

***Update on Genetic Non-Discrimination Legislation and the Activities of the Coalition
on Genetic Fairness
Joann Boughman, Ph.D.***

Now we're going to hear an update on genetic nondiscrimination legislation, and the activities of the Coalition on Genetic Fairness from Joann Boughman. Dr. Boughman is Executive Vice President of the American Society of Human Genetics.

Protection against genetic discrimination is this committee's top priority, as we determined in March, and by previous correspondence with the Secretary. We were encouraged when Senate Bill S.1053 unanimously passed in the Senate last October, 95 to 0. Following the March meeting, we wrote a second letter to the Secretary urging that continued pressure be applied to facilitate passage of this bill in the House.

Dr. Joann Boughman is here this morning to provide an update on the status of S.1053 in the House, and the related activities of the Coalition on Genetic Fairness. Dr. Boughman?

DR. BOUGHMAN: Thank you very much. Each of you in the table folders, and outside, have the list of slides, and we'll go through these slides very quickly, and then I think just get down to conversation and a couple of ideas that people might have.

Don't mistake the bad news slide being blank for the fact that there is no bad news. The bad news is that absolutely nothing has happened in any real kind of way. That doesn't mean there has not been activity, but there has been no real noticeable movement forward.

The good news since the March meeting, is that the session isn't over yet. We still have some time, and we will continue working folks on the Hill in every way that we can. The other part of the good news is that the members will be going back to their home districts, and we may be able to call on people from home to contact and discuss issues with their members.

As Dr. McCabe just pointed out, 1053 passed the Senate last fall, 95 to 0. There were three bills that were brought over to the House, 1910 and 3636 actually formally introduced S.1053, not yet having been formally introduced. Once introduced, HR 1910 was sent to two committees, and HR 3636 sent to one committee. Now, there are appropriations committees that do eventually see these bills on the House side, but the committees listed on this slide are the committees of real action and deliberation for this kind of bill that involves both work force, and insurance issues.

Our plans, or our hopes, have been to in fact get 1053 to committee, and then to the floor, or around the committees and directly to the floor. Another opportunity might have been to get 1019 through some committees so that 1053 could end up, or the wording in 1053, the concepts in 1053, could be the goal of compromise. We continue to believe that it is not useful to have 3636 on the agenda. If you remember, House Bill 3636 is very much a shell bill, and this is not really a Christmas tree bill as it is referred to on the Hill, but this is just a skeletal framework so

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that as it would go through the process, members would get more and more wording on it, and it would be more and more complicated to in fact negotiate this through the process.

We have had several meetings by advocates. We have had multiple meetings with the Chamber of Commerce, and the Chamber of Commerce has not been terribly vocal on this in a negative way. They have made some statements about some definitions in the wording.

We were very pleased, for example, to see a wonderful editorial in the Washington Post by the Insurance Association that said this genetic nondiscrimination stuff is out there. We don't believe that the insurance companies are discriminating, but we don't have a problem with the Congress telling us not to, because we think we don't do it anyway.

So in fact, they basically said in a very positive way, go ahead and pass the bill, we'll deal with the details in some sort of way. We thought that might be helpful and make some movement, but it has not. In the meantime, many of us continue with meetings on the Hill, and with members of a variety of agencies. These meetings are now even broadening. We are not just meeting with staff members of key committee members, we are meeting with staff members, and with members of Congress who are good friends of the staff members, and point blank asking them to nudge their friends who are in the right positions to get some of these things going.

We also continue to work on the leadership in the same kind of way, every opportunity any of us has to make that comment to any of the House leadership or members who have influence with the House leadership. Let me give you the kind of example beyond the formal meetings that we have.

I had been at a couple of events where Representative Chris Van Hollen from the District here in Maryland that represents a significant number of scientists, and FASEB is in his district as well. My conversation centered around our frustration on genetic nondiscrimination. He agreed with me, and basically I said, let's just not get frustrated anymore, it is time to get angry, it is time to really get upset about this and move forward. So those are the kinds of changes that we are trying to make with our friends that may have meaningful positions.

Since the March meeting, we have had a letter from distinguished scientists sent to the leadership. There have been a series of blast emails that have gone out via CapWiz and some other venues, to allow letters or emails to go to members. For example, I know from the American Society of Human Genetics, when we sent out our blast email encouraging all of our members to email their members, there were 1,100 emails that were received within about a 96-hour, or 92-hour period of time.

So in fact, we've had some of these waves of activity, and those were only the ones that I could count, and other organizations had some of those activities as well. When 1,000 or 2,000 emails show up on the Hill in a two or three day period, what basically happens is the staff members must take notice of this. When that level of activity happens, they must report that to their

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Congressman, and then the discussion goes on in the halls, which may be another way.

We have also prepared a one-pager of information from geneticists that we have given to the Coalition for Genetic Fairness. We are still working on some more good stories to get out there as well. We are also asking for more follow-up contacts by individual constituents.

Additional strategies that we would encourage everybody in this room to put forward are additional personal discussions with members. Maybe we'll just be able to wear them down. If we can't get them excited about it, maybe we can at least wear them down. I know that you can hear the frustration in my voice on this.

We are going to be continuously requesting personal contact by constituents, especially when the members are at home during breaks, and encourage strategic contact between members and leadership. What we have got to do is keep the Genetic Information Nondiscrimination Act on the agenda. As you all are keenly aware, there are many other things on the agenda, and the strategy that we just have to keep putting forward is that this issue, while maybe not as big, or as front page as many of the international, or even other national events, it is still the right thing to do, and this is something that they can do for the American public.

Hopefully by coming today and venting some of my frustration, at least among friends and allies, we can state a renewed commitment and gain encouragement from each other to try and move this forward. At that point, I'll be happy to answer questions. There are other members in the audience who have been at some of these meetings and have met with some of the members of Congress.

I would ask if any of them have specific comments, just reiterate the fact that while on the one hand, it is appropriate for us to continuously recognize that this is not the most important item on the agenda, and that we do have a special interest in this, and it is not self-interest. It really is a bill for the people out there, and to pass this bill, everybody could go home with a win.

DR. McCABE: Thank you very much, Dr. Boughman, and if you could join us at the table perhaps for this discussion.

While you are doing that, I'll just remind everyone that government employees and special government employees, and all of us on the committee, while we are acting for the committee, are special government employees, so we are precluded from lobbying. Therefore, it is just important to note that this is an update from ASHG, and represents the views of ASHG and the coalition. Our discussion here is really on how we can provide advice to the Department of Health and Human Services and the Secretary.

DR. BOUGHMAN: Dr. McCabe?

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DR. McCABE: Yes?

DR. BOUGHMAN: I would say that I am well aware of that, and hopefully people understood that this was the activity of an organization here in town, and the update on those activities, and recognize that we all wear a variety of hats, and that information and education to ourselves and to others that we work with about the importance of individual contact. I think one of the roles that this committee can continuously have is educating individuals about the situation, just where things are in fact.

DR. McCABE: I appreciate that very much. We were just clarifying that the "us" that you were using was referring to the actions of the ASHG and the coalition, not the actions of this committee. We discussed the possibility in March that further action by our committee may be required in the event that legislation is not passed in this Congress, and I hate to be pessimistic by stating that, but I think it is reality.

As a reminder, we discussed organizing briefings from individuals who have faced genetic discrimination, who paid out of pocket to keep their genetic information out of their medical records, and who chose to forego treatment due to fear of genetic discrimination.

I think it is important to remind ourselves that those were activities we considered, and that we might consider for the future, should this legislation not pass. We now have some time to discuss how we should proceed. I would take questions or comments from the committee for discussion, and particularly since we have Dr. Boughman at the table for her comment. Dr. Winn-Deen?

DR. WINN-DEEN: Yes. I just wanted to ask if you had had any success in gathering up some of these patient stories. I know you had mentioned at your last presentation for the committee that you were going to be working on that, and I think that would be extremely helpful, at whatever point you have those.

DR. BOUGHMAN: Yes. In fact, and I'm sorry, I failed to put this on, and it was a very important event. The Genetic Alliance is a very active member of the Coalition of Genetic Fairness, and it had a press briefing on the Hill. In fact, there was a very impressive woman who told of her case. At that time, we were reenergized to gather some cases.

We have not created other forums for the release of that information, but there has been some volleying back and forth. Coalitions of organizations, and coalitions of coalitions tend to be a little bit slower in getting some things done than we might like sometimes. But in fact, we have also worked at getting some of these cases, encouraging them to talk directly as constituents to talk to their congressional representatives, too.

I mean, this woman and her two children who were carriers and denied insurance, made a very impressive presentation. It clearly indicated what the challenge was before us.

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DR. McCABE: And we know also of cases where individuals have lost employment because, presumably at least in one case that I know of, because of concerns regarding insurance. I know that case appeared before the EEOC. I don't know if you'd wish to comment, Paul.

MR. MILLER: No, I think you articulated the issue.

DR. McCABE: Other comments? I would remind everyone that the first letter of the Secretary's Advisory Committee on Genetic Testing, wrote to the Secretary was about that, this issue, that our first letter, and the first letter of SACGT to the new administration, to the current administration, was about this issue.

Our first letter to the Secretary of the Secretary's Advisory Committee on Genetics, Health, and Society was on this issue, and we followed it up with another letter. So clearly this has been a top priority for these two committees, and I would guess continues to be. Yes?

MR. LESHAN: I'm Tim Leshan, sitting in for Dr. Collins today, with the Genome Institute, representing the NIH. I just feel like I'd be remiss if I didn't say that Dr. Collins has been providing technical assistance and working on this issue, both within the administration, and in responding to requests from folks on Capital Hill about this issue, and really thanks the coalition for its efforts in this area. NIH feels it is very important that we see if we can get this legislation passed, as you know. We're very encouraged by some of the press activity this year, but also concerned that we haven't seen some action, but still hopeful that we may in the future, and we'll continue to provide assistance and work on the issue as much as possible.

DR. McCABE: Tim, thank you for introducing yourself. I apologize for not recognizing you in my opening remarks. You are representing Alan Guttmacher, who will be sitting in for Francis Collins when he arrives. Also, I apologize to Suzanne Feetham for not recognizing you sitting in for Sam Shekar. Yes, Joann?

DR. BOUGHMAN: I also just wanted to remind the members of the committee that the situation that we're in is that there has been written documentation, the White House, the administration support of 1053, and it is actually in writing. If 1053 came to the desk of the President, he would sign it, basically, is the wording in this SAP, as it is referred to. So that any comments that would be made, or could be made to the Secretary, would be made in a context of already having documentation from the Executive Branch in support of the legislation that has passed the Senate.

DR. McCABE: Thank you. Other comments? Yes, Emily?

DR. WINN-DEEN: Are there some specific issues? Because the last time we discussed this, it seemed like the issue was, is this really an issue. Have we gotten past that? Is it just a prioritization versus other more pressing congressional matters at this point? Or what is the

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barrier that we need to overcome?

DR. BOUGHMAN: I think it is both height and width of the barrier. There are just so many very big issues going on, budgetary issues being one of them, along with everything else that is going on, that it is difficult to get the more focused issues onto a series of agendas. As you are well aware, several things that have happened, in fact, Congress spent almost all of its time last week on the issues and commentary on former President Reagan. So what issues were going to be debated during the week last week, slid another week. So that the challenge is both height and width, I think.

DR. McCABE: Paul?

MR. MILLER: I would just add that it is always in the context of these discussions, as I have heard and participated in them, it is always useful to reinforce, and to have more information about the reality of this problem, about the concerns, and to develop the issue of the concerns of real people out there, and the impact on the research and science. It is not the kind of issue that is sort of addressed, and then move onto something else. I think that that is constantly an issue and concern in the background underlying a lot of these discussions.

DR. McCABE: Debra?

DR. LEONARD: So beyond writing letters, which we've done now twice to the Secretary, and we clearly have the Executive Branch's support, what are specific steps that this committee could take to assist with getting this through the House?

DR. BOUGHMAN: My hope would be, and we will utilize the fact that this issue was on the agenda of this, a federally appointed committee, to look at these issues, that this was the top priority and the first topic of discussion. That fact will allow us, and anybody here in the room, to comment on the importance of this issue to the committee, responding in part to what Paul said. It doesn't enumerate individual issues. But in any way that we can utilize this support to bring forward more individuals who need to be supported to go see their Congressman or whatever, and we will be writing additional letters to the leadership and Congress once again, to try and do this. But we are using just about every venue that we know to use at this point, I must say. I don't know that there are additional specific actions that we could do at this point.

DR. McCABE: Well, I'd just remind everyone that we have discussed the possibility of having briefings where we would have individuals appear before us who had been the subject of genetic discrimination. I would ask if that is something that the committee would like to consider for our October meeting, should the House bill not pass by that time. Again, I don't wish to be pessimistic, but I think it is important for us to plan if the actions of the coalition and others were successful, then there would be no need for that, and we could change the plans for that briefing at that time. Is that something that the committee would wish to consider? Debra?

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DR. LEONARD: I think that we should do that. I don't know, five or 10 minutes for each person with a significant number, not just two or three people, so we can have an impact.

DR. McCABE: Okay. Is that something, Sarah, that the staff could work on for October?

MS. CARR: We can certainly try to do that. I guess I would also, if it is appropriate, to reach out to the coalition, because you've done so much of this already. If there is a way we can augment that work, or complement it in some way by bringing it to the attention of this committee, and thereby to the Secretary, we'd certainly want to, and would do whatever we can.

DR. McCABE: Is there anyone on the committee, among the members or the ad hoc representatives, who would disagree with that plan for October? (No response.)

DR. McCABE: Okay. Seeing no one wish to comment, then I'll assume that we will move forward and begin planning for that at the end of this meeting.

MS. CARR: Maybe it would be helpful if some of the members, we could form a little task force to help organize these briefings, and have your input on how much time to devote to it and so forth.

DR. McCABE: Does anyone wish to volunteer? Barbara, Debra, Agnes, Emily. Yes, please. We'll call on the ad hocs probably as well, but thank you to the two of you for volunteering, and Paul. You have been a leader in this in the EEOC. We may call on others of you as needed, especially among the ad hocs. If anybody has been shy and wishes to volunteer, at the break, please let Sarah know. Dr. Boughman, thank you very much for briefing us, and thank you for your efforts. They clearly fit with those expressed by this committee in our correspondence in the past.