

Genetic Discrimination Session
Question and Answer and Committee Discussion

DR. TUCKSON: Can you put the previous slide up again? On the first point, let me just try to go through this for a minute. Just so the committee, and especially the folks who are new to the committee will know, we did spend a considerable amount of time on the phone with the Chamber and AHIP -- we didn't do it with the National Association of Manufacturers -- and also with the coalition, to go over in some detail a point by point in the legislation where were the synergies and where were the differences, and why were there differences. So we have done that about a year ago, ballpark a year ago.

So the thought would be, if I understand your point, enough time has gone by, positions may have modified, and so maybe we might do that. The way we did it so that we didn't get ourselves into trouble was we did it as a fact-finding exercise that allowed us to write in our report more authoritatively what was the exact position of the organization. So it required enormous drilling down to detail by staff and us to sort of get their position. So I think that's a possibility that the committee may want to look at as Agnes takes us through the discussion. But I'm pretty sure that's what you're saying, that things have shifted and changed.

Now, NAM was not a part of our original group, and you're identifying NAM as being an important player.

MS. TERRY: Yes.

DR. TUCKSON: Okay. AHIP was in that original list as well. AHIP's issues were, as I recall -- this is the insurance industry association. Their issues were very specifically around the notion of not being able to use the information to coordinate care for complex people who required a variety of medical and non-medical social supports, and having the data there that allowed you to be able to coordinate care for individuals was a concern, an unintended consequence that they were worried about.

You don't have them listed. Is that because we've pretty much gotten that out of the way?

MS. TERRY: Yes.

DR. TUCKSON: So AHIP is off the table?

MS. TERRY: Off the table.

DR. TUCKSON: Terrific. So now I understand your point.

Ask the Secretary to invite the same organizations the White House -- we have done that in a letter to the Secretary previously. What we have actually said is here is what we understand the position of these organizations to be. You may want to try to bring them together to have a conversation about resolving these issues, having defined them, if I can speak reasonably that that was the strategy that we did. I'm just checking reality here.

Remind the Secretary that he works with Congress. Get the Genes and Environment Initiative funded. Cool. Make a clear and strong statement expressing concern about the chill. Cool. Send the Chairman the phone book. Cool. Okay, I think I got it.

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Any questions that you have here?

MS. BERRY: I realize that the cogent data that was presented just now is brand new. Have there been briefings on the Hill of the prior data that we received in our earlier meetings, and are there plans to brief, for example, the House Republican Policy Committee, which has a new chairman, the High-Tech Caucus and the House Republican Conference, which is led by Deborah Price? I don't know if she's a co-sponsor of this bill or not, but she has a strong interest in cancer and I would think would be very receptive, because the challenge seems to be that we're in an election year and it's a very compressed legislative calendar, and in order to pop something loose and get floor time in this environment where they have district work periods every single month, they're gone the entire month of August and they plan to adjourn in early October at the latest, you would have to convince members of Congress, and more particularly the House Republican leadership, that this is an election year issue that they need to pay attention to.

They do focus quite a bit on polling data. So to the extent that you can get this latest information in their conferences, in their policy committee discussions, I would think that would help, and I was interested to know what plans you might have. I mean, I have other suggestions, town hall meetings during these district work periods. If you have people in your coalition know in advance when the town hall meetings are taking place and you can have someone there to raise the issue --

DR. TUCKSON: Before you comment on that, let me turn the chair to Agnes, who is going to lead the discussion, because I think given what Cindy has done, we're in the discussion section now and I want Agnes to lead that.

By the way, I just want to make one other comment, because everything we do is on the record, and I just want to be very careful. It's nothing that you said.

We have names of organizations up here, and we're going to inevitably discuss some of these organizations. I want to be very clear and careful about how we categorize the participation of some of these organizations, like the Chamber and others. I will say that the Chamber was extremely responsive to our request for collaboration and participation and getting their position known; the same with AHIP and others.

The committee seeks to serve a brokering role, a coordinating and facilitative role, as appropriate to our mission. So I just want to make sure that as the record reflects conversation about the positions or the interpretation of positions of organizations, it is not done with any sense of disrespect to those organizations, any pejorativeness for those organizations, but respect for their having legitimate points of view which we seek to better understand and then harmonize. I just want to make sure the record is extremely clear on that point.

Now let me turn it over to Agnes.

MS. MASNY: Thank you, and thank you, Sharon.

I just wanted to ask also about AHIP. You said AHIP is off the table now for your whole trying to go after them, but have they have endorsed?

MS. TERRY: They've not endorsed, no.

MS. MASNY: They've not endorsed.

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MS. TERRY: They've done what usually is the best in these conditions, and that is to say they're not going to oppose. I think in our discussions with the employer community, they've been much more robust and wanted to engage and understand what we're doing. So it was quite different, whereas the insurance community seemed to say we're okay, we don't really even need to engage around this, it seems to be off the table for us.

MS. MASNY: Thank you.

I think now our goal actually as a committee is if we have any further questions to ask, we can do that, but with the focus of what then can we as an advisory committee come up with for recommendations from the Genetic Anti-Discrimination Task Force, and possibly even maybe back to the Large Population Studies Task Force, since some of the points that were brought up were about concerns that the public has for these large population studies, and maybe there's something specific that we can add to the large population study recommendation about the genetic anti-discrimination legislation. So I'll open it up to the committee.

DR. TUCKSON: And our speakers are still here to answer questions.

MS. WHITE: I just want to add one thing. As I was sitting here looking to see if there was any additional data regarding their willingness to participate in the national databank, we did ask the following question, which said if you could be assured that your identity would be protected and that you would in no way be discriminated against, how willing would you be to allow your genetic information to be included as part of the proposed volunteer national DNA information databank? So this was asked of the entire population, with a split sample being those who had heard the government terminology and those having heard the NIH terminology, and the number does jump from 25 percent for government to 37 percent, and 31 percent to 43 percent. So in the top two box. If we want to look at just the top box, which is often how you can draw projections of how might potentially actually participate, it's about 20 percent of Americans if they're assured that their information would not be -- that they would not be discriminated against.

MS. MASNY: Julio?

DR. LICINIO: I think I asked the same question the last time you were here, but here it goes again. This sounds so reasonable, but what are the roadblocks to get this legislation passed, particularly in Congress since it has passed in the Senate? I'd like to know not only the legislators themselves but I'd like to know the interest behind them, like what's opposing this.

MS. TERRY: So I think the concern is in the employer community, and it is about details in the bill, and they are very small details on one scale and large to them on another. I also think that as we've gone through especially these last two years, and certainly the last eight years, we've created a better understanding about what our goal is. Our goal is reducing the misuse of genetic information and not encouraging, as was originally assumed, frivolous lawsuits. So I think what we're seeing is an interesting conundrum that occurs in politics, and that is, as Cindy says, there's a lot of action right now. There are a lot of bills that need to be processed, et cetera, and this is low on the radar screen of most people. It's obviously very high on the radar screen of Mrs. Biggert, and she's worked very hard to do a lot of networking, a lot of bringing people on board.

What I think the Congress doesn't like to do is to cross entities like the Chamber of Commerce or the National Association of Manufacturers, and I think that what we will be seeing over the next few months -- and Cindy is also right that it has to be very fast, that we do this from here on or we're going to lose our window -- I think we'll be seeing the Congress and the committees begin

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to understand that, in fact, while the Chamber and NAM are not endorsing this bill, that they may be assured that we aren't going after such high and stringent difficulties or hurdles that they have to be as concerned as they have been in the past.

DR. TUCKSON: In that regard, then, I think clearly, as I understood the position of the Chamber and others, these people are very -- I'm taking it at face value and trying not to be naive and so forth and so on, but trying to understand where they are. They are very concerned about this idea of these frivolous lawsuits and what that means for people trying to run businesses every day in the country. I mean, this is not an insignificant concern that they have.

The question becomes has there been any change in the legislation or the provisions that speaks to that in ways that speak to them in terms of their concerns, or has the work been to just try to get them to be less concerned about that given the overall burden of the problem in terms of the risk/benefit ratio? What's the strategy here?

MS. TERRY: That's an excellent question, and I think we're actually doing a sort of two-pronged attack here, and that is that the legislation has not changed. Mrs. Biggert intends to put essentially 1227 into committee and onto the Floor, which is exactly the same bill as 306 in the Senate. There will be, however, some slight changes in some things that were quite reasonable in our discussions that emerged, and I think even some of those things came up on the phone call that you were on.

So while there will be some slight changes to the language or to various provisions in the bill, for the most part what has happened is a discussion that's allowed the Chamber and us to understand each other well and to, in fact, feel like we're working productively together so that they're assured that our intentions are not malevolent in any way and we're assured the same.

DR. TUCKSON: One last question, and this is a hard question for you to answer, I'm sure, but let me just make sure I get it the best I can. Why is it that there cannot be any provisions in the bill that help to protect from this problem, the potential of these frivolous lawsuits, or is it that it is the very essence of the bill that the opportunity to sue if bad things happen is basically the core of the whole deal? I mean, help me to understand why can't we do a little bit more, or if doing a little bit more basically cuts out the guts of the bill.

MS. TERRY: I'm going to answer that in lay language because I'm not a lawyer. From what I can see, of course, people who want to be protected want the right to sue if their rights are violated in some way, and we already have a body of law in this land that allows some action or some remedy, and what this bill seeks to do, and I think it seeks to do it pretty well because we have to remember we're coming all the way from the original Slaughter bill in whatever year that was to today, and it has changed during those years to a place where we're in a kind of moderate zone, we believe. So the coalition believes that, no, this doesn't give you the right, the minute someone looks at you funny, to sue, nor does it give you such limited protections that it really is just frivolous on our side either, and I think the employer community is finally understanding as well that there are, in fact, methods in the bill, methods for remedy that allow steps before a person could actually bring something to lawsuit, for example, and that there would be some iterative process that people would have to go through to get to a point where they would be able to seek a remedy.

It's extremely complicated, and my colleagues, Frank Swain and others, have helped us kind of wade through this mess to see where we are at and certainly not to get into the sausage making that is legislation but to keep always on the table that the intent is we don't want this to be

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onerous for employers. I'm an employer. It would be horrible to have another law that makes things difficult, and on the other hand we can't let things like Burlington Northern continue.

MS. MASNY: So from the committee's perspective, are there any particular recommendations that you would like to make for the Genetic Anti-Discrimination Task Force to go forward from here?

DR. FROHBOESE: I think, as has been pointed out, this committee really has served a very valuable role in terms of gathering information, distilling the issues, trying to understand varying positions, and to get information out both within the Department as well as to Congress about our findings. Given that, and given the Secretary's response to the last compilation of material that we sent, I do think it would be worthwhile to explore another meeting with both the coalition as well as groups that continue to have concerns with the legislation and to identify any issues there where we can serve a role of helping to further explore potential ways to address concerns. Certainly I think with a changing leadership in Congress, getting information, as has been suggested, to the chair of the Education and Workforce Committee is important as well.

DR. TUCKSON: With that, given that you have the chair, I would propose that we would focus our strategy on point 2, which is that we would send a letter to the Secretary as expeditiously as possible urging him to use his good offices to bring together these organizations and the White House Domestic Policy Office to move the administration's position forward. In preparation for such a letter and for clarification of status and issues, it would mean that we would request a meeting on the first bullet to gather the facts and data and information necessary to write such a letter.

So taking those first two for now, I would propose that we do that, and we can work through the same mechanism that we used the last time to achieve that. So let me stop there and put that on the table as a proposal.

MS. MASNY: Joseph?

DR. TELFAIR: I just have two questions, one for each. The first one is on the research that you're doing. You may not have this in your database at all, but one of the things in the large population studies project was a real concern about not only just what your finding the basic understanding is but the other side, which is the education side of things. I was wondering are there any questions in there from the point of view that are being surveyed about what would be needed essentially to provide them with information? I mean, you've given them questions that clearly are asking them specific types of things, but I was kind of bothered by the fact of how big the numbers were, 70 percent I think it was, that knew nothing about anything going on related to protections and that sort of thing, and I was wondering is there anything in your data that speaks to better ways of getting that information to them.

MS. WHITE: This research doesn't look at the actual ways in which to communicate with them, but there's other research that we have but not specific to genetic information but just health. We do a lot of work in nutrition and communicating with consumers about health and nutrition. There may be some learnings from there, but I'd have to go look at that information and let you know.

DR. TELFAIR: The other question is for Ms. Terry. In relationship to this, I was wondering what is your sense of -- and you may have already answered this, so just correct me if I'm wrong, but I'm still concerned because it seems that education is a pretty critical thing. What is the

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understanding that people have related to this? I mean, it seems to me that if what you answered as to why it's not moving forward, it seems to me there's a gap there.

MS. TERRY: And I think in fact one of the things that we've agreed completely on with our comrades at the table is that both the employment community and we will have to do an education campaign. One of the things that I think will happen right away is that some of our partners are the American Society for Human Genetics, the National Society for Genetic Counselors, and I know Don Hadley presented his information here. I think if researchers could say I don't have to tell you that your information could be misused, when they're asked is my information going to be misused, if they could say in fact your information is protected by federal law across all 50 states, I think that will allay fears for at least a clinical trials scene.

As far as the genetic testing scene, I think again the workforce, whether it be the laboratories, clinicians, genetic counselors, et cetera, are going to be able to say, no, in fact, you can be tested and not worry about being a carrier for something and having your employment or insurance disturbed. So I think there's going to be grassroots education, but I think there will also be very practical clinical education that will have to happen around this.

DR. TELFAIR: So the grassroots education is targeted to what groups specifically? I mean, you mentioned a few. It sounds like part of it is not just the general public but part of it is also those who are in practice at some level or another. I guess I was also concerned about their level of communication to those who are in positions much higher up who make these kinds of decisions.

MS. TERRY: So are you asking should those individuals also be speaking to administrators of hospitals, legislators, et cetera? Yes, and I think the societies that we're working with are going to educate their workforce that way. I would hope that the employer community would educate itself, and then I think we're going to have to have regular old public service announcements around this stuff as well. We see that sort of as a second prong if we could at least allay the fears of people who today are going to go somewhere and try to have a test done and can't have it done.

DR. TELFAIR: Given that information, it seems to me that that's a clear recommendation that we can make. I mean, that's something that we can suggest. If we're going to do number 2, which is invite organizations and groups, part of what we might want to say to them is sort of taking some of the structure here in terms of what targeted types of groups to educate, what are some of the targeted issues are that we need to educate about, if we're going to do that. I'm speaking as a Large Population Studies Task Force member.

MS. MASNY: I'll just ask the committee that. Are we asking for that for another meeting, or would that be sort of what Reed was proposing, like the way we did it in the past with some behind-the-scenes telephone conversations to gather that information so that we could present that to the Secretary?

DR. COLLINS: Let me just say, as has already been pointed out, time is of the essence here. The window for legislative action in this current year will close. If we wait until the next meeting of SACGHS to invite these discussions with the Chamber and NAM, precious time will have been lost. So I think the telephone route, just from a practical perspective, would make a lot more sense.

MS. MASNY: So then would the committee be in agreement with the proposal that Reed made that we do behind-the-scenes telephone conversations so that we could include that information from these organizations to the Secretary?

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Debra?

DR. LEONARD: I agree with that and would like to extend what's the content of the letter, not simply asking for the meeting but also including the next two bullets in the letter, which would be the third and fourth bullets, asking him to mention H.R. 1227, the importance of that for the Genes and Environment Initiative, and as you do, you provide background information. I mean, that's kind of what this fourth bullet would be, making a clear and strong statement. Then also I don't know whether we send the phone book or the Secretary does, but asking him to do that, not only to McCann but also to the people that Cindy mentioned. I don't remember their names, but there were others who should be getting this information.

So I do agree that it has to move quickly. It should be a behind-the-scenes meeting or phone conversations, and then the letter should go as promptly as possible to the Secretary.

MS. MASNY: I think we can recommend that we send the phone book with the DVD disk. We don't know whether that will actually happen because I think we did already send the phone book and an analysis of the law and the DVD with about 150 copies so that that could be distributed. Is that correct, Sarah?

DR. LEONARD: But these are new people in new positions, so they may have left their phone book in their old office.

MS. CARR: We can request that that be sent forward by the Secretary, yes.

MS. MASNY: And then also maybe what we could do is give some of these to Sharon so that if Sharon sees them, that she could distribute the things directly to them, rather than waiting for the whole group.

DR. COLLINS: They are public documents.

MS. MASNY: Right, exactly.

MS. CARR: They're also on our website, too. You can just point people to our website.

MS. TERRY: Yes, and we certainly do regularly, but to have more copies of it, I would definitely distribute it freely and frequently.

MS. MASNY: So I think we have a plan. Just one other question is would we want to ask the Large Population Studies group specifically under the heading of privacy and confidentiality to sort of make a stronger statement about supporting genetic anti-discrimination legislation in that context?

DR. TELFAIR: That makes sense.

MS. MASNY: Cindy?

MS. BERRY: Just to clarify, is the purpose of the meeting, the White House meeting with the organizations, is there some hope that the Chamber and NAM and others would, after this session, work out some kind of an agreement and then say, okay, we're satisfied, we will communicate to the Republican leadership in the House that we don't have any opposition to this and you can go forward with it, or is there really no hope of that? In which case perhaps the

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meeting focus might be not necessarily exclusive of but in addition to this the leadership in the House, because if we think they may say, okay, here are our concerns, you've addressed them, we're fine with it, that would pop it loose from the standpoint of the folks in the House. But is that a realistic expectation or hope, or are we in the mode of just continuing to find out what their concerns are and hoping that we can understand them better? That won't really get us to the next point.

MS. TERRY: I think that it's not at all unrealistic to think that we might come to common ground, and I think we're just about there. I think the advantage of a higher-level meeting is to give them a place to express these concerns in a more formal forum. They've done so with us. I think they're ready now to make those concerns, in the more moderate form, to the public, and also they are ready to at least sign off, if not say that they will in fact help move the right kind of legislation forward. I think what we're seeing in the committee chairs is it has been for a long time a chicken and egg kind of situation where the chairs have said we're ready to go as soon as they're ready to sign off, and they've said they're ready to sign off as soon as the chairs are ready to go. I think we just need to have everybody in the same room, so to speak, to say we're ready to go and we understand that it's timely, it's important, and we have the forces behind it now.

We have more momentum, and I've personally been working on this for nine years and have never seen this much momentum. I mean, we have this huge rock to the edge of the precipice and just need a little more momentum to get it over the edge, and we do need to do that very, very soon, I would say within months, or we're going to have to go back to a new Congress with it.

MS. MASNY: Cindy?

MS. BERRY: One more follow-up. Maybe this was addressed while I was making my pit stop, but the data that Christy presented was very, very compelling, and do we intend or did we talk about incorporating some of that in this communication to the Secretary?

MS. MASNY: I think that would be essential, yes.

DR. TUCKSON: Let me just try to keep track, then, of where we are on this issue. Let me just try to summarize this because we've got about 12 things. If I recall where we are, and everybody can add on from here, I just want to make sure, we've agreed to do number 2, which requires number 1. We have agreed to do number 3, and we've agreed to do number 4. Then we've agreed just now to include in that some of Christy's data. So we've added that to it. So for those who are keeping score, of whom I hope there is someone, that is what the committee is getting ready to vote to accept.

Now, we're going to have some other comments, and you need to decide where it fits, either addition to that or if you're trying to subtract something.

DR. TELFAIR: Can I just ask for a modification on the last point there? Just that if we are going to add the information from Ms. White, that we actually get the more refined, because she made it very clear that this is preliminary data, and if you're going to send something forward, you want to make sure that -

DR. TUCKSON: That's good. Also, Madam Chair, I also forgot in my summary to indicate that there was a timeline of expeditiousness that was brought forward by Francis that would be a part of the spirit of the motion.

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MS. MASNY: Debra?

DR. LEONARD: You mentioned that the chairs -- is that the chairs of the committee who are going to go with the bill? Should they be at this meeting also?

MS. TERRY: Yes, that would be terrific.

DR. LEONARD: So I think that that needs to be requested of the Secretary, that not only the same organizations and the White House Domestic Policy Office, but also the chairs of the committee that the bill is in are at that meeting, because then the communications are direct and everybody is hearing the same thing at the same time.

DR. TUCKSON: I'm just trying to think technically. Does the Secretary have that opportunity?

DR. LEONARD: And people other than me know that. I don't think he does.

DR. TUCKSON: He has to go through the Domestic Policy. That's why he's got to meet first with the -- Debra, I think he has to meet first with the Domestic Policy Office. You can't jump that.

DR. LEONARD: But can't the Domestic Policy Office organize the meeting?

DR. TUCKSON: That's why he's got to go to them and get them to buy in, and then it's like a jump scotch thing.

DR. LEONARD: Okay.

DR. TUCKSON: But let me just say, I think in terms of the spirit of what you're asking, let me just try to rephrase what I think I hear you saying. You're saying that given the press of time, we would urge the Secretary to try to arrange a meeting with the Domestic Policy Office, and also to try to urge them to have the Congress people decide to come as well, recognize that they're the ones who have to do it, as opposed to him.

DR. LEONARD: Right.

DR. TUCKSON: I think we can try to figure that out.

DR. LEONARD: Can we also make sure we have on the work list that all of the new members of Congress, the appropriate members of Congress get the phone book and the DVD? So they're all equally educated.

DR. TUCKSON: That's in addition to the summary that we had.

MS. MASNY: So is everybody in agreement, then, with the proposal that Reed so aptly pulled together, be accepted by the committee members?

PARTICIPANT: So moved.

MS. MASNY: Anybody opposed?

(No response.)

MS. MASNY: Okay.

DR. TUCKSON: Terrific. Thank you, Agnes, for getting us through that. Thanks to everybody. Thank you very much, Christy and Sharon. We appreciate it. We will go forward.

We now have the opportunity before the break to hear from public comments. Again, we continue to emphasize that one of our critical functions is to serve as a public forum for deliberations on the broad range of human health and societal issues raised by the development and use of genetic technologies.

By the way, I want to make sure -- where are the responses to the survey about how well we as a committee work? I want to make sure that everybody goes back. I keep reiterating the mission, but I want to make sure that we get 100 next time on the mission. Where is our charter statement? I wanted to take this opportunity, because I want to make sure we get 100 every time. We keep saying it over and over again, and people may not realize that we're reciting the mission every time we talk about one of our critical functions is to serve as a public forum for deliberations on a broad range of health and societal issues raised by the development and use of genetic technologies. So we do greatly value the input we receive from the public.

So again, that's pretty much word for word what we are, but I'm remembering again that our mission as an organization is, the purpose is -- well, actually I want to read from the function. Here it is. We have the responsibility to provide a forum for expert discussion and deliberation and the formulation of advice and recommendations on the range of complex and sensitive medical, ethical, legal and social issues raised by new technological developments in human genetics; to assist the Department of Health and Human Services and, at their request, other federal agencies in exploring issues raised by the development and application of genetic technologies; and to make recommendations to the Secretary concerning how these issues should be addressed.

The public forum for that is essential. So I wanted to make sure of that. I now see people looking at the survey, so let me just quickly do that.

"Are you aware of what is expected of you on the committee?" To be brilliant and sharp and smart, and to bring your particular expertise to bear. If you're not sure about your expertise, see me at the end of the meeting and we'll remind you of what you're supposed to be expert about.

"Do your opinions count?" Well, they absolutely do, and you need to make sure that we do respect them very much. In fact, most of the committees -- I mean, we've got a bunch of committees that are chaired by you or that you are participating in. So there is nothing that can count other than you. You're it. So if you don't like something, look in the mirror.

"The committee's mission is clearly defined." I think you've got it in front of you.

Our procedures. Again, I think we put a lot of attention to form and formality around how we behave, and particularly how the subcommittees behave and how you can influence that. But again, if you're concerned about that, let me know.

If you're not being given enough time to view the materials, it's only because I screw the staff up by basically micro-managing every word that they write and making them rewrite it 12 times if I don't like something, which is never rational anyway. So if I would just be less irrational, they would get it out to you sooner. So I'll try to be better on that.

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"We have clear agendas." I hope you see that, and they are dictatorially adhered to by the chairman. So hopefully we're doing a good job on that.

I really do feel strongly about this issue of is the committee accomplishing its mission. I do require the staff to always put up at the beginning of every meeting that slide on our strategic direction and what is our status on that. So we're being pretty strict about looking at our scorecard and seeing where we are for our scorecard. So I hope that you think we're doing that.

DR. LEONARD: Reed?

DR. TUCKSON: Yes?

DR. LEONARD: This is probably anonymous, but do we know which of the ex officios are in the 3 category of neutral as to whether we're accomplishing our mission, and do they have any feedback to us as to what we could do better?

MS. CARR: It was an anonymous survey, so we don't know which ex officios responded that way. But we are having a meeting of the ex officios next month, and we'll explore that with them, and also explore with them the concern that the committee members had about feedback on their recommendations.

DR. TUCKSON: So that's serious, and we'll find out which of you are unhappy with us.

I will leave it to you about whether the meetings are productive. I'll make no comment. I certainly will make no comment about the efficiency with which the meetings are probably not run.

DR. LEONARD: But you don't take feedback?

DR. TUCKSON: In the sense that I wouldn't embarrass you now. You can call me off sides, beat me up later. I'm not going to put anybody on the spot to agree that they're run inefficiently now. See me later.

But given that wonderful point, it proves that points of view are balanced. I'm just kidding. So I guess the question would be to ask the ex officios in that meeting what points of view are not balanced and where they see that as a concern. That is serious, and I think Debra is absolutely right for raising it. We're two issues for the ex officios.

"Meetings are open and participatory." Again, we got into this whole jag by the fact that we're about to go to public testimony.

"The work of the committee is appreciated by HHS and other departments and agencies." Here is where our big issue is, and we talked about that at the beginning of the meeting.

"Federal officials provide sufficient feedback when recommendations are made." I think that this is an issue, again, that I think we could get more from the ex officios on. So we will clearly be bringing that forward for conversation.

"Open-ended comment questions." People want more time to review. Our agendas are apparently too ambitious, and I think that's a legitimate concern. On the other hand, we might want to talk more about that. On this issue of the agenda, if people would like to email me about

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that if there are some issues from the committee members on that, let me know, because every time we have an issue it's almost always we don't have much time to respond to it. I don't know what we can dial back, so we'll see. People do enjoy having different individuals lead the discussions, and I certainly do as well.

New members need better orientation to the committee. I'll try to be more sensitive to that.

Membership needs to be more balanced so that certain perspectives aren't overrepresented. We'll need to try to learn. Again, if anybody would like to send forward an email about that, we would appreciate it.

Recommendations should advise many agencies, not just a few. Better feedback on recommendations needed from federal officials. Disconnect between the committee efforts and the Secretary.

This is a very legitimate exercise. When did we do this, in October?

MS. CARR: Right.

DR. TUCKSON: That was October of '05, so let's really look forward to doing this again in October of '06. But staff, help me out on this, because I really want to get 100 percent the next time around on this. So it's up to you.