

**Update on the Status of the Genetic Information Nondiscrimination Act of 2005
(S. 306/H.R. 1227)
*Sharon F. Terry, M.A.***

DR. TUCKSON: Sharon, do you want to come forward and give us a sense of the status of the genetic information Nondiscrimination Act of 2005, S.306/H.R. 1227?

MS. TERRY: Sure. Christy and I switched order because she said she would show there was a fire, and I will show how maybe we can put it out.

I'm basically representing the Coalition for Genetic Fairness as their chair. This is a familiar timeline that many of you have been involved in as we've gone through this, various events that have occurred along the way since 1996 regarding genetic information on discrimination, and you've had much testimony and many individuals stand here and give you a description of various things, and you yourselves have engaged in a number of things, including the letter and DVD to the Secretary last May.

More recently, and again most of you know this, in the 109th Congress we had President Bush say that he supported this fully. It passed. 306 passed unanimously in the Senate for the second time in a second Congress. 1227 was introduced and referred to three committees in March of last year, and today there are 170 sponsors. Actually, that's of yesterday, so I'm not sure this is correct today, 94 Democrats, 75 Republicans, and 1 Independent. Those numbers are fairly important because we've been working fairly hard and steadily on increasing the number of Republicans. These were fairly skewed numbers when we first started out.

So the coalition has really been working on supporting Representative Judy Biggert from Illinois, Anna Eshoo from California, Ney from Ohio, and Slaughter from New York, and increasing the Republican sponsorship. So our grassroots work has primarily been on finding Republicans who would sponsor this legislation. We've noted almost a 1-to-1 correspondence. In other words, if we go to see a Republican, usually he or she signs on. It's really a matter of them just getting this particular piece of legislation on their radar screen.

There is some indication that if we could level out those numbers, make them approximately equal, then perhaps the committees would start to move the legislation forward, assuming of course that many Democrats would sign on right away, and we have in fact been holding off Democrats and believe that we're well over 220 when we do a count of who would sign on.

Another major activity of ours has been engaging the Chamber of Commerce, the National Association of Manufacturers, and the Society of Human Resource Managers in a dialogue. As some of you may recall, some of those individuals have presented here, in fact, and have answered questions for you. We've basically engaged for many, many months with some of the steering committee from the coalition working to find some commonality, some common ground, and had very productive and good discussion with them such that we feel that we are, in fact, moving toward a position where we might be able to give the Congress an indication that we're really ready to see this bill move and that there has been substantial dialogue that has established some common ground.

The other thing that we're doing is working with companies and trade associations. So some of you know, perhaps, the IBM established a company policy last fall after much looking at this bill in many ways, decided not to endorse the bill but to endorse the principles company-wide and really took a very strong stance, including announcing it internationally, giving their company

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employees education around the issue, and even holding a national teleconference that Tim Leshan from NHGRI participated in, giving privacy officials from companies all around the world information about what IBM did and why they did it.

The other piece of information that's important here is that more recently the biotechnology trade association industry organization has signed a letter and sent it to Anna Eshoo saying that they support this legislation, and that's fairly significant since, of course, the companies that would most benefit from this legislation are members of BIO and PhRMA.

So when I look at what this august body can do, and I know that you have done a great deal, and I certainly wish you could do more but I also know that your charter is limited by what all charters for the Secretary's committees are, so I'm not certain that you can do these things, but here are the things that I would recommend. I would have you request a meeting with the Coalition for Genetic Fairness, the Chamber, and the National Association of Manufacturers. I think it would be very interesting for you to hear from them firsthand what their concerns are with the legislation, because I think they're fairly limited. I think there's some solid basis. I think that while maybe two years ago we would have stood here and said that many bodies aren't really sure that there's discrimination occurring, I think now they're not questioning that we do need this legislation. It's just the precise details that are of some concern.

You could ask the Secretary to invite these same organizations and the White House Domestic Policy Office to a meeting. We've met with the White House Domestic Policy Office. They have said that, again, President Bush is ready to sign his bill as soon as it comes across his desk and that they're supportive of this legislation. So it would be interesting to hear perhaps maybe some more ways that the Executive Office could be involved and could encourage the Congress to move this legislation.

To remind the Secretary that as he works with Congress on getting the genes and environment initiative funded, that he should explain to Congress the importance of H.R. 1227 and the relationship, and I think Christy's data illustrates that very well, and I'm sure that perhaps he has some sense of the correlation between those two things, but given the large number of bills in Congress all the time, I think it might be a good idea to make it explicit in some way.

To make a clear and strong statement from this committee expressing concern about the chill on research and its impact on the investment made for biomedical research in this country, including the trend toward offshoring clinical trials by pharma and biotech companies. I think that for me as a patient advocate and the individuals I work with, that is of most concern, that we are seeing the kinds of things that Christy showed in her data. We're not capitalizing in this investment that's been made, and it's really critical for us to bring this to the next level, and we're not going to be able to do it until this simple piece of legislation is passed.

Send the Genetic Discrimination Report, what you called the phone book, to the new chairman of the Education and Workforce Committee. He is the brand new chairman and would be very interested, I'm sure, in receiving your report. Then if you as individuals as members of this committee -- I know that while you're here as members and representing this committee you cannot do this, but when you're on your own time, so to speak, and not representing the committee but representing the organizations you come from -- could work with your constituencies as knowledgeable experts around this issue to move them to support the legislation, that certainly would be very beneficial as well.

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And then again, the coalition is made up of about 140 organizations. Many industry groups have signed on with us, as well as certainly all the advocacy organizations and health professional associations, hospitals, clinics, et cetera.

That's all I have.