

Update on the Genetic Information Nondiscrimination Act
Sharon F. Terry

DR. TUCKSON: So, Sharon, take it away.

MS. TERRY: Okay. This will take about two minutes. So you don't have to worry I'm between you and leaving.

Of course, as you all know, things changed with the November election. We were working toward getting the bill on the docket and on the floor before the November election, and we failed to do that largely because of the chairman not putting the bill forth, despite the fact that I think we're up to about 246 cosponsors right now. So we've done a great job, even though in other years we've had 260. That was mostly Democrats. This is almost evenly split, Republicans and Democrats.

With the change in the Congress comes a lot of changes overall, leadership of the committees, et cetera. We do have right now what's called a lame duck session. If I had to predict, I would say we have about a 10 percent chance of passing this bill during this session. So it's not completely dead. It is possible that the Republicans would decide that they did want to put this forward now. It's also very possible they'll decide not to. They have a lot of things they need to do, things like funding the budget and other things that are important in terms of resolutions.

Then our work begins with the 110th Congress in January, new chairs, new committee structures. I just heard today that Senator Obama is on the HELP Committee, which will be helpful to us in the Senate. We have to reevaluate the House and look at who should be the chief cosponsors again, et cetera, have the bill dropped again in both houses, and work again.

This is Genetic Alliance's 11th year trying to lead this cause. We're hopeful. And I say that every single time, but I have seen politics at its best with this bill, and that's basically all that's keeping it from being passed, is a lot of politics.

DR. TUCKSON: What is the bill, by the way, that's in play now?

MS. TERRY: The bill is H.R. 1227.

DR. TUCKSON: And the sponsor as of today is?

MS. TERRY: Is Mrs. Biggerts, Mrs. Eshoo, and Mrs. Slaughter. Mr. Ney was a sponsor, but he's not a sponsor anymore.

DR. TUCKSON: By the way, Sharon, 11 years you've been at this, and thank God for you in what you're doing. It's extremely appreciated.

Do any of the members have questions? Yes.

DR. EVANS: What committee is responsible for it?

MS. TERRY: Three committees. That's part of the problem. Ways and Means, but a very, very small piece and they signed off long ago, and then Workforce and Energy and Commerce are the other two committees.

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So there's an insurance piece pretty much signed off on and an employment piece that you all have been trying to help us with with your production of the phone book a year or so ago and some other pieces. Those two committees we've spent a lot of time talking with. We've spent a lot of time talking with the business community. I think we moved the ball far this year. So I don't think it was all for naught. I think we have gotten a lot of consensus around what needs to be done.

DR. TUCKSON: Cindy?

MS. BERRY: Sharon already knows this, but just for everyone else's benefit too, the Democratic committee staff of the committees that have jurisdiction over this have indicated that genetic nondiscrimination is one of their top priorities. It's important because, while this olive branch and outreach and touchy-feely, good stuff is going on, it probably won't last. But while it lasts, they're going to be affirmatively looking for bills and issues that have strong bipartisan support, and this is one of those areas that the Republicans and Democrats can hold hands and sing "Kumbaya" and actually pass in this honeymoon period, however long it lasts. So I'm encouraged by that statement from some of the key staff where they indicated this was one of the ones that they wanted to kind of extend the olive branch on and hope to get some action moving in the next Congress.

DR. TUCKSON: Terrific.

Peter?

MR. GRAY: Sharon, just a question. When you were here last time, you were here with the Chamber. My question is do you have a sense as to whether it would be the Senate bill that was passed by the Senate unanimously that will sort of be the template for the bill that does get sort of reintroduced? And where do things stand now with sort of the changes to the bill that you and the Chamber had discussed?

MS. TERRY: So we did discuss some changes that we never made. So H.R. 1227 is still on the table, which is Senate bill 306. My expectation would be that Senate bill 306 would be introduced.

It will be interesting -- and this is a completely academic exercise at this point -- to see if it will pass the Senate 98 to 0 when the Senate knows that the House is controlled by Democrats. The other thing we've heard is that the House is more conservative, despite the fact that it has more Democrats. The moderate Republicans are not there anymore that were there, and many conservative Democrats got elected. And something called the Blue Dog Democrats are alive and well and very interested in being fairly conservative, fairly aligned with business, with insurance, et cetera.

The future is not easy. So where I think some people may have naively thought that if the House switched leadership, we would sail through, I think we're still going to have a lot of work to do.

DR. TUCKSON: Other questions? This is terrific.

(No response.)

DR. TUCKSON: Well, Sharon, keep at it. My goodness, don't get tired.

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(Laughter.)

MS. TERRY: I'll be back next year.

DR. TUCKSON: I don't know whether to feel good, bad, nervous, or anything. We'll just play it out.

All right. The floor is open for any last comments from the committee. Yes, please, Emily.

DR. WINN-DEEN: I just want to say, as the member emeritus here in an ad hoc status, it's once again a pleasure to be here. And I encourage the Secretary's staff to send all of the new Congresspeople coming to Washington a "welcome to Congress" packet of the genetic discrimination pack that went to everyone else that was in Congress in the last session.

DR. TUCKSON: Wow. So we have to ask the Secretary to do that. Right? We can't do it. Okay. Well, actually that's pretty cool. So there are people here who can hear that.

Now, one of the things I do want to end up on -- let me ask, is there anything else that the committee has?

(No response.)

DR. TUCKSON: I do want to end up where we started. Anand, I wish you would take back again to HHS Central and to your colleagues at the Secretary's office that we have duly noted, on more than one occasion during the course of this meeting, the interest on the part of HHS at the Secretary's office that we have not had before, and we really do hope that you all will continue to be attentive, taking leadership, bringing our things back, given that so many of our interests are aligned. Well, I mean, they are always, but really aligned right now.

I think the comment from Emily was actually a pretty good one. It's really a nice thing to do. So it would be a nice gesture to do that. So thank you.

Thank you all for a terrific two days. I appreciate it. See you next time.

Thanks to the staff.

(Applause.)

(Whereupon, at 3:11 p.m., the meeting was adjourned.)