

**Congressional Update**  
*Jaimie Vickery*

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DR. TUCKSON: We are very happy that we have been able to be joined today by Ms. Jaimie Vickery, who is a legislative assistant from the Office of the Honorable Judy Biggert, U.S. House of Representatives. As you've heard, Representative Biggert is the original sponsor of the House bill. It is very timely that we hear some perspectives sort of from the Hill and how you all see where the status is.

Feel free to present either from your chair there or from the podium. Thank you very much for taking the time to join us.

MS. VICKERY: Good morning. Thank you for giving me this opportunity to speak. I'm very pleased to be here this morning. It's very nice to be able to get off the Hill. I feel like I've been chained to my desk and forgot what fresh air and sunshine feels like.

Let me warn you, first of all, I'm not a scientist. There is a reason I was a political science major and not a hard science major. So I'll leave the nitty gritty details of genetics to all of the scientists and researchers in the room, and focus on the political efforts to prevent genetic discrimination.

Now, as you know, my boss, Congresswoman Judy Biggert, along with Louise Slaughter of New York, Bob Ney of Ohio, and Anna Eshoo of California, has introduced H.R. 1227, the Genetic Nondiscrimination Act of 2005. Congresswoman Biggert sits on the House Science Committee, where she is the chair of the Subcommittee on Energy. This is the subcommittee that has jurisdiction over the Human Genome Project.

Now, I don't have to tell you all that the sequencing of the human genome was one of the most significant scientific breakthroughs of the past century. The implications of this breakthrough are mind boggling. Because of the genetic testing made possible by this discovery, individuals can, for the first time, know their risk of developing more than 1,000 genetic disorders.

They can adopt better habits such as exercising, eating better, going to the doctor, or going to the gym to lessen the impact of their condition, and they can mentally prepare themselves and their families for what may happen down the road.

However, as we have heard today, the ability to predict disease through genetic testing and family history opens the door for discrimination, particularly in the employment and health insurance fields. When individuals are afraid that this information will be used against them or their families, they will not be tested. The research is not being used to its full advantage.

Some people have said that they wouldn't want to know. No doubt finding out that you or your child could suffer from a debilitating disease could be disconcerting. But this should be an individual's choice to make for themselves. The fear of losing their job or their health insurance shouldn't be a factor.

As we have just heard, existing laws, including ERISA and HIPAA, are unclear on the topic, and are really no more than a patchwork. To be frank, they're Swiss cheese. This means that in order to protect an individual's genetic privacy, we have to enact legislation specifically prohibiting differential treatment on the basis of genetic information.

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That is why it is so important that we get H.R. 1227 passed. Opponents of the bill say it's not necessary, that's it's a solution and need of a problem. But no one should lose their job or their health insurance before we enact legislation.

Specifically the bill prohibits employers or health insurance from making employment or coverage decisions based solely on someone's genetic information. The bill is very, very similar to the bill Louise Slaughter introduced in the last Congress. However, we realize that given the current political climate, a bill introduced by a Democrat probably wasn't going to go very far.

So she and her staff very graciously let Congresswoman Biggert take the bill. In keeping with this current political environment, we made a couple little changes to make the bill more business friendly, and to make it easier for Republicans to get on board. None of these changes substantially change the bill or take away any of the enforcement mechanisms.

The bill now places limits on the amount of damages a wronged employee can seek based on the size of the company, and contains protections against frivolous or opportune lawsuits. It also includes so-called water cooler gossip. If your office is anything like mine, everybody knows everybody's business, and it is not always true. There is nothing that your boss, as much as they try and control it, can do about it.

This is the exact same legislation that passed unanimously in the Senate, and is strongly supported by the Bush administration. So what is happening with the bill? Unlike the Senate bill which only went through the Health, Education, Labor, and Pensions Committee, the House version has been referred to three committees. Education in the Workforce, Energy and Commerce, and Ways and Means.

Because the nondiscrimination provisions apply to the Medigap insurance people can buy to cover what Medicare doesn't cover, Ways and Means needs to sign off on this bill. One tiny provision in the bill, and it goes to a separate committee.

However, the ranking member of the full committee, Charlie Rangel from New York, and the chair of the Health Subcommittee, Nancy Johnson from Connecticut, are both cosponsors of the bill, so I don't think we'll have any problems in Ways and Means.

I'll be honest with you. Like I said before, there are some in the business community that are opposed to this bill. Although the Education and Workforce Committee held a hearing on genetic nondiscrimination in July of last year, nothing more came out of it.

These business groups are afraid that this new legislation will set up a new regulation on how they do business, or that it will create an administrative burden. Let me assure you this is the last thing we want to do. Ms. Biggert is a member of the Education and Workforce Committee and a member of the Employer/Employee Relations Subcommittee that has jurisdiction over this bill.

She understands these concerns. We're trying to work with these business groups to address their concerns without taking away any of the guarantees of genetic privacy. Although these groups are still opposed, they're not nearly as adamantly opposed as they once were. So I'm cautiously optimistic that they will adopt a neutral stance and not work against H.R. 1227.

Right now we have 105 cosponsors. When you consider that there are 435 members of Congress, this means we've got nearly one quarter of them on this bill. However, the problem is that a

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majority of the cosponsors are Democrats. We've got 74 Democrats to only 31 Republicans. In the Republican controlled Congress, that is not all that helpful.

This is a bipartisan bill, and we need the co-sponsorship to reflect this fact. So right now we are focusing on getting Republican cosponsors. For a lot of members, it's a good way to show that they are pro-patient and pro-medical research without having to deal with this sticky stem cell issue.

It is also a good way for members with large genetic labs or biotech companies to show their support for their constituency in their districts. Ideally you'd hope members would get on this bill because it is a good bill and it's the right thing to do, but in reality, you've got to sell a bill as what it can do for a member. That's what we are trying to do.

Here is where you all come in. Now, I know it's sort of a delicate position because working for the administration, you can't really lobby for the bill, even though the White House does support it. I'd encourage you to let agency leadership, including Secretary Leavitt, know how important this bill is, and encourage them to encourage House leadership to get the ball rolling.

There has been two statements of administrative policy in both the 108th and 109th Congress, but we haven't heard much from the White House other than that. They're not getting real involved. So anything that the administration can do to sort of kick leadership in the pants on this would be very helpful.

As you know, this issue has been around for quite some time. In fact, Congresswoman Slaughter has introduced this bill, or something very similar to it, in every Congress since 1997. This is the furthest we have ever come in the legislative process, but we've still got a long way to go. I'm confident this is the year we can finally do it and protect individuals' genetic privacy. We all know that these provisions are long overdue.

I know you've got a lot to fit in today, so I'll wrap it up. Once again, thank you so much for this opportunity to be here with you today, and thank you for all that you've done on this issue in bringing it to the forefront. I look forward in working with all of you in getting this bill passed.

Thank you.

DR. TUCKSON: Well, thank you very much. We very much appreciate your taking the time, and also your offer that we'll be able to be connected to not only you, but the Congresswoman as well.

MS. VICKERY: Yes.

DR. TUCKSON: I think now with that, if you could still please join us at the table still, we would appreciate it.