

Testimony of Kathy Hudson, Ph.D.

We'll begin, then, with Kathy Hudson.

DR. HUDSON: Thank you for inviting me to discuss with you what we've learned about the public's hopes and concerns about advances in genetic testing.

Amanda, are you going to be able to do my slides for me?

My name is Kathy Hudson. I'm the director of the Genetics and Public Policy Center, which is a part of Johns Hopkins University. The Center was funded by a grant from the Pew Charitable Trusts, and our mission is to provide information about genetic technologies and genetic policies to the public, to the press, and to policymakers.

Over the past two years, we have conducted fairly extensive qualitative and quantitative research to understand what the public who does not yet know about their genetic risks thinks about advances in genetic technologies. We've surveyed over 6,000 citizens in two separate surveys, the first in December 2002 with 1,200, a second one this past April with 4,800 citizens. In addition, we've done focus groups, 21 in five cities across the country, and most recently this summer we completed a series of public engagements called "The Genetic Town Halls: Making Every Voice Count."

I'd like to share with you first results from our survey in which we ask respondents if a genetic test shows that a person has an increased risk for a genetic disease, does -- fill in the blank -- have the right to know, and you can see here that in 2002, 85 percent of those surveyed said that no, an employer should not have access to that information, and 68 percent thought that insurers should not have access to that information. Those numbers went up in 2004 to 92 percent for an employer and 80 percent for an insurer. I would note that if you look at those who have higher education levels or prior awareness of genetic testing, the percentage of those saying no goes up even higher.

We also conducted 21 focus groups across the country, and focus group participants were presented with a series of scenarios involving genetic testing in the reproductive context. In those focus groups and in the scenarios presented, we did not specifically ask about genetic discrimination, but participants spontaneously raised this as a major concern.

Focus group participants went on to speculate about the availability of reproductive genetic testing and if insurers had that information that it may possibly be used to coerce or influence their reproductive choices.

You can move the slides ahead, and one more.

One of the concerns about survey work in particular is that you're asking people for their off-the-cuff reaction to a question without having a lot of time to learn about it, to think about it, to ruminate on its possible implications. That's also true in focus groups. So what we did was we adopted a model of deliberative democracy which has been used to explore other central policy issues, although not in science policy previously, and tried to develop a program to find out what Americans think once they've had an opportunity to learn a little bit about genetic technologies, the issues they raise, and have an opportunity to talk with fellow citizens about these issues.

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So this summer we did six cities in six weeks, town halls involving over 500 citizens, and we also did online town halls where citizens from across the country were engaged in discussions over a three-week period with other citizens through the miracle of Internet technology. Participants in both our online and in-person town halls were asked to consider three major issues in reproductive genetic testing: acceptable uses, safety and accuracy, and the impact on individual families and society. We provided background information about the technology, as well as a broad range of views from experts in medicine, policy, bioethics, and theology.

Participants were queried at various times during the town halls about their optimism and concern about these technologies. Two of the questions that were posed to the town hall participants were what do you think are the factors that should be considered in setting limits for the use of reproductive genetic testing, and what are some of the possible benefits and harms for individuals, families, and societies?

Participants were given an opportunities to talk with their table mates about these issues and then called out the issue of most concern to them. If a concern had already been called out by another table, that table was asked to move to the next concern on their list. Once all the concerns were expressed, they were projected up onto a screen and the entire group had an opportunity to talk about those concerns, and then with electronic keypads to vote on those that were of most concern to them.

If you could put up the next slide.

That shows our people across America talking to one another about genetics.

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The issue of genetic discrimination based on genetic test results came up as an issue in every single town hall. In fact, in Sacramento and New York, genetic discrimination ranked as the number one issue of concern when considering potential harm from reproductive genetic testing for individuals and families. In Seattle, Fort Worth, and Nashville, it ranked as the second concern. In Sacramento, every table listed it as a concern and said, as one participant did in Sacramento, will you have trouble getting a job because you have this gene that may cause cancer, whether or not you have cancer?

Like the focus group participants, the town hall participants feared that insurance coverage would be a factor in guiding reproductive choices.

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So in conclusion, our research shows that an overwhelming majority of Americans do not want insurers or employers to have access to genetic test results, and that there's widespread concern. This concern is first and foremost on average Americans' minds. This high level of public concern makes it important to think about what we will do when, not if, we enact legislative protections, and this gets to Brad's point, that I think we will have to put some focus on making sure that we get public information out to both providers and to patients to let them know what their rights are so that they don't let concerns about newly unlawful practices influence their genetic testing decisionmaking.

Thank you.

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MS. MASNY: Thank you, Dr. Hudson.