

Perspectives on Genetic Discrimination- Introduction
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DR. TUCKSON: All right. For the next part of our effort, we're going to devote from now until 12:45 on a pretty serious discussion on genetic discrimination. You will remember that this is a top priority for our committee. We've written two letters to the Secretary urging support for the enactment of federal nondiscrimination legislation. At our March and June meetings we discussed the question of whether there were additional efforts that we could take to inform the debate regarding federal legislation in this area. The United States Senate has subsequently unanimously passed a genetic nondiscrimination bill a year ago, but the House Subcommittee on Employer/Employee Relations has held a hearing on this in July without further action that we are aware of. There is a summary of those hearings in your Tab number 4.

The purpose of this session is to gather additional public perspectives on genetic discrimination and information about the nature, magnitude, and scope of this problem in society. The session was planned and organized by our Task Force on Genetic Discrimination. Agnes Masny, who has been terrific as chair, and Barbara Harrison and Debra Leonard and Emily Winn-Deen and Robinsue Frohboese and Tim Leshan, former EEOC Commissioner Paul Miller, Joann Boughman of the Genetic Fairness Coalition, all were extraordinarily involved in this, and we thank them for it. Amanda, I want to thank you for your lead staff work on this. I also want to thank the members of the panel for participating and taking note of the written comments that have been submitted. They have been compiled in a separate binder, which I hope you all have. A copy is available for review at the registration desks.

Now to lead us through this, let me introduce Agnes. Thank you, Agnes, for your hard work.

MS. MASNY: Thank you very much.

I'd also like to thank Dr. Tuckson, who is going to help co-facilitate this session, and again thank Dr. McCabe for his leadership, bringing us thus far, and to the staff, Sarah and her staff, for helping coordinate, and especially Amanda Sarata, who has been working by my side in helping to pull all this together; and most especially to thank all of the speakers who have come from far and wide today to be able to give testimony today so that we will be able to document for the record the experience of the public, health professionals, and others regarding this very important issue of health discrimination, genetic discrimination.

As Dr. Reed mentioned, what led up to forming this particular task force and the members that he already indicated have been presented, and then as was mentioned is that one of the reasons why we have actually established having a public hearing today is that because from the past we've recognized that the evidence about genetic discrimination, and particularly the fear of genetic discrimination, has been very hard to document. There are very many reasons that have been brought forth to the committee regarding the public's concern about genetic privacy, and presenting their information in legal cases is very hard to do. So that's one of the reasons why we wanted to have this hearing.

Also, because to date there has been lack of sufficient evidence, and this lack of evidence has been actually brought up as one of the reasons as a barrier to going ahead with legislation for anti-discrimination. So at the 2004 June meeting, we did decide to undertake this public hearing in order to provide the Secretary with additional information that might be useful in addressing the potential obstacles regarding genetic discrimination and moving it forward for legislation.

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So the purpose of this session, as Reed has already mentioned, is to learn more about the magnitude and scope and the nature of genetic discrimination throughout society, and to provide all of us with this public forum to be able to both hear the testimony and then to be able to discuss the issues that will come forth from this hearing.

Then the last step will be for us as a committee to then look at what are the next steps that we have to take to hopefully move the legislation forward.

So what we're going to be doing today is we're actually going to hear from three panels: members of the public, health care providers, and then additional stakeholders. The patient panel will consist of members of the public who have experienced genetic discrimination or who have altered their health care because they have a concern about genetic discrimination either from insurance or from employment, or those who have had to pay out of pocket because of their concern for genetic discrimination.

We also took time to look at, as a task force, getting members of the health care community providers who have that first-hand experience with the patients, hearing their concerns about genetic discrimination, to also be able to come and testify. So again, we hope to hear from the providers about some of their patients who may have altered their health care decisions or who have not participated in genetic research because of genetic discrimination and other concerns that they have regarding discrimination.

Then the third panel will be additional stakeholders that will hopefully give us an additional perspective, and this from employers, from the health insurance perspective, and from the society at large, and this primarily through a representative from the Center for Genetics and Public Policy who, over the past several months, have held town meetings across the country on the issues of genetics, and genetic discrimination was one of the issues. So we'll be hearing that particular perspective as well.

The committee and the SACGHS had requested written public comments through the Federal Register notice, through the SACGHS website, through the major distribution lists of SACGHS, and then we also targeted specific medical groups like the American College of Obstetrics and Gynecology to be able to go directly to their membership to ask about this particular issue, whether they as providers have come in contact with genetic discrimination or the fear of discrimination from their patients, and then also various listservs from health professionals, physicians, nurses, and genetic counselors to request public comments.

So we did receive 43 public comments. Twenty-two were from the public, 11 were from health care providers, 9 from professional organizations, and one very nice, thoughtful testimony from Representative Louise Slaughter, who has co-sponsored the House version of the bill 1910.

So we're going to begin, then, with the most important part, to actually hear from the public, and we're going to start first with the patient panel. We're really very fortunate to have with us today a panel of seven members of the public who would like to share their personal stories and experiences and their own perspective on genetic discrimination. They come to us from across the country.

What I'll do is I'll introduce the whole panel as a whole, and you can just kind of go in order across from the table. We will ask the speakers that they'll have 10 minutes to present their public testimony. We'll try to keep track of the time for you. Then after everyone has had the opportunity to present, then we will open it up for questions from the advisory group, and the ex

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officios will have an opportunity to ask any additional questions after the end of all of the testimony, okay?

So again, we'd like to thank and welcome our first panel. We have Heidi Williams from Cecilia, Kentucky. Phaedra Malatek is here with her family, her two sons, from Chicago, Illinois. Rebecca Fisher from Oakton, Virginia. Tonia Phillips from Roanoke, Virginia. Paula Funk from Little Rock, Arkansas. Maria Carolina Hinestrosa from Washington, D.C. Phil Hardt from Phoenix, Arizona.