
19 much more accessible.

20 It was suggested to me that it is still is not kind of accessible enough
21 and that we need extensive simplifying and rewriting to make it mores.

22 (Simultaneous discussion.)

23 DR. GREIDER: So what I need is feedback about the level of

1 accessibility.

2 DR. SHAPIRO: Kathi?

3 (Simultaneous discussion.)

4 DR. HANNA: Yes. I think we want to add that there are figures--I

5 think there are six figures--that an artist is working on that might help--(Inaudible.)

6 (Simultaneous discussion.)

7 DR. HANNA: And also a glossary.

8 DR. GREIDER: And those figures were given in the last version.

9 They are--(Inaudible.) But they are the same figures with one addition.

10 DR. : (Inaudible.)

11 DR. GREIDER: Normal fertilization--(Inaudible.)

12 (Simultaneous discussion.)

13 DR. COX: Where did you get that figure from?

14 (Laughter.)

15 DR. SHAPIRO: I think that the science chapter does present us with
16 a significant challenge in the sense that the science, to understand it, requires a certain
17 amount of detail. You can't put a limit to how simple one can make it and still get it
18 right and still provide the information that is necessary.

19 I was particularly struck with the story I told Carol earlier today. I
20 found myself on a plane a few days ago sitting beside a few chemists coming from the
21 West Coast to the East Coast--(Inaudible.)--seemed like pretty good chemists. I don't,
22 can't value that myself.

23 PROF. CAPRON: Would you assume, if they were going in the

1 opposite direction, the same thing?

2 DR. SHAPIRO: Well, that is harder. That is harder.

3 (Laughter.)

4 DR. SHAPIRO: But the--

5 PROF. CAPRON: Harold. David, are we going to sit still for that?

6 DR. SHAPIRO: But I was discussing this with them and I was
7 reading the chapter and I shared it with them as I was traveling. I was really quite
8 surprised by how much they learned from reading. And so even at the level of the
9 audience that--(Inaudible.)--not their area and so I wasn't surprised that they were
10 reading--(Inaudible.)--about the information that was there. And that also is an
11 important audience, a very important audience for us.

12 DR. DUMAS: I think that-- I found it--(Inaudible.)--water it down--
13 -(Inaudible.)--so that that could be done and get the text over--(Inaudible.)

14 I really think that for those people who have an interesting--
15 (Inaudible.)--I think they will read it with enough understanding. And I can't come up
16 with any ideas about how to make it simpler and clearer. So I would be on the side of
17 maybe erring and having it a little bit above the heads of some people, but generally
18 readable and understandable.

19 DR. SHAPIRO: Let me turn to Bernie because--(Inaudible.)

20 (Simultaneous discussion.)

21 DR. SHAPIRO: --suggestions that I haven't thought about having to
22 do with looking at each of the sections. Bernie, I--(Inaudible.)

23 DR. LO: Let me say that I think this really does do a wonderful job

1 of really laying out a lot of information--(Inaudible.)--sort of telling it in an organized
2 way. And it is very difficult to both be vigorous enough so that distinguished
3 scientists learn, but also having it accessible to non-experts.

4 And one suggestion I had is to-- At the beginning of each of the
5 sections that starts with a bold- headed--(Inaudible.)--say we want that section, or the
6 main point of that section is going to make, you actually do that very nicely.

7 On page 12 we are going to have a series of bullets and we are going
8 to talk about--(Inaudible.)--just so we know it is coming.

9 Then after each of the next level of headers have a terse sentence
10 after that, sort of summarize the main point of that whole section.

11 I have tried to sort of do that for a couple of things. Several times
12 you just need to clone the last sentence in the section and move it up to the beginning
13 so we know what is coming before we get there and then, after we have gotten there,
14 say you have just arrived at the place that we told you were going to.

15 Some of the sections I have been having trouble doing that because I
16 am a little bit sort of-- I don't know the science well enough to know what the key
17 point is.

18 But, you know, I always find things--(Inaudible.)--doing in the NIH
19 grants. The grants I liked the best are the ones where, if I just read the header or the
20 terse sentence after each header, I get a flow of the argument and it just makes it easier
21 to read. And that way you can have the complexity of the argument in each section
22 because there is sort of a clear road-map of where we are going and when we got
23 there. So I am going to do it a little bit.

1 I just want to make sure that I don't, in my attempt to say what the
2 main point is, miss the point because I think we really need a scientist to say that key
3 point we are making in this section--(Inaudible.)

4 DR. SHAPIRO: Well, I think that is a helpful suggestion and any
5 example you can provide, Carol, I think would be very helpful. And so thank you for
6 that.

7 Next thing, you will have to find out what the study section is on.

8 DR. GREIDER: (Inaudible.)

9 (Laughter.)

10 DR. SHAPIRO: Alex?

11 PROF. CAPRON: I had a question, Carol, on the relatively limited
12 discussion on page 18, of potential applications in organ tissue transplantation, and
13 this is not something where I can suggest language, otherwise I would simply follow
14 the chairman's directive that I do so.

15 We had discussion early on of the potential in somatic cells to create
16 with nuclear transfer--this is in the future as a result of this animal work you are
17 talking about--to create specialized tissues beginning with the transfer of the nucleus
18 and then the manipulation so it goes through a pluripotential and then is targeted
19 toward the organ or tissue that is desired--pancreatic tissue, or whatever, liver,
20 whatever.

21 Is there any way of describing that, that is not so far-fetched? I had
22 thought, from some of the things that Rossant(?) had said to us and Horton(?) had said
23 to us that this was an avenue of research that people would be interested in.

1 DR. GREIDER: That is the entire section that is entitled "potential
2 application of sub-based therapies." I can't tell you the page because my--

3 PROF. CAPRON: It is right after that.

4 DR. : Page 18.

5 MR. HOLTZMAN: I think it is page 19. Turn the page. It starts on
6 line 12 and runs-- It is line 12 through line 29.

7 PROF. CAPRON: Okay.

8 And a question about the assisted reproduction area. The major
9 discussion there--

10 Well, let me hold off and ask-- There is discussion there of this
11 problem with the 277 nuclear fusions with Dolly, and so forth. Is there a table earlier
12 on in the discussion? Because that has been discussed earlier in the chapter as well. Is
13 there going to be a table there that reproduces the Nature Table, or something?

14 Because I found when we were doing that e-mail discussion, and I
15 went back and looked at it, when I saw it in tabular form, it was much easier to follow
16 than our various e-mails going back and forth.

17 DR. GREIDER: Personally I find the Nature Table very difficult to
18 follow.

19 PROF. CAPRON: Oh, really?

20 DR. GREIDER: Because there are a number of footnotes with a
21 number of separate--

22 PROF. CAPRON: Well, I don't think you have to--

23 DR. GREIDER: (Inaudible.)--going on.

1 PROF. CAPRON: You don't have to address the non-Dolly
2 categories there, do you?

3 DR. GREIDER: No. But, I mean, there really are only two things.
4 One, the number of cells that were fused. Three things. The number of cells that were
5 fused, 277; the number of morula that resulted from that, which I believe is 29; and the
6 number of sheep that were formed--one. So that is the table.

7 PROF. CAPRON: Well, there is also-- There were apparently 13
8 sheep used for implantation, meaning that some of them had multiples or something?

9 DR. GREIDER: Yes. That is right.

10 PROF. CAPRON: Okay. And there was also this intermediate
11 figure of 249. Did that have any significance?

12 DR. GREIDER: Very little to what we are talking about here. I
13 mean, there are--

14 PROF. CAPRON: What-- Well, what--

15 (Simultaneous discussion.)

16 PROF. CAPRON: Could you explain?

17 DR. GREIDER: Of the 277 fusions that happened, there were 247
18 that they, by looking in the microscope, deemed appropriate to be able to go on and
19 divide, but of those only 29 really did so.

20 So the real relevant-- It is very subjective. The 247 was fairly
21 subjective. That was just--(Inaudible.)

22 DR. COX: Just a point of clarification. So that after they did the
23 fusion themselves, there were 277 that survived, after looking in the microscope.

1 Then they took those cells and they put them in--(Inaudible.)--to divide. And out of
2 the--(Inaudible.)--came the 247. And then, of those, the ones that developed--
3 (Inaudible.)--were 29.

4 And so the intermediate step of the 277, the 249, you know, is a--
5 You know, they could have been lost in the shower. Who knows? But the question
6 that there is a big loss, a big differential between the 200+ some and the 29 that even
7 developed enough--(Inaudible.)

8 But I think that the table that Carol looked at, and all of us can go
9 back and look at that, is a confusing table because it shows proportions that are
10 relative proportions of these different things. It is very confusing.

11 So I quite agree with you, Carol, that these numbers, 277, that is
12 how many things when you fuse them together that were there. Twenty-nine, that is
13 how many turned into an embryo that was able to be implanted. Twenty-nine were
14 implanted and you got one animal out of it. And that is the thing that is crystal clear
15 and--(Inaudible.)

16 PROF. CAPRON: Yes.

17 DR. DUMAS: I think we are agreed that you get lost in all this
18 detail.

19 DR. SHAPIRO: Other comments or questions?

20 DR. CASSELL: I just wanted to say--

21 DR. SHAPIRO: Sorry.

22 DR. CASSELL: --that this is so clear and there is a limit to how
23 simple--(Inaudible.)

1 DR. GREIDER: Yes.

2 DR. CASSELL: And this is much clearer. The jargon is mostly
3 gone, almost entirely gone.

4 DR. COX: We listened to you, Eric.

5 DR. CASSELL: Thank you.

6 DR. GREIDER: We defined the DNA for you, Eric.

7 DR. CASSELL: What?

8 DR. GREIDER: We defined DNA just for you.

9 DR. CASSELL: I saw that.

10 (Laughter.)

11 DR. SHAPIRO: Finally, there is one thing--(Inaudible.)

12 (Laughter.)

13 DR. SHAPIRO: Any other comments or questions?

14 (No response.)

15 DR. SHAPIRO: Okay. Thank you very much.

16 SUMMARY AND ADJOURNMENT

17 DR. SHAPIRO: Let us summarize where we are before our
18 adjournment.

19 One, just to go through the various aspects of the material, we had--

20 (Inaudible.)--today, and I don't think we are going to need to, the introduction. I do

21 have some additional material that some of you have supplied and we will look at that.

22 And the introduction evolved as the chapters evolved along with it.

23 And in addition to the material that has been provided--(Inaudible.)--

1 -material--(Inaudible.) Alex provided some material we will try and work on.

2 And depending what happens on some of the other chapters, the
3 introduction will form itself--(Inaudible.)--and so that--(Inaudible.)--questions--
4 (Inaudible.)--process. We should have the new drafts out to you--(Inaudible.)

5 Diane, I am sorry, you had a question.

6 DR. SCOTT-JONES: I just had a couple of comments about the
7 latest version of the introduction. I didn't want to interrupt you.

8 DR. SHAPIRO: No.

9 DR. SCOTT-JONES: I can wait until you finish.

10 DR. SHAPIRO: That is fine.

11 DR. SCOTT-JONES: I had a couple of comments and I was curious
12 what everyone else thought about it.

13 One--and I am just looking back to find them--one is that I think
14 some of the discussion of the importance of considering religious perspectives takes
15 up too much space. The same points are made several times and I have marked where
16 on my draft. I think, given that we have a whole chapter on that, it just went on a little
17 bit too much, not that it was unimportant.

18 And then the other comment I had-- Again I am looking for it. It
19 was a point where-- I am just trying to find it. I am sorry. It seems to me that when
20 we talk about science and ethics we shouldn't ever place them in opposition as if
21 scientists are going to not be as concerned about ethics as ethicists, so I had a little bit
22 of concern about that. And, again, I have marked it and I can just give it to Kathi.

23 DR. SHAPIRO: Let me mention two things.

1 That would be very helpful, Diane. Thank you very much.

2 That is certainly-- If that is true, it certainly unintentional so we
3 may want to change that.

4 I have also made a number of changes in the introduction which are
5 not in the current draft because I made them yesterday afternoon, which had-- It was
6 responsive to concerns some commissioners had regarding whether we had somehow
7 put in a bad light those people who were against--(Inaudible.)--I guess--(Inaudible.)

8 DR. SCOTT-JONES: Yes.

9 DR. SHAPIRO: Most people commented against progress against
10 change and so on. That was unintentional because, as I am re-reading it, I could see
11 where that would come up.

12 DR. CASSELL: I made a change in that phrase--(Inaudible.)

13 DR. SHAPIRO: Yes. And so I made some changes along those
14 lines which I think are well taken. A number of you mentioned that and at least I
15 made some changes in that regard. And you will see those on Wednesday yourself
16 when that comes out.

17 And Alex?

18 PROF. CAPRON: If I could just say a word of explanation. I tried
19 drafting a new beginning to the introduction and it needs more of a transition to go on
20 to what is already there. But let me tell you why I did it.

21 It was in response to what I also saw in Zeke's e-mail and several
22 other people also commenting on the beginning of the introduction being, not taking,
23 not making it clear why this had become such an issue.

1 And it seemed to me that rather than beginning once again with
2 Dolly leading to us being given orders to do something, it might make sense to set the
3 stage and then in comes Dolly and it generates this kind of a reaction. So that was my
4 purpose in doing it and--

5 DR. SHAPIRO: I think that is very helpful. I think we all should
6 have copies of Alex's suggestions. I will just pass it around here. I haven't looked at it
7 carefully yet.

8 DR. : (Inaudible.)

9 DR. MIKE: Yes. There is a page.

10 PROF. CAPRON: I was just trying to explain, since people are
11 looking at it, what my intention was, rather than arguing for the particular language.

12 DR. SHAPIRO: (Inaudible.)

13 So I really do appreciate those. And if you can get your comments
14 to Kathi or myself, either way--(Inaudible.)--that would be very helpful.

15 Now, just to review where we stand just on through to the science
16 chapter. You all know what--(Inaudible.)--ditto the chapter on religion, and law and
17 policy.

18 We spent quite a bit of time reforming on the ethics chapter which
19 Bernie is going to try to-- He has made some assignments for others in his area. If
20 you would help him to do that.

21 We hope-- I hope to have kind of another thought of this.

22 Bernie, I think, will try to finish early in this coming week. So those
23 of you who have assignments from Bernie--(Inaudible.)--so that he can provide

1 something which then Kathi or I will take as far as gathering another draft for our
2 consideration.

3 And once we get that far, of course, you will start putting some
4 words around the conclusions and recommendations, some of which you have in the
5 other draft there and we certainly welcome comments on that. (Inaudible.)

6 David?

7 DR. COX: Sure. I think-- This is sort of a generic comment. And
8 I am just going to make it now, but I am going to look at the specific areas so I can
9 make the comment.

10 Based on comments here I have some questions--(Inaudible.) I
11 think that--(Inaudible.)--someplace we talk about adult cells, other than places we talk
12 about somatic cells, other places we talk about differentiated cells, it becomes real
13 confusing, particularly with this embryo business--(Inaudible.)

14 And I think somatic cells, certainly always the case, and that what
15 we need to do is just be pretty-- I will try--(Inaudible.)--look at it in the context of--
16 (Inaudible.)

17 DR. SHAPIRO: That would be very helpful because I have been
18 struck--(Inaudible.)--various drafts in the chapter. I tried to dig up some language--
19 (Inaudible.)--in the science chapter thinking that that would probably--(Inaudible.) I
20 really-- That is an issue.

21 DR. COX: It can be very confusing to people.

22 DR. SHAPIRO: And it is not consistent.

23 PROF. CAPRON: Could we figure out what that will be since many

1 of us are writing things and ought to use the language now?

2 DR. SHAPIRO: Well, maybe Carol--(Inaudible.)

3 DR. GREIDER: I was urged to make a comment on--(Inaudible.)--
4 the same thing I think that Steve brought up in an e-mail. The exact sort of the thing is
5 true for what have we been saying about a human clone, cloning a human being, or
6 there was some language that Steve had suggested in an e-mail that also should be
7 consistent, however we are going, you know, determine that. So I think that we
8 should address both of those issues maybe now--(Inaudible.)

9 PROF. CAPRON: Yes. Yes.

10 DR. COX: I will make a recommendation with respect to the cells
11 and that we call it a somatic cell.

12 DR. CASSELL: Nuclear transfer from a somatic cell.

13 MR. HOLTZMAN: (Inaudible.)--latest draft recommendations
14 which is creation of a child by adult cell nuclear transfer.

15 Now it could be creation of a child by somatic cell nuclear transfer,
16 but I think--(Inaudible.)--by itself.

17 DR. SHAPIRO: That is in fact the language I used when I made my
18 suggestions to Jim regarding the chapter on religion. (Inaudible.)

19 I think that at least-- Although one might--(Inaudible.)--used
20 initially, I have to say. I have come to believe that is very useful. That is a very useful
21 language. Hopefully, it is accurate. If it is not, of course, it will be confusing.
22 (Inaudible.)

23 DR. MIIKE: What--

1 (Simultaneous discussion.)

2 DR. MIKE: What are we using? Now I am confused.

3 PROF. CAPRON: Could Carol or David or anyone else who knows
4 explain to us what, to the sophisticated ear, would be the difference between the
5 phrase "somatic cell nuclear transfer" and "adult cell nuclear transfer?"

6 DR. GREIDER: An oocyte is an adult cell.

7 PROF. CAPRON: A what?

8 DR. GREIDER: An oocyte is an adult cell. I mean, the difference
9 between "adult" and "embryonic" has to do with the age of the first one. A somatic
10 versus germ line.

11 PROF. CAPRON: Right.

12 DR. GREIDER: Right. So an oocyte comes from an adult, or a
13 sperm comes from an adult, but it is not a somatic cell. So, strictly speaking--

14 PROF. CAPRON: So somatic would be preferable then?

15 DR. GREIDER: Somatic is preferable.

16 DR. : That is what I believe.

17 (Simultaneous discussion.)

18 PROF. CAPRON: I, I--

19 DR. MURRAY: (Inaudible.)

20 PROF. CAPRON: Yes.

21 DR. MURRAY: --just refer to adult cells. I mean, cloning from
22 children's cells would be--(Inaudible.)

23 PROF. CAPRON: Yes.

1 DR. MURRAY: (Inaudible.)

2 PROF. CAPRON: It isn't permissible, but it is easily misunderstood
3 by people who don't--

4 (Simultaneous discussion.)

5 DR. COX: Talk about loopholes. I mean, this is one.

6 PROF. CAPRON: Yes. So we--

7 DR. GREIDER: Somatic is the preferable one unless somebody has
8 another--

9 PROF. CAPRON: So what about the other part of the phrase of
10 what we are doing with this? Is it creating children through somatic cell nuclear
11 transfer? Is that our [sound effect]? What we mean by cloning human beings for our
12 report is...

13 DR. SHAPIRO: That is right.

14 DR. DUMAS: Yes.

15 DR. SHAPIRO: That is what I have just started to--(Inaudible.)

16 Creating human beings by means of somatic cell nuclear transfer.

17 PROF. CAPRON: Or it is creating a child. Creating a child through
18 somatic cell nuclear transfer.

19 DR. CASSELL: Can we avoid the use of "the clone" or "clone" as
20 the noun, so we are not using the word "clone" as the noun?

21 PROF. BACKLAR: Right. It would then-- We would refer to this
22 child-- We refer to this child always as--

23 PROF. CAPRON: Microphone please?

1 PROF. BACKLAR: --by somatic cell transfer every time you talk
2 about this type of child?

3 PROF. CHARO: One of the advantages of using "child" over
4 "person" is that it keeps in people's mind clearer that you don't have somebody the
5 same age as the person--(Inaudible.)--we used, which is the weird misunderstanding
6 out there.

7 (Simultaneous discussion.)

8 PROF. CHARO: So it is a helpful--

9 PROF. CAPRON: Reminder? Sure.

10 PROF. CHARO: --reminder.

11 DR. LO: (Inaudible.)

12 DR. : Your microphone?

13 DR. LO: Also--

14 DR. SHAPIRO: So let us--(Inaudible.)

15 (Laughter.)

16 (Simultaneous discussion.)

17 PROF. CAPRON: At other times we have used--

18 (Simultaneous discussion.)

19 PROF. CAPRON: At other times we have used the phraseology
20 about implantation of or transfer to a woman's uterus of a cloned embryo. Now, is that
21 phrase one that we are going to use any more?

22 DR. GREIDER: No. That is not correct.

23 DR. SHAPIRO: No. I don't see--

1 DR. GREIDER: A cloned embryo can mean a lot of different things
2 besides creation through nuclear transfer from a somatic cell.

3 DR. : (Inaudible.)

4 DR. SHAPIRO: Oh, yes, absolutely.

5 PROF. CAPRON: Oh, absolutely. Yes, it does.

6 DR. MIIKE: Just a minority voice. It sounds like scientists talking
7 to scientists. I would have preferred "adult" cell rather than "somatic" cell because,
8 for the general public, I think "adult" has a better connotation. But if you folks are
9 seriously concerned that adult in your environs means it could come from a child, then
10 I sort of give in, but somatic to me is sort of like you are using your own jargon again.

11 DR. MURRAY: I am bothered by the same point that Larry just
12 brought up.

13 Technically, I think, if we are using the phrase repeatedly we want
14 to make sure the use of somatic cell is the right one to use. We need, at some point,
15 probably in the letter, probably in the introduction to the report, to say, "Here is why
16 we are using it. Here is what it means." (Inaudible.)--and for the sake of precision we
17 are going to use the scientific terminology.

18 DR. MIIKE: Just a question for clarification, Harold. Kathi, are we
19 going to have a short glossary?

20 DR. HANNA: (Nods affirmatively.)

21 DR. MIIKE: Oh, okay.

22 DR. HANNA: You should have received one at some point.

23 DR. : It has been in the previous reports.

1 (Simultaneous discussion.)

2 DR. SHAPIRO: --quite complete or indeed quite accurate.

3 DR. HANNA: But it is in process.

4 DR. SHAPIRO: But it is in process.

5 DR. : The May 9th.

6 PROF. CAPRON: Could I put my name on a list to get it because I
7 don't think I have seen it?

8 PROF. BACKLAR: I didn't get it either.

9 DR. SHAPIRO: Well, it came at the tail-end of one of the drafts of
10 the science--

11 DR. : The May 9th.

12 DR. SHAPIRO: It came I think it was two drafts ago, or something
13 of that nature, and it was more or less--(Inaudible.)--but not quite what we intended.
14 Some words that you use and some words we have used weren't in there, so it needed
15 further work.

16 DR. LO: The May 9th version has the--(Inaudible.)

17 (Simultaneous discussion.)

18 PROF. CAPRON: Tom and Larry, I think I agree with you that very
19 early in the introduction we should explain the word. We shouldn't just rely on the
20 glossary for it. We should highlight it.

21 But it makes-- I agree with Carol that it makes a lot of sense--and
22 David--to use the word because we can say in the process that reproduction in the past
23 has always involved this unique subgroup of cells which are distinguished from other

1 body cells called by scientists "somatic" cells and what is unique about this process is,
2 for the first time, the source of the genetic material would be a somatic cell. And then
3 that leads into the whole discussion of differentiation and so forth.

4 So I think it--

5 DR. MURRAY: We are in complete agreement on that.

6 PROF. CAPRON: Okay. Well, Larry still seemed resistant. And I
7 think once it is put that way, the reason for using that term would be quite clear.

8 DR. MIKE: It is only because I am infantile, so that is why.

9 (Laughter.)

10 (Technical difficulties.)

11 DR. SHAPIRO: --we will deal with some of these issues, including-

12 -(Inaudible.)

13 But, David, you will do these various drafts, I will draw on you and
14 Carol to keep us upright in this area so that--(Inaudible.)

15 Carol?

16 DR. GREIDER: Just search and replace on the word processor.

17 (Laughter.)

18 DR. GREIDER: (Inaudible.)

19 DR. SHAPIRO: Okay. I don't think that there are any other issues
20 on people's minds regarding any of the chapter issues that we need to discuss together
21 this afternoon.

22 Excuse me. Diane? I am sorry.

23 DR. SCOTT-JONES: One thing that I thought was really good in

1 the science chapter, and in some other parts of the report too, is that the excitement of
2 this comes through; that it really is something that is exciting and remarkable.

3 And I think we should make sure that we keep that idea in the
4 report; the sense of excitement, of discovery, along with all the problems.

5 DR. SHAPIRO: That is helpful. (Inaudible.)

6 (Laughter.)

7 DR. SHAPIRO: (Inaudible.) But we will try our best. Thank you
8 for the comment.

9 Okay. Any other comments or suggestions?

10 (No response.)

11 DR. SHAPIRO: Before we adjourn, can I ask the committee
12 members to stay an extra few minutes for some of the committee messages because
13 that is not our, not strictly speaking, committee business.

14 So is there anything else before we adjourn?

15 (No response.)

16 DR. SHAPIRO: Okay. We are adjourned.

17 (Whereupon, at 2:12 p.m., the commission adjourned.)