Public Comments 10/18

Let me thank the committee for your hard work so far today, and now let's turn with great attentiveness to the public comment. One of our critical functions is to be able to receive input from the public, and we appreciate the views that they're sharing with us. We also have received written comments that can be found in your table folders. In the interest of time, commentators are to keep their remarks to five minutes, and as I said, we do have your written testimony which we will be looking at very carefully.

Let me say that I've got right now on my list first Kelly Ormond from the National Society of Genetic Counselors -- well timed -- Sharon Terry from the Genetic Alliance, Miriam O'Day from the Alpha-1 Association, Gary Martucci from Myriad Genetics, Christine Broderick from the National Partnership for Women and Families, and Donald Horton, director of public policy and advocacy for Laboratory Corporation of America. I'm sure that Sarah will get me if I've missed anybody else.

Let's start with Kelly Ormond from the National Society of Genetic Counselors.

MS. ORMOND: Thank you. It's a pleasure to be speaking here today. I'm Kelly Ormond, president of the National Society of Genetic Counselors.

As you are aware, the NSGC is the leading voice, authority, and advocate for the genetic counseling profession and represents over 2,000 members. Together, our members provide genetic counseling for prenatal, pediatric, and adult genetic indications, as well as work in academia, research, and biotechnology companies. A high percentage of our clinically practicing members offer some form of predispositional genetic testing on a regular basis, whether carrier testing or presymptomatic testing, for adult-onset disorders.

Today, we would like to primarily address two issues related to the provision of genetic services, genetic discrimination, and coverage and reimbursement of genetic counseling services.

NSGC would first like to address the issue of genetic discrimination by employers and insurers and the related topic of genetic nondiscrimination legislation. We have testified on this issue at past SACGHS and SACGT meetings. NSGC has also provided testimony to other organizations, including the National Conference of Insurance Legislatures in February and July of 2004, and is an active member of the Coalition for Genetic Fairness. We've also recently collaborated with FORCE, a cancer advocacy organization, to develop an educational brochure on genetic discrimination.

Our organization is disappointed that Senate bill S. 1053 was not taken up by the House for discussion in the past year and we are committed to working with all stakeholders to develop policies that are equitable and fair to the American public.

We would like to address three points with regards to genetic discrimination, beginning by reflecting upon the current status of documented genetic discrimination. It is clear that there are few documented cases of genetic discrimination in either the insurance or employment setting, but the oral testimonies this morning, written testimonies, and cases presented in other resources, including the "Faces of Genetic Discrimination" booklet published by the Coalition for Genetic Fairness, have reinforced that it is clearly an ongoing problem for at least a small percentage of families with inherited disorders.

In a paper that is currently in press, 7 percent of survey respondents at risk for colon cancer perceived that they or a healthy family member had experienced genetic discrimination based on genetic testing or family history. These reports were primarily around difficulty or denial in obtaining health or life insurance coverage or in denial of screening coverage. It remains unclear, since the bulk of these anecdotes remain unpublished, whether the individuals are experiencing discrimination due to a specific disability as compared to discrimination occurring solely based on genetic status and the extent to which discrimination may or may not be occurring.

Second, regardless of the rate at which genetic discrimination occurs, data suggests that individuals want to keep their genetic information private, as they do all health information, and that individuals are afraid that they will be discriminated against on the basis of genetic information. As a result, the topic of potential genetic discrimination is frequently discussed in genetic counseling sessions. As was reinforced by the health professionals panel earlier, this is usually brought up by the client, rather than the genetic counselor.

We have also heard that data, further backed up by published studies, suggests that a proportion of individuals who are candidates for genetic testing and for whom medical management may be changed based on test results, declined testing based on this fear of genetic discrimination. Specifically, two recent studies document that nearly half of surveyed individuals are highly concerned about genetic discrimination. This fear may result in at-risk individuals declining genetic counseling as well as genetic testing, undergoing testing using an alias or in an anonymous manner, not billing health insurance for genetic testing, or obtaining life insurance or other policies prior to undergoing genetic testing.

There are also studies that document that a high percentage of individuals at risk for breast or colon cancer do not tell their physicians or insurers about these risks or that they ask that the information not be recorded in their medical records. Such behavior certainly has personal and public health implications on medical management if individuals do not undergo early screening or if they choose not to share genetic test results with health care providers.

While education through the media and health professionals will be useful in minimizing the perception that genetic information is different than other personal health information, fear related to genetic discrimination appears to be pervasive.

As we discussed this morning, it seems clear that both state laws specific to genetic discrimination around health insurance and/or employment discrimination and the federal ADA, HIPAA, and civil rights statutes may not be comprehensive and that there are gaps between state legislation which become relevant in our highly mobile society. One critical point that was not discussed earlier is that research data suggests that neither primary care providers nor the general public are aware of the potential protections these bills provide.

As was noted in our 2002 physician statement, "The NSGC opposes discrimination against an individual with regards to eligibility for or maintenance of employment, insurance coverage, or medical benefits on the basis of genetic information. Genetic information includes the results of genetic testing, other tests which reveal genetic information, and information gathered upon review of family history. Consideration of this information is appropriate only when used to protect the individual's best interest."

While the NSGC does not support a position of genetic exceptionalism, we strongly support the passage of federal genetic nondiscrimination legislation. Such legislation would likely alleviate the majority of concerns regarding genetic discrimination and allow members of our society to

use genetic information to help clients make informed medical and personal decisions. To quote Paul Miller from a publication several years ago, "Whether it," genetic discrimination, "is a huge problem or a small problem, it should be prohibited."

DR. TUCKSON: Terrific. Kelly, let me ask you to do this.

MS. ORMOND: Can I have one more minute to just finish really quickly?

DR. TUCKSON: Can you do it in a minute?

MS. ORMOND: Yes.

DR. TUCKSON: Go for it.

MS. ORMOND: In summary, NSGC supports federal legislation for genetic nondiscrimination and we are available to work with SACGHS to further this matter until such legislation is passed. We are also committed to working with SACGHS and other medical and public policy organizations to educate the members of our society regarding the key issues around genetic information and privacy and to address the misconceptions which have unfortunately become prevalent.

Finally, I would like to state that in our quest to improve the access of our American society to high-quality genomic medicine, it is critical that this committee consider not only the need to decrease risk of genetic discrimination, but also ways to increase access to both high-quality and affordable genetic services. As such, I would like to conclude by addressing the issue of coverage and reimbursement of genetic counseling services, primarily addressing services provided by masters-trained genetic counselors.

Issues of billing and reimbursement are among the most pressing that face members of the NSGC and it is one of the three areas prioritized in our recent strategic plan. Through our past testimonies, this committee is already aware that coverage and reimbursement for genetic counseling services are limited by the lack of CPT codes and ineligibility for non-physician provider identification. While some payers contract directly with the health plans to include genetic counseling as a covered service and some services are covered by Medicaid and Medicare when provided to individuals with disabilities, the bulk of genetic counseling services are not currently reimbursed.

While we have only preliminarily reviewed these newest draft recommendations, NSGC is pleased to see that SACGHS and the Secretary's Office consider ways to address these two points. In particular, we are heartened to see that SACGHS is promoting the development and funding of evidence-based studies around clinical genetic services through any agencies. NSGC offers its strong support in developing and conducting such studies and have repeatedly been told that studies documenting such value will be critical. We are also pleased that SACGHS is continuing to advocate for the inclusion of masters-trained genetic counselors as recognized providers in both private health plans and national provider identification systems.

If NSGC can be of additional help as SACGHS works on these issues, including offering formal testimony on our efforts towards licensure or documentation of the value of genetic counseling, please do not hesitate to contact us.

DR. TUCKSON: Are you going to be around tomorrow, by the way?

MS. ORMOND: I'm going to be here until 1 o'clock, and I'm happy to address any of these issues at that time.

DR. TUCKSON: Great. Well, I really want to thank you, first of all, for coming and also for getting your stuff on the record and reading as quickly as you did.

MS. ORMOND: Well, I try.

DR. TUCKSON: You're very good.

MS. ORMOND: I'm sorry. It was long.

DR. TUCKSON: That's all right. I'm the one that's in trouble. But thank you for that, and actually, you heard the discussion earlier and we can't stop for questions, but if you all could amend your testimony based on what you've just heard us go through, and if you want to really underscore that, we would really much appreciate even more specificity based on what you just heard. Thank you so much.

MS. ORMOND: Thank you.

DR. TUCKSON: Sharon Terry from the Genetic Alliance.

MS. TERRY: So I'm going to help you out, Reed, and I told Kelly I'd give over some of my time to her. I'm only going to be three minutes.

I'm Sharon Terry, president and CEO of the Genetic Alliance, which is an alliance of 600 genetic disease advocacy organizations that represent 14 million individuals. The Alliance is a founding member of the Coalition for Genetic Fairness, a coalition of organizations working together against genetic discrimination.

We understand the promise of basic and medical research and are appalled that many families and individuals experience genetic discrimination and fear both knowing their own risk and participating in research as well. You have heard some of their stories here today. The Coalition's "Faces of Discrimination" provides you with more stories. We believe that all genetic information, including family history, deserves strong protections against misuse in health insurance and employment. Such safeguards will protect the rights, privacy, and confidentiality of the individual and their family.

This is an exciting and hopeful time for medicine. It is imperative, however, that we the public take full advantage of new medical advances that could help prevent disease before it develops. Genetic nondiscrimination legislation will reduce the likelihood of genetic information being misused in health insurance or employment decisionmaking. As you well know, simply having a positive genetic test does not mean one will develop a disease. Thus, this information should not be used to make decisions about insurance coverage or employment.

You have heard here from both consumers and professionals that as biomedical research advances, genetic testing is a critical tool in the provision of health care. As a result, many people know their own genetic makeup, putting them at risk of genetic discrimination. People who would like to avail themselves of genetic testing already have enough to worry about. They should not have the additional burden of genetic discrimination.

In addition, it is important that we who carry mutations for diseases are encouraged to participate in genetic research. A fear of discrimination discourages that participation, adding another hurdle to the pathway from basic science to health care services.

The Genetic Alliance and the Coalition for Genetic Fairness have worked for years on this issue. In the past year, we presented a letter to Speaker Hastert signed by hundreds of organizations and hundreds of individuals. We held a press conference with Heidi Williams and Dr. Collins on Capitol Hill. We continue to work together on this issue and plan to go forward until legislation is passed in a spirit of cooperation and compromise.

Therefore, on behalf of millions of consumers and advocacy organizations, I convey to you our strong support of genetic information nondiscrimination legislation. The Senate passed 1053 95 to 0, as we have heard, and President Bush has said he will sign it, as we have also heard. We've come here today to ask that you be bold and clear in your communication with the Secretary. Please ask the Secretary to ask Speaker Hastert and Representatives DeLay and Barton to move this legislation. Public policy must keep pace with scientific advances and provide those advances with a climate conducive to their translation into health benefits for all.

Thank you for the opportunity to bring these voices to the table. Thank you also for your leadership. We need you in this fight.

I will submit a much longer document and a copy of our letter and the signers to you in writing.

Thank you.

DR. TUCKSON: Well, that's just terrific, Sharon. Thank you.

You did so well and you only did two and a half minutes, so let's take a couple of questions.

DR. McCABE: Sharon, you said I think 14 -- one, four -- million people? I couldn't tell whether that was 14 or 40.

MS. TERRY: Fourteen. One, four.

DR. McCABE: Fourteen million. So 14 million. That seems like a lot of people.

We've been told that genetic discrimination doesn't occur. We had limited resources in terms of time to hear anecdotes. I'm sure we'll be told that this was just seven anecdotes or it doesn't occur. I would ask you to please document and help assist us as we accumulate this documentation. Among those 14 million, I hope we could find more than seven anecdotes, so that we could document that this is in fact a serious problem that does occur.

DR. TUCKSON: Terrific.

Anyone else? We're at three and a half minutes.

(No response.)

DR. TUCKSON: Great.

Would you also, in terms of what you submit back, because you had prepared your comments, because you're always prepared, that you heard our discussion this morning and I think you hit one of them for sure in terms of what we're going to do, and that's the three members of the House that we need to prioritize. If you have any other things that come up as a result of our conversation, I'd ask you to be a little more flexible. Take what you've already sent in and add to it. That would help us out.

Thank you so much. Really appreciate your being here.

Miriam O'Day from the Alpha-1 Association.

MS. O'DAY: Yes. Good afternoon and thank you for your time today. I have submitted to you a copy of the Alpha-1 Association and Alpha-1 Foundation statement. You have heard from a patient. She has talked about her children's carrier status. You heard from a provider today. My testimony I hope will sort of round it out from the organizational perspective of organizations that serve individuals with alpha-1.

Certainly, we believe that alpha-1 is a very good model for discussion on genetics, health, and societal issues. As you know, it's a pediatric liver disease. It's pediatric cirrhosis. It is the second leading cause of transplantation in the pediatric population. It's an adult-onset lung disease. In fact, it's genetic emphysema. It is treated in end stage with lung transplantation. Lungs are now going through an allocation process and we feel that individuals with alpha-1 are being disadvantaged in that allocation process. So we have a huge battle and barrier there.

It also has, as you heard Dr. Brantly discuss, a very large environmental component, and in fact alpha-1 is related to the fourth leading cause of death, chronic obstructive pulmonary disease, and there is a belief that COPD is going to have very strong genetic components and alpha-1 is the first identified genetic component.

The organizations that I'm here representing have taken responsibility for finding their way around the labyrinth of the patchwork that exists in state legislation, and in absence of federal protective legislation, what we have done is we use an ELSI Working Group. We have invested heavily in bioethics, and in fact we've had our ELSI Working Group take a look at the question of neonatal screening and population screening, which has been suggested by some of the physicians who treat these patients. In fact, our ELSI has felt that it's not ethical to do so in absence of protective legislation, and so what we do is we do targeted screening and detection. So this has seriously impacted our ability to identify those 95 percent of patients with alpha-1 that are unidentified.

In addition to that, and I've shared with you a copy of our ACT trial brochure and it's been handed out to committee members, our ACT trial, which is funded by the Alpha-1 Foundation and conducted at the Medical University of South Carolina, offers a free and confidential finger-stick test that can be completed at home. The results are mailed directly to the individual participant. Since 2001, the ACT trial has done 2,400 test kits. We have shared this protocol with NIH at their request. We've been very pleased to make it as public as possible.

The test is administered through a research study that evaluates the perceived risks and benefits of genetic testing. It does that through sending out a follow-up questionnaire. In that questionnaire of the people who have responded to our survey, we found that over 30 percent report fear of losing insurance as a reason for seeking confidential testing, 34 percent report concern about facing higher health care costs if the results were made public, and 85 percent seek testing for the

genetic knowledge. In fact, that was the most popular response.

We would be very pleased to provide you with any additional information that you'd like to have as a committee and we strongly endorse the need for federal protective legislation.

Thank you very much for your time.

DR. TUCKSON: Terrific. Thank you.

We have about 20 seconds for a question.

(No response.)

DR. TUCKSON: The one thing I want to add from what you've done that we didn't explicitly have in our earlier testimony, as I wrote down a little list of all the issues that come out the concern around discrimination, we had the HIPAA issue come up, we had the chilling effect it has on research, but the just overall screening policy was not a category that I recall was explicitly stated. So I would urge staff to add that to the list of chilling consequences of the absence of this, screening policy, and here we've got an organization that feels ethically it cannot recommend screening in the absence of this kind of thing, and I think that's a very important category that you've brought to us.

MS. O'DAY: Thank you.

DR. McCABE: And I would ask, because that's something different than we heard this morning, that perhaps it be added to this packet of material that we will be forwarding also.

DR. TUCKSON: Yes, yes, a very, very nice contribution.

MS. O'DAY: Thank you.

DR. TUCKSON: Gary Martucci, and I hope I'm saying that right.

MR. MARTUCCI: It's Martucci. Correct, yes.

DR. TUCKSON: And you are, by the way, with Myriad Genetics.

MR. MARTUCCI: I'm with Myriad Genetic Laboratories, correct.

Good afternoon. I think what we've heard today is that it's clear that the fear of genetic discrimination is preventing high-risk patients from accessing appropriate care.

Myriad began providing clinical and genetic testing for common hereditary cancer syndromes eight years ago. In 1996, two of the greatest barriers to genetic testing were the fear of discrimination and the unknown rate of reimbursement from insurance carriers. Since 1997, I have been responsible for securing coverage and reimbursement for genetic testing from health insurers and managed care organizations nationwide. Myriad's experience is such that genetic testing for common hereditary cancer syndromes is paid by insurers 90 percent of the time at an average of 90 percent coverage. Therefore, the insurance coverage barrier has effectively been eliminated.

However, the fear of discrimination has not been. For almost eight years, I've had the opportunity to discuss genetic services with hundreds of medical directors, physicians, and patients across the United States. The concern and fear about discrimination arises in virtually every discussion.

To reduce anxiety around genetic discrimination, Myriad has implemented a policy that patient test results are not released to anyone except the ordering health care provider or designee without the patient's express written consent. Insurance plans representing approximately 200 million covered lives comply with this policy because they recognize the clinical value of cancer genetic testing, which leads to the most effective medical interventions.

Our policy, along with numerous state and federal laws that prohibit employment and health insurance discrimination, results in numerous protections for consumers of cancer genetic tests. Yet there still remain gaps. The fear of genetic discrimination remains the most commonly cited reason for both patient and provider not to utilize genetic services to prevent life-threatening cancer.

We find ourselves in an awkward place. A large body of literature demonstrates the benefits, both clinical and psychological, of cancer testing. While peer-reviewed literature suggests that actual genetic discrimination is not a significant problem, the media continue to portray genetic discrimination as a common risk to individuals poised to take advantage of the health benefits offered by genetic services.

Roth, et al., echo many experts' opinion when they state "Unless these people believe that they and their families will be adequately protected from discrimination and from the possibility of losing or being denied health insurance, many will choose not to be tested for genetic conditions or predisposition to disease." Therefore, comprehensive legislation is a necessity or the media and other uninformed stakeholders will continue to use the fear of discrimination to dissuade patients from appropriate health care.

In the arena of hereditary cancers, genetic services and testing offer the hope to reduce the burden of disease that many families suffer. Fortunately, tens of thousands of individuals have benefitted from the power of genetic tests to guide their providers in the most appropriate medical management. While this number may seem impressive, there are over a million in the United States who carry mutations predisposing them to cancer, yet fewer than 2 percent know it.

While we know there are several key issues that underlie these statistics, such as a lack of awareness of genetic tests and the need for additional education and clinical support to health care providers, we consistently found that the fear of discrimination is a top reason for refusing genetic services and testing.

To integrate the promise of the Human Genome Project into clinical care, patients, clinicians, and insurers need the best available information to coordinate medical management. Without the information available from genetic risk assessment, patients and health care providers are left with only limited knowledge of how best to manage the risk of disease. Not only does this dilute the benefit of medical management for the patient, it often results in poor allocation of resources. Truly high-risk patients may not pursue risk-reducing options, while the very low-risk individuals may in fact overutilize the medical system due to their fear of disease.

It is our experience that patients interested in obtaining potentially life-altering genetic services sit idle in fear of discrimination. The science and technology to positively influence a patient's

outcome are with us today. It is our responsibility to make sure that patients are confident that there will be no negative consequences in insurance or employment for pursuing this important information.

Perception is reality, and the public's perception is that genetic discrimination is a serious threat. People have allowed an essentially nonexistent or limited risk for discrimination to prevent them from managing a very real risk of developing cancer. We must eliminate the fear of genetic discrimination to allow the public to participate in the benefits of genetic medicine. Comprehensive legislation will reassure the public and get media coverage to spread the word. Comprehensive legislation will eliminate the confusion and mixed messages sent to individuals who need these technologies the most.

Ladies and gentlemen of the committee, comprehensive legislation prohibiting and banning genetic discrimination is the answer.

DR. TUCKSON: Thank you very much. Right on the money. Thank you so much.

Christine Broderick from the National Partnership for Women and Families.

MS. BRODERICK: Good afternoon. On behalf of the National Partnership for Women and Families and also the Coalition for Genetic Fairness, thank you for holding this hearing to gather information about the scope and nature of genetic discrimination.

The Senate has taken an important step in advancing genetic testing and research by passing the Genetic Information Nondiscrimination Act. This is legislation that would provide much needed protection for all Americans from genetic discrimination in health insurance and in the workplace. We join with you in the hope that the evidence presented today and also in the data that was noted in the accompanying articles will encourage the House of Representatives to take action to enact this legislation.

With the completion of the Human Genome Project last June, the possibility for genetic testing and research is expanding rapidly. There are now genetic tests for hundreds of disorders and some of the most widely available tests are for women. Women and families stand to benefit from improved prevention, detection, and treatment of diseases like breast and ovarian cancer.

However, all the advances in the world will not help women and families if, by participating in genetic research or taking a genetic test, they can or fear they can be denied job opportunities, health care, or both based on their genetic information.

In addition to being long-time proponents of genetic nondiscrimination legislation, the National Partnership for Women and Families leads the Coalition for Genetic Fairness, a diverse group of disability, women's advocacy, and civil rights groups that recognize the need for meaningful protections against genetic discrimination. The scope of this group reflects the impact that this issue has on all Americans.

To illustrate the impact of genetic discrimination and the fear of genetic discrimination, the Coalition evolved a report, "Faces of Genetic Discrimination," which is included in your briefing book. The report notes telling statistics about the overwhelming opposition of individuals to allowing employers and insurers to access their genetic information, but also shares the stories of individuals like some of those you've heard today, like Heidi, Kim, and Mary.

Heidi was denied health insurance for her children because they were carriers of a gene for a liver condition. Medical professionals knew that the children would never develop this disease themselves, but the insurance company denied coverage because they carried the genetic marker.

Kim, a social worker for a human services agency, was fired because of her employer's fears about her family history of Huntington's disease, which she revealed during a staff workshop on caring for people with chronic illnesses.

Mary has a family history of breast cancer, but decided against being tested for the genetic mutations that make women more susceptible to breast cancer because she feared a positive result would jeopardize her chances for promotion at her law firm.

To allow individuals like these three to realize the full benefits of genetic testing and keep genetic discrimination from standing in the way of improvements in public health, strong, meaningful federal protections must be enacted. The Coalition has developed four core principles that we believe must be part of any legislation.

All genetic information that predicts future health risks, including family history, must be protected. Health insurers and employers must not be allowed to collect predictive genetic information and use it to discriminate in the health care system and the workplace. Individuals who experience genetic discrimination must have the right to seek redress through legal action with access to meaningful remedies, and entities holding genetic information about individuals must be prohibited from disclosing it to third parties without the individual's permission.

As science progresses ever more swiftly, it becomes more critical that Congress act to ensure that Americans are protected from genetic discrimination.

Thank you.

DR. TUCKSON: First of all, thank you very much, and I would urge the committee to refer to Tab 4 of your briefing books for a very important document called "Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People," which I believe you all had a lot to do with and I think is a very important addition to our material.

I also hope that, again, if there are any specific things that you want to send forward based on the discussion this morning about specific things that the committee can do to try to be a part of this solution, part of the leverage, the coalition building, and all that sort of thing, please, would you send that forward?

MS. BRODERICK: Certainly.

DR. TUCKSON: All right. Thank you very much for being here and congratulations on this really excellent document.

MS. BRODERICK: Thank you.

DR. TUCKSON: Terrific.

DR. LEONARD: This document will be included in the information we send? Because it's right now in our book and not in this.

DR. TUCKSON: So the point is that the Tab 4 material is not in the bound material, and Debra's

sort of urging, requesting, that we augment the material we send forward with this report.

DR. LEONARD: Yes.

MS. CARR: Are you amenable to that, to make this part of our record as well?

MS. BRODERICK: We would be, yes.

DR. TUCKSON: Terrific. That's great.

Our last speaker today is Donald Horton, director of public policy and advocacy for Laboratory Corporation of America.

MR. HORTON: Mr. Chairman and members of the committee, thank you for the opportunity to speak with you today. As a national leader in genomic and genetic testing, LabCorp views genetic discrimination and the coverage and reimbursement of genetic tests and services as being very serious, highly important issues, the resolution of which will have very long-lasting, long-reaching effects on the future of genomics, and therefore on the future of medical care in general.

I have to salute the individuals who very bravely came here today and told their personal stories of genetic discrimination. They were very powerful and very compelling.

Like those individuals and like the groups who have spoken here today, LabCorp supports federal legislation to prohibit discrimination on the basis of genetic information in health care and health insurance and employment matters. We believe that's the only way that the full benefits of genetics and genomics can be fully realized because that's the only way, we believe, that fear of genetic discrimination and its actual practice are going to be banned from the health care system entirely.

We support that for many of the reasons that you've heard today. Existing federal law is simply inadequate. When you put together HIPAA, when you put that together with the ADA as well as Title VII of the Civil Rights Act of 1964, all of those together do not create a comprehensive federal framework to protect against genetic discrimination.

We do have some good state laws, but they vary significantly in their depth and scope of protecttion, and even when you have a state that does have a good state law, you have ERISA that jumps in and preempts that, and ERISA does nothing to protect that information.

So it's critically important that we move forward. I think your next steps that you've identified today are right on target. I would just throw out a couple of things.

First of all, don't give up. This is an issue that's not going away regardless of what happens in this session of Congress. It's extremely important that this remain on the agenda and that we be persistent and consistent in moving this idea forward that we need comprehensive federal protection.

Secondly, I would say that let's not let the perfect be the enemy of the good. There probably is a little bit of room for negotiation here and there to get the parties together. Let's get something on the books and then we can do what we need to do down the road to polish it up a little bit. But we're very, very close. We need to take this opportunity now that we have it.

And just a moment if I could just to speak to coverage and reimbursement issues. I'd just like to thank you for considering the real-world examples that our own Dr. Paul Billings and Tammy Karnes offered to your Coverage and Reimbursement Task Force last month. We believe that those observations will be very helpful to you in putting together the final draft of the report.

Thank you.

DR. TUCKSON: Well, you all are terrific.

Let me just stop first and thank you, and make sure, is there a question on this issue? Yes?

DR. McCABE: Actually, not a question, but while you were speaking and referring to Tab 4, I was looking through other materials that should be included. I would think all the correspondence both to and from the various Secretaries of both committees might be included.

I know that we were told that the U.S. Chamber of Commerce was not adamantly opposing this, but I would refer people, after the "Faces" document, to the testimony of Mr. Lorber before the hearing of the House Committee on Education and the Workforce Subcommittee on Employer-Employee Relations. Read that testimony and read his questions under the end.

When we were told by their mouthpiece who was sent here this morning for them that they were not blocking this legislation, it is very clear that they blocked the legislation single-handedly in that subcommittee, and I challenge again, include this. Let's name names. Let's recognize who is doing this to the people of the United States.

If this continues to go forward, Mr. Chairman, and I know that we should not give up, and I'm glad to hear you say that, then let's request yet again -- you'll do it in a much more diplomatic fashion than I would sitting as a member, I'm sure, but I do not think they should be able to get away with this and then obfuscate by sending a mouthpiece to deny.

DR. TUCKSON: Yes. Me, diplomatic. I like that.

(Laughter.)

DR. COLLINS: I wonder if I might ask a question of the LabCorp folks. You, I assume, employ folks all over this country. So you're a large employer who has to deal with these laws, on the other hand, as well, and I'm wondering if you have experienced any difficulty in complying with the various pieces of legislation in many states in terms of genetic discrimination, and if so, do you think it would be easier to have a federal piece of legislation to comply with rather the many different state laws as a large employer?

MR. HORTON: Well, it would certainly simplify things to have a single comprehensive federal law. You know, we're in all 50 states. Quest Diagnostics has the same situation and a number of other labs face that very same situation. So yes, it would simplify things greatly.

DR. TUCKSON: Terrific.

DR. COLLINS: Maybe you can talk with your colleagues in the Chamber of Commerce, as you're a large employer, and maybe be a voice within that community as well.

MR. HORTON: I don't think we're members, actually.

DR. TUCKSON: One other request as we close out here, and that's for the public. Again, if we could also ask you, each time we develop materials, if you could make sure they got to your constituencies, we sure would appreciate it. I know you keep them well aware of what we're doing as a committee, but I would really want to explicitly get from you a sense that you can distribute the summaries or whatever it is that we're doing to your constituencies in whatever way. Whatever it is, through your newsletter, but something that keeps this pipeline going back and forth between you and us I think would be just terrific.

As far as Ed's challenge to us, I think we'll probably have to have a little staff meeting to figure out, because this is important. We've got quite a lot of material that we want to transmit. So we're going to have to figure out how do we put a summary document on the frontispiece and then have the appendices because we're going to be sending out a telephone book, but that's because I think we have a lot of things to say. I think that's the challenge. I think Ed really appropriately challenges us to think about that.

DR. McCABE: I think it's important to send a telephone book, given that we have been told that this is a problem that does not exist.

DR. TUCKSON: No, I think you're right on the money. I think we'll work with him and others on trying to get the summary document and then the additive material.

We are starting tomorrow at 8:30, on time, and you all have put in a heck of a hard day. As a result, you get this reward that Sarah is going to tell us about.

MS. CARR: All the committee members and the ex officios who are attending dinner should meet in the lobby at 6:40 or meet us at the restaurant if you're coming independently. There's a little purple sheet in the table folder that has the address and so forth. So see you in the lobby at 6:40.

DR. TUCKSON: Thank you all. Good day's work.