
Follow Up Questions for Panel One

Now we're going to open up to the committee a question and answer period to be able to direct questions to our panelists, if any members of the committee would like to direct any questions to them.

DR. TUCKSON: I just want to, just as we get into this, just say to each of you that on behalf of all of us on the committee, we really appreciate your taking the time to come and talk to us. I can imagine that it's not easy to do what you all just did. I will assure you from the chair's desk here that as we go forward in our work, we're going to make sure we do everything in our power to make it worth your while, that something will come of this.

I know you'll go home and people will say what happened? We're going to try to make sure that something happens as a result of your doing this. So before my colleagues get into the specifics, just a real big thank you to you all.

DR. COLLINS: I also want to thank all of you for the very powerful and moving stories that you have told, which certainly underline in stark and compelling terms the need to do something about a situation which grows worse every day. It is, I'm sure, a great disappointment for all of you that we haven't fixed this by now, when the arguments are compelling, when you can see that the likelihood of more and more genetic testing being offered is inevitable, and therefore the likelihood of more and more people facing up to the dilemmas that you have faced also becomes inevitable.

I must say that after a year ago, just about exactly, seeing this bill pass the Senate unanimously, it seemed as if this was finally going to get solve, and yet here we are.

Becky Fisher, I know you have been a very effective voice in terms of carrying this message on the Hill. What do you hear when you speak to people, particularly on the House side, about the importance of doing this? What's the roadblock that is getting in the way right now given how compelling the arguments are, as all of you have presented? What do you see as the reason why this hasn't been solved, and what do you see as the way around that?

MS. FISHER: Thank you for asking me that, Dr. Collins. Someone else asked me that, actually, at the D.C. City Council. They were considering the legislation for the City of Washington, and my response wasn't exactly politically correct, but it is what I believe. The United States Chamber of Commerce is the strongest, loudest voice speaking out against this legislation. Without going into too much detail, they have a lot more money than a medical librarian housewife living in northern Virginia, and they have a lot more clout than we do.

The only problem is they don't have any moral authority. So I still continue to believe that we will get it done. With all due respect to the National Breast Cancer Coalition, I think their support of the Senate bill would be a huge, huge help for us, because most of us don't really want private right of action, we just want the protection. So I would like to go on the record as expressing that for myself and for literally hundreds of people that I know who are in the same boat.

MS. MASNY: Ed?

DR. McCABE: This is really two parts. Again, I wish to share what has been said before. These are powerful, very important statements that all of you have made, and I appreciate all of the

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sacrifices that you have gone through before, you and your families, and the sacrifices that you make just to appear before us today. So thank you very much.

We as a genetics community, and also as members of the public, have been told that genetic discrimination does not exist. We've been told that over and over. In fact, scholarly articles have been written and are referenced in the genetics literature where the authors made inquiries to insurance companies, and guess what? They said there is no genetic discrimination. Yet, all of us know that it exists, and that's why this is so important today.

I would ask perhaps Mr. Chairman that the National Chambers of Commerce be invited at some future meeting to appear before us so that they could explain why it is that they value individuals as commodities more than they value them as individuals, because I am very concerned that these members of our communities have this as such a profound policy position, so profound that they have protected this bill from leaving the desk in the House of Representatives. I don't know if it has left yet.

But to be able to freeze a bill that passed unanimously in the Senate without leaving the desk, we heard in a previous meeting from a House of Representatives staff person that the House has to have separate hearings. They can't simply ride on the coattails of the Senate. There have been no hearings because it did not leave the desk, and I would like to hear from the most powerful group that has protected that.

We've also been told in previous meetings and op-ed pieces, in the literature, that there is no need for legislation because we are already protected by legislation, and there's a litany of laws that are cited, including the ADA, to protect individuals against genetic discrimination. I would ask, and I'm sorry to put you on the spot, Dr. Majidi, but I would ask has the Department of Justice ever gone through a systematic review of the current legislation to document that, in fact, as citizens of this country we are protected by the existing laws?

DR. MAJIDI: I'm afraid we haven't been quite approached to do that review yet. So as of now, I don't have any specific information for you.

DR. McCABE: Who would need to approach you to do that review?

DR. MAJIDI: Basically, the Secretary for Health and Human Services would be a good starting point.

DR. McCABE: Well, given that we have been, and that I until recently have been writing laws to two Secretaries of Health and Human Services, if another letter from this committee could move that agenda forward and determine whether in fact we are protected or are not protected, I would ask the committee to give consideration to yet another letter.

MS. MASNY: Yes, we will take that into consideration.

Also, for the record, just to mention that the Chamber of Commerce was invited to this meeting with a specific invitation today, but actually referred us to another group who we'll be hearing from in the stakeholder panel, the third panel.

DR. McCABE: What is the name of that group, please?

MS. SARATA: The Society for Human Resource Management.

DR. McCABE: And we have a document from them also documenting the laws that exist, which was part of what precipitated my question. I would ask if the Society for Human Resource Management considers themselves a spokesperson for the National Chambers of Commerce. So perhaps they can be prepared because I will be asking that question when they speak.

DR. FROHBOESE: Good morning. I join my colleagues on the committee in thanking each and every one of you for your courage and important advocacy in this important area.

Following up on Dr. McCabe's question about various laws and their coverage, I know several of you, I believe Ms. Fisher and Ms. Hinestrosa -- I'm sorry if I'm mispronouncing your name, Ms. Hinestrosa -- mentioned a HIPAA gap, and I wondered if you could address that a bit more from your perspective. I'm particularly curious as to whether it has to do with the privacy rule, which my office within HHS Office for Civil Rights is responsible for enforcing, or if it has to do with other aspects of HIPAA.

MS. HINESTROSA: Well, the protections that HIPAA brings about really are for people who are members of a group plan and don't extend to people in the individual market. So that is an important group of people who are not well protected by HIPAA.

MS. FISHER: I would just like to add to that, that my understanding of the HIPAA gap is that -- well, the biggest problem is it doesn't address any workplace concerns at all, biggest problem. It only deals with insurance. If you're just considering the insurance pie, then that pie is sliced up again into people who are protected and people who aren't protected by HIPAA provisions. Those who are protected are protected under group health insurance plans.

This is important because most people don't understand this. HIPAA does not extend to ERISA-exempted state plans. Seventy-seven percent of employers offer at least one state self-funded insurance plan. So that means that if my husband works for Bank of America, which he does, we have the choice every November of getting 10 different choices of plan that we could subscribe to. We could go with a Blue Cross or an Aetna and be in a group health plan, or we could go with Bank of America self-insurance plan. That's Bank of America betting that they're going to do better than Blue Cross is with that money.

Blue Cross happens to administer that plan, so I don't really have a clue that I'm not protected under HIPAA. This is a big problem. There are 100 million people in this country who are having the same problem, and they don't even know it. So I think this is a really important piece of information to get out there.

Dr. Collins asked earlier what was the pushback on the Hill. The pushback is, "No problem, we did HIPAA." Well, guess what? HIPAA doesn't work for a lot of us, and I'm glad to have the opportunity to tell you all this because my guess is that it's never gotten that granular with any of you either. But those of us who know what we're up against know this.

Thanks for asking that.

MS. MASNY: Once again, we'd like to reiterate what we've heard from every one of the members here, to thank you very much for your testimony. We certainly have heard you and we already have some actions that we'll be ready to take as we discuss further.

Yes, Ms. Williams?

MS. WILLIAMS: I'd like to reiterate the fact that a lot of these people come forward and take a chance, that when they go back to wherever they come from that they could be summarily fired, that they could have their insurance policies pulled from them. I come here with nothing to lose, okay? The VA takes care of me and I'm on disability. I have nothing to lose. But these people who sit to my left have a lot to lose when they go home, and they know that, and they come here at great risk to themselves and their families, and I want everyone to understand this.

I want the House to understand this, that there are people here at risk, and my children who are here today are still at risk. As they get older and they choose their careers, my daughter is a competitive gymnast. She's 8 years old. She wants to grow up and be a gymnast. But there is a chance that she could be discriminated against because she is a carrier of alpha-1. My son, he wants to be a research scientist. He wants to build habitats on the moon. He's 10 years old. There's a chance that when he gets to that point, he may not be hired in his chosen field. He may have to, God forbid, flip burgers at McDonald's.

Let's see, at age 9 he was considered to have an estimated 138 IQ, and it's a lot more than that now. I mean, he may have to let his considerable IQ go to waste. And nothing against McDonald's. They fund college educations all over this nation. But my son has the potential to do great things, and that may not happen. But I am more concerned with the people to my left right now because I know what can happen to them. I've heard it, I've seen it, and that's what I want everyone to understand.

Thank you.

MS. MASNY: Thank you, and we will definitely work today not to let any of your own experiences go to waste. Thank you.

What we're going to do is we're going to take a break now, and that will be until 10:45, and then we'll reconvene for Panel 2, which will be the health care providers.

(Applause.)

(Recess.)

MS. MASNY: Our second panel, then, is of health care providers. The committee, then, will be hearing from them regarding their own patients' experiences that they have been in contact with, and they'll be telling us about their patients concerns, about the impact of genetic discrimination.

So our panel, then, will be three, and again they'll each have 10 minutes to present, and we'll have 10 minutes for questions after their presentations. So we'll be hearing from Jeff Shaw, who is an oncology genetic counselor from Penrose Cancer Center in Colorado. Then we'll be hearing from Don Hadley, who is a researcher at the National Institutes of Health in Bethesda, Maryland; and from Mark Brantly, who is the director of the alpha-1 antitrypsin testing program at the University of Florida.