Questions for Panel Three

We are going to open it again for questions, 10 minutes, and then we will proceed with a larger roundtable discussion.

So any questions for the panel? Yes, Dr. Collins?

DR. COLLINS: So I'd like to ask Mr. Aitken, a number of the issues that you raised are certainly ones that have been discussed for several years as various versions of legislation have been debated, drafted, redrafted, and so on. I frankly think a number of the points you made have already been taken care of.

So specifically, what would your recommendation be, starting with S. 1053 as a template which, after all, did pass the Senate 95 to nothing, what additional changes would need to be made in that bill for SHRM and presumably the Chamber of Commerce to be comfortable with it? Can you be explicit about that? Because the general sense I think many of us have had is that there's a cloud of objections without really getting down to the kind of specificity that would imply an intent to work something out.

MR. AITKEN: Well, if I may, Dr. Collins, the employer community has worked with the Senate and both Republicans and Democrats, as well as in the House, as well as with other stakeholders, and have been fairly consistent in where we've raised our concerns. I would concur with you, I think the Senate did a very good job in trying to meet a lot of the issues that have been raised by the employer community with regard to that.

There have been some continuing lingering concerns with the genetics bill, and we've seen this -- particularly a state law, and Jane mentioned, as well as Joanne did, about some of the state law efforts. One of the concerns with S. 1053 is that there isn't a sunset provision, and that is because we've seen -- our experience has been with the 30-some state laws that have been enacted that the states have had to go back and revisit those statutes because they found problems with how they've interacted either with the health care plans or with the employer state laws, and it's caused problems and conflicts.

One of the things that's been advocated is a sunset provision to give an opportunity to review the implications, and as genetic advances are made and more discoveries are made, that there may be things that need to be done to modify that legislation to look at that issue.

Second, there's no federal preemption in S. 1053, meaning that the federal law does not trump the various different state laws that are out there, and there is a concern that you could have situations not just within the employment side but also with regards to the health care plans where plans might be complying not only with the federal statute in addition to the state statute and have conflicting laws with regards to that. That's another aspect that's been raised.

It's certainly not my area of expertise, but in talking with others, there's the definition of "family member." Many have felt that it's an overly broad term as described within the setup bill, although it's better than earlier versions. But there is a concern that it's not narrow enough. I understand there are different trains of thought out there within the geneticist population, but those are some of the main concerns that have been raised.

I will say that we have raised these concerns with supporters of 1053 and we've asked them to try and go back and address those, and as yet we've not heard back. EEOC, in fact, shepherded

through an informal meeting with stakeholders on all sides back in April, and it was specifically asked of the others to come back and try to address some of those issues, and we're still waiting. The employer community has not put its foot down and tried to destroy the genetic discrimination bill. We've worked very closely with all on this.

DR. COLLINS: So can I then ask you directly, is it a goal of the SHRM to see effective federal legislation pass to prevent genetic discrimination in the workplace?

MR. AITKEN: I think that we would certainly be supportive of that. The concern becomes -- you remember who we represent, as well. We're giving our employers another cause of action to have to deal with, and you're never going to have employer groups standing around the table supporting that type of effort. I think, frankly, that the least that you would see is that we wouldn't oppose that effort, and we didn't oppose S. 1053. We continue to work with the Senate in crafting that in that effort.

MS. MASNY: I have Cindy, and then Ed.

MS. BERRY: Perhaps Dr. Licata can help with this. A point of clarification, because I was wondering about the plans that are apparently exempt from HIPAA. I was wondering if you could help us clarify that. Are ERISA plans subject to HIPAA, or are they not? I thought they were but have heard that perhaps some may fall under some sort of exemption.

DR. LICATA: Right. There is an exemption, and it's basically these smaller self-insured plans that fall out. I think this is kind of relevant to understanding what ERISA does, because ERISA does have some federal preemption. In addressing the issue of this concern about having to deal with lots of different state rules or different rules even within federal guidelines, what is intended by S. 1053 is it creates a threshold. So basically, if you have a state law that is more strict, like New Jersey, those are enforceable. But everybody has to come up to at least one consistent national level, and what that national level is is that these same standards that are currently applied would generally now apply to all individual plans and to all group plans.

The thought is that if you're covered by ERISA, once you're in the federal legislation, you do have preemption, and this is one of the issues that was discussed before Congress as well. Another aspect of this is understanding who is covered and who is not covered. There was a great debate about the concept of the family members and so forth, and the compromise that was made in the Senate there was to focus on a definition of the use of genetic tests instead of getting all hung up again on this definition of genetic information, and also to include people that might not necessarily have a blood relationship because they're covered by the plan, such as the gentleman was explaining with his adopted children.

When a claim gets made against a plan, against a particular member's plan, then you have to go into the explanation of whether this is a relevant risk to this person or not. So the burden has now been shifted. That's part of the compromise to protect the individual member or beneficiary so that they can maintain their insurance and not feel threatened while that's being sorted out and that there's not a limitation on the blood relationship there.

I think everybody took very seriously the concerns of the employer and was trying to make it simpler and to address these concerns by saying we're going to do some risk shifting here. We're going to be concerned about protecting the individual's rights, but at the same time we're going to give more certainty to the business in knowing that they're going to apply to a generalized federal standard that is a threshold, and it will call now all group plans in and all individual plans in.

DR. McCABE: Thank you, and thank you for appearing before us. First I have a comment and then a question.

I just want to follow up on Agnes' question to Mr. Aitken, where he said that he was not a spokesperson for the National Chambers of Commerce. I would just like to point out, then, that the National Chambers of Commerce basically gave this committee a response of no comment when we asked them to appear before us, and any of us who have had media training know that no comment implies a concern about guilt.

(Laughter.)

DR. McCABE: So I would just like to point out that I'm not judging the National Chambers of Commerce, but they did respond no comment to us. Perhaps they will wish to continue that in the future, perhaps not. That will be their choice.

I would be insulted, by the way, except for my interpretation of their response.

The other is a question for Mr. Aitken. First, perhaps you weren't in the audience this morning for the initial panel. If not, then I would encourage you to read the testimony of those individuals who appeared before us in the initial panel today, because it was really quite powerful.

You said that there was no evidence of widespread use of genetic information in employment discrimination, and yet in your presentation you raised a number of examples of potential for genetic discrimination, like the water cooler scenario and those sorts of things. You also said, or I have a question. If there's no evidence of genetic discrimination, then why is there the fear of widespread litigation around an issue which doesn't exist? Your testimony seems somewhat internally inconsistent to me, and I'd like you to clarify it for me.

MR. AITKEN: Sure. I think there's a difference between the actuality of cases being brought and fear, and I did not hear the first panel. But even hearing my colleagues on the second panel talk about was the fear of the discrimination. I do not discount that, nor does the SHRM. We certainly heard that, but we're not hearing from employers even wanting to have this information. I know that the EEOC has had very few cases brought under the ADA in terms of a discriminatory content, and I don't have the exact figures, but I know on the 30-some state laws that are out there, there have been very few cases that have actually been brought.

I guess our concern about the litigation has to go back to the Title VII, the Americans with Disabilities Act, the Family and Medical Leave Act, and the other litany of employment legislation that employers are required to comply with right now. What we've seen sometimes is even the laws that are well intended, we don't take exception to what the intent of folks' efforts have been to try and craft legislation to prohibit genetic discrimination. But our HR professionals deal in the land of Murphy's Law and the law of unintended consequences. Often what happens is it's not the employees -- the employers get faced with frivolous lawsuits. If a law is not carefully crafted to address some of these issues that we've raised, they end up in court. The burden shifts to the employer to prove that just because they had the knowledge that somebody may have a genetic marker, that they in fact discriminated against that individual.

What we've been concerned about is most of the earlier versions of the legislation focused principally on trying to control the information, and our concern is that it's already out there. It's already been required to be out there for compliance with a variety of different federal and state

laws. If discriminatory content, that's something entirely different. If somebody is discriminating on this, on genetics, then that's a different issue, as opposed to the information itself.

MS. MASNY: Thank you.

We do have to move on because we're already behind on our roundtable discussion. So I have to move us on to that because we have only until 1:15 for our particular discussion.