

**Update from Key Stakeholders on the Status of the Federal
Genetic Information Nondiscrimination Legislation**

Michael J. Eastman and Sharon F. Terry

DR. TUCKSON: All right. Well, thank you again, Scott. So we'll get an update on this from you as it goes forward.

Now to the genetic discrimination section.

We're going to get an update from key stakeholders.

As you know, we have been actively interested in this for a long time. One of the things, and I will not get a chance to spend a lot of energy today because of time on the meeting that I had representing you in front of the director of NIH but I will say, just as a general statement, that I could not be more pleased by his interest in what you are doing. I found him to be exceedingly responsive to our agenda. He was excited, enthused, fully attentive and aware.

I will say that Sarah is doing a great job in her own right and with Lana Skirboll, who was there as well, and they really were up on it.

So I just want to--and I'll find another time, hopefully, to be able to give you all the things that he said but he had a lot of ideas about ways in which we can enhance the value of our work. He, in fact, has taken assignments on a couple of things where he personally wants to do more to ensure that our work is getting the implementation and the visibility within the department that it deserves. So he has got a whole bunch of strategic things that he wants us to do and what he suggests that we might consider, and things that he wants to take the ball and run with.

One of the areas in which he was most engaged was on the issue of discrimination, genetic discrimination, and he has--he is going to give us a report back that we will distribute to you--in terms of the things that the government has done in this regard. And he, personally, as a result of our pushing forward in terms of our statements to the secretary, which have then been translated into a presidential directive of support for getting this legislation passed, and then he has then emboldened, and he started ticking off a list of the members of congress that he has met with to push this forward so what he's going to do is make sure we know those things that he has done and that's a report that's coming from him.

So I just wanted to be real clear that we were sort of wondering how much stuff the administration was doing based on our report. He made it very clear that our reports are well known in the administration, that they have acted on those reports, and that he and the secretary have authority and empowerment to go forward and to try to help move this stuff forward so he was very engaged in that regard.

Well, we have been really pleased to have had a chance over time--I'm going to try to bring the new members up-to-date--to have a chance to have a number of conversations from the advocacy community, the business community, and the health insurance community. And we've been able to sort of have conversations where we were sort of--of having a chance for common dialogue inform behind the scenes and individually and one-on-one as these very responsible organizations have moved forward with this agenda.

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I am particularly pleased that Mr. Eastman, Michael Eastman, Director of Labor Law Policy at the U.S. Chamber of Commerce, is here and that Sharon Terry, CEO and President of the Genetic Alliance, is here on behalf of the Coalition for Genetic Fairness.

I think that what you clearly have seen in all of this is a really, I think, noteworthy example of constituency groups being responsible, willing to talk with people who share perhaps some differences, willingness to discuss those differences in an open and honest way to try to get to solution. I think that's really, really, really noteworthy and so I commend both of you for your leadership and your willingness to be collegial in trying to reach a consensus of opinion, and you deserve to be noted therein.

Let me ask you, either one of you which wants to go first, and let's see where things are today.

MR. EASTMAN: Thank you, Mr. Chairman.

I would like to do two things in my remarks and then turn it over to Sharon, and then open it up. The two things I want to discuss are, first of all, how the Chamber of Commerce--or the fundamental concerns that have driven the Chamber of Commerce in its position that it has taken historically on this issue and, then, secondly, I want to turn the page and discuss common ground and where we are today.

So, by way of background, our position has been that if there is to be legislation dealing with discrimination based on genetic information, then it should be narrowly drafted to ensure that it accomplishes its goals without inviting frivolous or unnecessary litigation or burdensome--undue burdens, excuse me, on employers as they try to implement the new law. So that has been one of our fundamental concerns as we've gone through this process.

Number two is that legislation dealing with genetic information has appeared to be serving a different purpose than traditional civil rights legislation, and let me explain that. From our perspective, Title VII of the Civil Rights Act, the Americans with Disabilities Act, the Age Discrimination Act and so on, were created to remedy a long history of ongoing pervasive discrimination. In this case, it appears to us, that while that may be a concern, the primary purpose is to deal with a fear that people have, a fear that is keeping people from availing themselves of genetic services, genetic tests and so forth. Because those purposes are a little bit different that may mean that some of the ways in which the law is implemented may need to be different as well. So those are two sort of fundamental themes that we've kept in mind as we've looked at this legislation over time.

I should also point out that most of the Chamber's involvement in this issue has dealt with the employment discrimination piece, not the insurance discrimination piece. We do understand from some of our colleagues that there are some concerns with that part of the bill, the so-called Title I part of the bill, but our primary focus has not been on that. It has been on the Title II, the employment discrimination piece.

Now, I don't want to spend a whole lot of time talking about numbers and statistics. I just want to give one example, though, that I think serves to illustrate how the unnecessary litigation is a big concern, and that is with current EEOC statistics on existing civil rights laws. Using last year's data, 2005, there were about 75,000 charges filed at the EEOC. The agency found no reasonable cause in 62 percent of those cases. They found reasonable cause in 5.7 percent. It doesn't add to 100 because there were settlements and other things in there. So I think that, while not conclusive, certainly that's evidence of the scope of the problem that's out there and the amount of

cases that are filed without merit. Keeping in mind that employers spend somewhere between, I think, \$30-50,000 to defend the run of the mill case, it's a significant burden, and that's what we're concerned about.

I just want to give a few examples of our thematic concerns we've in the past before turning to where we are now. Our three, I would say, fundamental concerns have been dealing with the issue of damages and what the appropriate scope of relief is for true victims; with whether or not the bill has preemption of state law; and, third, the extent to which the bill goes beyond discriminatory conduct and addresses the collection and flow of information that employers have. So those have been our three thematic concerns. There are many other serious, though more narrow focused, concerns that we've had as well.

Turning the page, I'd like to talk about where we are today. A little over a year ago, maybe a year-and-a-half ago, when the Genetic Alliance asserted more leadership in the Coalition of Advocates for Genetic Information Nondiscrimination Legislation, we found things had changed, frankly, in the environment in which we'd been working. We found it much easier to talk to proponents of legislation and we sat down in a series of meetings, I would say, over at least a six month period. Long, long meetings where we tried to shut out all preconceptions and just talk about issues and concepts, and we started very big and we got down to very detailed, just trying to understand where each other were coming from, and we made great, great progress, I think.

While we do not have a detailed legislation before us today, we do have common ground principles that we agreed on and I'm happy to share those with you today. They fall into eight categories.

The first category is "fear" and that we recognize that many people are not availing themselves of new technologies or treatments in health care or participating in scientific or clinical studies because they fear being discriminated against based on their genetic information. We also recognize that employers, employees, health care providers, patients and others fear the unknown. None of us know what new treatments may be produced by the burgeoning genetics field and we don't know what the consequences of new legislation will be, including the potential for new unforeseen litigation.

Category two is the "Standard and Scope." We agree that legislation, which would be enacted to create a single national standard with regard to nondiscrimination, providing the same protections, obligations, remedies, enforcement and exceptions from state-to-state, the scope of the law should focus on discriminatory conduct, for example, broad employer testing, and not the flow of HR information or unrelated processing of health care information.

Number 3: Enforcement process. A particular process for an individual bringing forth a claim should be filtered in some way to weed out un-meritorious cases. Now one such model would be the current Title VII model, a three part remedy--well, excuse me. The current Title VII model in which the EEOC acts as the filter. It reviews the case, tries to get conciliation and then that does weed out a number of frivolous cases, and then the individual can proceed directly to court if they wish.

Under "remedies" we envision a three-part process. This is number four, "Remedies." Including injunctive relief, equitable relief and additional remedies for egregious cases. The law should offer basic protections that will allow individuals to receive genetic services without fear of discrimination and that will minimize challenges for employers in implementing and administering new protections.

Legislation should not invite non-meritorious or frivolous litigation. It should encourage protection and not litigation. One possible option we discussed but by no means the only possible option is creating a mechanism so that the EEOC could provide immediate expedited injunctive relief and equitable relief, make whole remedies incurred through loss of work, health care coverage, et cetera, in most cases, and in the egregious case an individual could pursue additional remedies.

Category five: The "Definition of Family Member." We believe that family members covered under legislation should be limited to three generations, grand-parents, parents, siblings, spouse, children, including adopted children.

Number 6: "Permissible Exceptions and HR Compliance." Inadvertent collection of genetic information should not be the focus of legislation. An employer should not be required to violate an existing law or be punished on occasions when it is reasonable for the employer to take action based on the employer or prospective employee's genetic information. For example, compliance with other laws such as the Family and Medical Leave Act, employment benefit counseling, wellness programs or direct threat situations.

Number 7: "Sunset Clause and Independent Study Commission." A new law enacted today could present unforeseen negative consequences in the future for individuals, employers, health care plans and participants. As such, we believe that an independent review of any new law should take place within six years in favor of some sort of truly independent commission to examine all aspects of the law. If legislation is kept narrow and there is a truly independent commission, we do not believe there's a need for a sunset clause in the legislation.

Finally, number 8: "Communication and Education." An education and communication campaign will be necessary to help carry out the purposes of the law, reducing fear and educating constituents about the law. The campaign should be aimed at employees, employers, health care participants in plans, and focus on individual rights, responsibilities and obligations.

That's where we are in our common ground today and I'm going to leave it there and turn to Sharon, and then we'll have some discussion.

MS. TERRY: And I actually am going to keep my remarks very brief because, as Mike and I have been doing this together, sometimes I do all the talking and sometimes he does all the talking but neither one of us needs to talk much if the other has presented these points.

We've been able to present these to Congresswoman Biggert, who then decided that we were really ready then to meet with the Ed and Work Force Committee staff, which we did. We had a very good meeting with them. They are ready now to sort of go into the weeds and look at what do these common ground principles mean for this legislation and how can we move this piece of legislation forward. So we continue to work together, albeit with less intensity because we certainly did have some intense months of locking ourselves up with each other so that we really did understand where we came from and you can see we've come a very long way to a very common place.

So I'll leave it open to your questions.

DR. TUCKSON: My gosh! Kevin.

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DR. FITZGERALD: Just a quick question. Based on these eight foundations of your common ground, how close to these foundations is the current legislation do you think?

MR. EASTMAN: Well, I would say that we certainly kept in mind the current legislation as we came up with these common ground principles. Some of them are a direct response to what's in current legislation. Some of what's in current legislation directly addresses some of these problems. For example, an exception for Family and Medical Leave Act issues.

I want to keep the door open in terms of what the best way is for legislators to proceed. Some of these provisions will be difficult to draft, I have no doubt. Some of what we have talked about in terms of damages is not quite equivalent to some of the other laws out there and it's going to take some bright people some time to work through. I hope that they begin doing that and we'd be happy to be part of that.

Other provisions, I think, are relatively minor changes and could be done quickly.

DR. TUCKSON: Good. A good question.

Cindy?

MS. BERRY: I was wondering if you had gotten any commitment from the committee and/or from the leadership in the House about moving the legislation. Specifically, I wanted to hone in on Health Week, which was supposed to have occurred in the House--was it--last week. It kind of fizzled. I think they're talking about doing another one since the first one was such a resounding success but I think part of the new Health Week will be taken up by the Health Information Technology legislation, which is critically important and a lot of what we do and what we're talking about. I can see where there's a good linkage between HIT and this bill, and I was wondering if it had come up that it could be potentially a candidate for that new Health Week, whenever that is.

MS. TERRY: So yes to all of that. It was supposed to be part of the first Health Week perhaps. I have learned from my incredibly naive position that this is very, very complicated. You know that old thing about it's like making squash or not squash--

MR. EASTMAN: Sausage.

MS. TERRY: Sausage, yes. It's worse than that. So we are working on a number of fronts to move this forward so we're working on the number of co-sponsors. We're up to 208. That's keeping the democrats that want to get on off so that we keep the balance between republicans and democrats. This past week we faxed 120 offices. We have another ten visits in the next couple of weeks. So that's one piece of momentum.

The other piece is the committee piece and whether or not they're willing to work it. They so far have not given us a commitment to a date or time. They do understand that both in terms of privacy issues in this nation right now this might be a very good thing to pass, as well as a Health Week related kind of issue. They are certainly very busy with a lot of things and I certainly understand that and we keep bugging them to move this stuff as quickly as we can go.

I don't know, Mike, if you have any other--

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MR. EASTMAN: All I would add to that is certainly we saw a time this year where the committee's activities slowed down around the transition when they got a new chairman this year through the new majority leader challenges. So I think the committee did have a little lull. They're reassessing their priorities and I believe they're now beginning to pick up speed again.

DR. TUCKSON: Great. We have Debra, Francis and James.

DR. LEONARD: Can you explain to me where this legislation is? Is it in one committee or three committees? Does it have to be--it then goes to a House vote but at what point? And then it has to be rationalized with the Senate bill? Or is this the same bill? Can you just give me an update on the legislative process? Also for the new committee members.

MS. TERRY: Sure. This will be definitely the quick and dirty and non-expert explanation. So it's the same bill as the Senate bill that passed 98:0 at the beginning of this session, which was last January, January of 2005. It is a bill that is in three committees. It's in Ed and Work Force, Commerce, and Ways and Means. We've met with Ways and Means. They said, "This really has a very insignificant piece in it that has anything to do with us and we'll sign off immediately once we need to do that." Commerce doesn't seem right now to have too much--paying too much attention to it because of the insurance kinds of problems with the bill, at least the people that we talked to. They pretty much signed off on the bill and said, "It's okay with us. It really is just the work force or employment provisions."

So right now it remains--again, this is a balance that I don't quite understand all the pieces of but the committee that our Congressperson, Mrs. Biggert, has decided to have go first on this, so to speak, is this Ed and Work Force Committee. They'll need to move it. Once they move it, then the Commerce Committee has to take it up, and so does Ways and Means, except that they will probably sign off on it. And then it can go--once it's marked up--go to the floor of the House for a vote. If it substantially changes in that process and it is passed in the House, if it's so very different from the Senate, it has to conference with the Senate bill and they have to make a decision together about what the final signed law looks like. If it passed in its current form, it's the same bill and that should be a very easy process.

And then there are other parliamentary procedure kinds of things that could happen if we had more than 218 republicans, which means then-- Mrs. Biggert is sure that there's enough support in the House--it could actually go to the floor without going through the committees but I hear that that's not a very common thing and that usually the various congress people like to give the committees jurisdiction over what they have jurisdiction over before they move them.

DR. LEONARD: Can this be accomplished in this year?

MS. TERRY: That's a great question and we have, from the beginning of the year, felt like we need to do it today, as in January, so we get more and more worried every single week because we have a very short year. As soon as congress recesses for the summer, they come back and they get re-elected essentially.

DR. LEONARD: And you start all over.

MS. TERRY: There are those in congress who say, "Yes, it could move if it wants to move if the committee chairs decide it's going to move."

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The other alternative is a very sad one for us because you know that we've invested a great deal of energy in this and that is we would drop it in the next congress, and maybe hope that we could get the Senate and House to drop it together, that we could get all these people to sign on again, but the enormous amount--I mean, my feeling is like we've rolled this rock to the very edge of the top of the hill and we just need to get it over. So we're having a Hill briefing Thursday. Mrs. Biggert is going to speak and Joanna Rudnick is going to speak and show her film. We're hoping that will build some more momentum and help people understand why we need to do this now.

DR. LEONARD: Is there anything we can do to help with this process?

MS. TERRY: You have helped a great deal. We have the phone book and we have brought it to about 25 offices physically where we plunk it on their desk and say, "Look at this." We've sent a lot of people to the web site to the testimony that you recorded last year or whenever that was. I think to just keep vigilant-ing (sic) your various communities about making sure that people in your private sector like are contacting their congress people. And then these kinds of things, I think, help a lot because the transcripts and that web cast, and these sorts of thing are very beneficial to point to.

DR. TUCKSON: Thank you.

Francis?

DR. COLLINS: So I just want to really thank both of you for the incredibly hard work you have done, along with many other colleagues, to arrive at what sounds like a real path forward and, particularly, thank Mr. Eastman from the Chamber of Commerce for rolling up his sleeves and trying to figure out what could be arrived at here in terms of a solution that would protect employers against the kinds of frivolous lawsuits that I know have been a concern. I really want to thank the Chamber for deciding to negotiate on this instead of just trying to basically say we don't want to talk about it. So thank you. That's really gratifying to see how far that has come. I know everybody has had to bend a little bit in that regard. I think we're all very anxious now about the waning days in the 109th Congress and how possible it's going to be to get this through.

I guess my question is to what extent are you, in fact, staying in regular communication with the Senate side so that if there are going to be new bits of language inserted into this bill you already have a sense about whether that's going to create another problem in that maybe somebody on the Senate side didn't quite like what you said and then you end up in a conference that goes on longer than our current congress is going to have to resolve this? Is this something that can be optimized a bit by making sure that the two sides of the congress are actually chatting with each other as you're considering doing a little re-crafting here?

MS. TERRY: Francis always asks very pointed questions. So, yes, we have been in touch with staff in the Senate. Ryan Peterson, who is the Health LA for Mrs. Biggert, has also been in touch with those staff. So we do keep in conversation with them. We have, however, not, for example, presented these points partly because, as Mike said, we don't know where this is going to go. There are certain things that are well beyond either his or my group's purveyance and that will be decided by the congress.

We have asked Mrs. Biggert and her office to make sure that she is keeping the Senate side informed and asking for when can we go and do that as well.

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So our hope, too, is that there's no surprise; that the bill passed in the House--let's hope--in the next month or two isn't one that the Senate says, 'Oh, my gosh, this is really completely against what we had hoped for.'

MR. EASTMAN: Let me just add that one of the hardest things you can do is get the House and Senate to talk to each other. It is going to be a challenge. It's a challenge, also, because the Senate has a very clear position which it has adopted two congresses in a row. If the House does something different than--that may present challenges but I have had informal conversations with Senate staff indicating that if the House did something different, they'd certainly be willing to take a look at that in a positive way.

DR. TUCKSON: James?

DR. EVANS: My questions already got answered. Thanks.

DR. TUCKSON: Great. Well, once again I just really think that this is terrific. I'm glad that Debra asked the question what more can we do and I think that it's good to know that again on another issue we did something that added value, both--I left out Julio. How shameful! Please.

DR. LICINIO: My question was partially addressed before but it has to do with some of the limits of the legislation. From Sharon's perspective, do you think that it's too restrictive now or is this kind of completely okay for both sides in the way it stands?

MS. TERRY: So I think if we stay in an ideal world then it's probably not very good for either side but I think what Mike and I and our groups have decided, coming together, was that the world is not ideal and we need to figure out a way to live together well so that we get rid of the fear but don't put too much burden on the employers. So the points that we have come together on, we're very comfortable with on both sides that they take care of what we need them to take care of and we both--both sides can live with it feeling comfortable.

Now, I should also say there are groups within the Coalition for Genetic Fairness who did not renew three years ago to be members of this coalition because they wanted to see much stronger remedies and much stricter provisions in this legislation. They are holding to an ideal that perhaps we should hold to. My group, the coalition, at this point feels it's better to get this practical thing done so we can raise the flag and tell people to go ahead and be tested without fear, and that is a much more practical and important way to go.

DR. TUCKSON: Terrific. I didn't mean to cut off questions. Julio, I'm sorry. Is there somebody else?

MS. AU: What was the decision about state preemption?

MR. EASTMAN: Well, we talked a lot about this issue and we certainly feel very strongly about it but we realize that a lot of members of congress have--in particular, have a strong concern about preemption and they don't like to use the "P" word. So we have come out with a position in favor of one single standard and we've described a little bit about what we think that means but at the end of the day we're going to have to see what congress does with that.

MS. TERRY: And part of our concern there was on both sides there are good state laws and there are poor state laws. There are republicans and democrats who have passed those laws who both feel strongly about that. It really is a mishmash across the states. We understand that, both for

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our members and for employers, one single standard would be a very good thing. And if it was an adequate standard or more than adequate standard then that would be fine. But, also, that it wasn't something that we felt like we could resolve and bring it to the congress. Like the definition of family, I don't think they're going to quibble with us. This definition, I think they would have some problem with us taking the control away from them in terms of that determination.

DR. TUCKSON: Joe?

DR. TELFAIR: I want to again thank you all for the hard work you've done because actually you've answered one of the questions, and Julio asked the same. I was concerned in terms of after this. I have kind of watched this and talked to a lot of people but my concern is that I know that there are people who feel very strongly of saying they want something beyond what it is you are having. I'm wondering do you have--this may be--maybe I'm being optimistic in the sense I expect something to happen. But after the fact, what is your plan in terms of trying to work to bring these other folk back into the fold because the groups that I have seen that they are pretty important to us who work in the field. So I'm wondering do you have some idea, and this is specifically to you, Ms. Terry.

MS. TERRY: So while those groups sort of left probably three years ago or so, my conversations with them more recently, because we work on other issues together, are that they are not opposing now what we're doing. They are just neutral on what we're doing. What they are claiming is it's not a priority issue for them. I think that's a nice way of them being gracious about what we're doing and I appreciate that a lot.

So I don't foresee any problem with working with them, for example, once we develop some kind of education campaign. I'm certain that they'll want to disseminate that information as well. At the same time, would some of them want to mount a campaign later to pass even more stringent legislation at some point? And maybe they would. Again, coming from where I come from, serving 600 groups who serve 1,000 diseases, I keep thinking we have very important things to do and I don't have the time or energy to then go and mount the next campaign but maybe some group would. I also know that it's very hard once legislation is made to change it and I think it won't be practical, and I think they are pretty convinced of that as well.

So I would say it isn't the problem it was maybe two or three years ago, and I think we've all moderated in our views and come to a more common ground overall.

DR. TUCKSON: Well, thank you again. I'm behind you. I snuck around you.

(Laughter.)

Once again, I think that--quite frankly, I think you both deserve, really, a round of applause for what you all have done.

(Applause.)

And we wish you good luck on translating the shared vision and the principles documents and all that into legislation in a timely way but, whatever happens, you couldn't get there unless you did what you have done, and it really is a shining example. So thank you both for joining us. We appreciate it.