

Update on SACGHS Efforts
Agnes Masny, R.N., M.P.H., M.S.N.

DR. TUCKSON: To give us an update on genetic nondiscrimination legislation and where efforts are, let me turn to Agnes Masny.

MS. MASNY: Thank you, Reed.

I also would like to take this opportunity to once again thank the Committee on Genetic Discrimination, as well as to all the committee members for all of their input. Most specifically, to Sarah and to her staff, and Amanda Sarata, who has been exceptionally helpful in pulling all of these materials together that you're going to be hearing about. Most importantly, to thank the public for their continued input that has been so helpful in directing us on this important issue.

So what I'm just going to do, we're going to briefly just go over sort of where we are to date with what has been happening in this whole area of genetic discrimination. I'll give you an update on some of the recent developments that include the correspondence and what has been sent to Secretary Leavitt, as well as to a brief legislative updating of what is happening in the House.

Then we're going to have a presentation by Peter Gray on the legal analysis that was requested by this committee to look at the current legislation, what exists and where potentially there are gaps. Then we're going to have a legislative briefing from Jaimie Vickery. She is from the staff representative Judy Biggert's office. Then we'll have a committee discussion to see what further things we need to do as a committee to move this forward.

The task force members have been myself, Cindy Berry, Barbara Harrison, Debra Leonard, Reed Tuckson, Emily Winn-Deen, Joann Boughman, Robinsue Frohboese, Peter Gray, Tim Leshan, and Mildred Rivera.

So with regards to the congressional developments, the Genetic Information and Nondiscrimination Act was introduced to the House in March. This was a bill that was sponsored by representative Judy Biggert, and co-sponsored by Bob Ney, Anna Eshoo, and Louise Slaughter, and has a total of 101 co-sponsors.

What has happened is that after the bill was introduced, it has been referred to three subcommittees. One, to the Energy and Commerce Committee, second to the Education and Workforce Committee, and third to the Ways and Means Committee. The Education and Workforce Committee has also referred it to a subcommittee on Employer and Employee Relations.

The bill that was introduced into the House is very, very similar to that of what was passed by the Senate, but it differed in only one way. There were some provisions in the Senate bill that addressed and potentially would amend the internal revenue code. So these have been omitted from the House bill.

These were measures, though, that only affected church plans. So there is some thinking that at any point in the future, they could be put back in, but currently they have been omitted. We'll hear more detail, of course, from Ms. Vickery regarding the legislative update.

So onto the correspondence that has been sent on to Secretary Leavitt. After our last meeting, we drafted and sent on then another letter to the Secretary. That was included in your briefing books.

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There are also four enclosures that were sent on. One was the compilation of the public comments. We wanted to make a telephone book, and we received our own telephone books in the mail, along with the DVD that was a compilation of the public comments, summarized though and abridged, it wasn't the total version. We're going to actually view that in a few minutes.

Then there was a copy of the America's Health Insurance Plans' letter of February 22nd to Representative Boehner, and an analysis that we're going to be hearing about shortly of the current law. So this was all transmitted to the Secretary by the NIH Director.

So all of the public comments that had been received either by email, by mail, or people that presented here to the committee between September 24th and November 24th, as well as any research articles that were also sent to the committee, all of these were compiled in that book that were sent along to the Secretary.

The content of the letter, we were urging the Secretary of course to exert his influence and leadership to bring about enactment of federal genetic nondiscrimination legislation. In the letter, we reviewed some of the stakeholder's perspectives. That was the perspectives of the patients, the general public, and the Coalition for Genetic Fairness.

In brief, we summarized the deep-seeded fears that the public has about potential misuse of genetic discrimination. Health care decisions being shaped by fear rather than by best medical practice, patients who are seeking genetic testing outside the formal health care system, patients requesting that the results be kept out of medical records, and opting for anonymous testing, or potentially even foregoing testing that could actually prevent disease. The concerns about the lack of specific federal protection against genetic discrimination was also summarized in that letter.

We also pointed out the perspective of some of the other stakeholders and consumers, such as AHIP and the Chamber of Commerce, noting that these are complex issues and deserve further analysis. So we recommended that the Secretary meet with any key stakeholders and groups that were interested to advance this consensus building regarding genetic legislation.

Lastly, the Secretary's letter gave a summary conclusion about the analysis of the current law. The goal for including this analysis of the law was to inform the Secretary and provide a debate around the claims that the current law provides adequate protection against genetic discrimination.

So we specifically wanted to look at and analyze the law and identify if there were, and point out where there were potential gaps. So to date, in summary then what was said to the Secretary was that no federal law directly addresses the issues raised by the use of genetic information. The current law and court decision does leave substantial gaps in coverage, and offers inconsistent and uncertain safeguards. The current avenues for relief are uncertain and likely to lead to confusion, and as well, maybe costly litigation.

So from the perspectives of the public regarding genetic discrimination, we put together the compelling testimony in an abridged version of the public from our October, 2004 meeting. We are actually going to view that now. But before we do, I just wanted to credit and thank those people who were instrumental in putting this DVD together.

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That's Scott Tuddenham and Peter Tuddenham from WebConferences.com, Larry Thompson from the National Human Genome Research Institute, and Alvaro Encinas from Medical Arts at the NIH.

(DVD played.)

MS. MASNY: I think that this DVD is as compelling in its shorter version as it was for the testimony that we heard that day. I think that it was done extremely well. Later in our discussion, we can look at what we'll be able to do even with the DVDs, because more than one copy of course of what was sent to the committee members, there have been 150 copies, the same number that matches all the members of the House, so that we could look at what we might want to do with these DVDs.

So I again want to thank the committee, because I think this sort of shows almost the fulfillment and the culmination of so much hard work regarding this issue. I think it is very compelling. It says that we are moving this issue on, and hopefully we'll have some positive outcomes from all the work of the committee.

So next what I'm going to do is turn the podium over to Peter Gray, who is going to give us the summary of the legal analysis. This was the analysis that was sent onto Secretary Leavitt.