Roundtable with Selected Organizations on Their Efforts in Genetics Education and Training Facilitator: Dr. Reede

DR. McCABE: If everybody could take your seats, please. We're now going to proceed with a roundtable discussion with the eight organizations on their efforts in educating and training health professionals in genetics.

The purpose of this roundtable discussion is to explore in greater depth the efforts of key professional societies and educational organizations to enhance knowledge of health professionals in genetics and genetic technologies, and to identify what steps, if any, need to be taken to advance these efforts.

At this time, I'd like to welcome our roundtable of participants. You've already joined us at the table, so I don't need to extend that invitation.

I'll now turn over the gavel to Dr. Reede, who will lead the discussion and introduce the roundtable members, or have them introduce themselves.

Joan?

DR. REEDE: Thank you, and thank you very much to those who are participating in this roundtable discussion.

I'm going to introduce them, and they're not in order. They're Joann Boughman, who is the Executive Vice President of the American Society of Human Genetics, a medical geneticist and adjunct professor in the Departments of Pediatrics, Obstetrics, Gynecology, and Reproductive Sciences at the University of Maryland.

Joe McInerney, who is the Director of the National Coalition for Health Professional Education in Genetics. He was also, in the past, Director of the Foundation for Genetics Education and Counseling.

Felissa Lashley, and Dr. Lashley is Dean of the College of Nursing at Rutgers, the State University of New Jersey. Previously, she was Dean and Professor at Southern Illinois University School of Nursing, and a clinical Professor of Pediatrics at the University's School of Medicine.

Dawn Allain, who is a genetic counselor for the Children's Hospital of Wisconsin in Milwaukee. She is a genetic counselor and clinic coordinator for the Cancer Genetic Screening Program at Froedtert Hospital in Milwaukee, and is the current President of the National Society of Genetic Counselors.

Judith Lewis. Dr. Lewis is a professor in the Maternal Child Nursing Department at Virginia Commonwealth University, and also Director of Information Technology for the School of Nursing.

Georgia Dunston. Dr. Dunston is professor and chair of the Department of Microbiology at Howard University College of Medicine and founding director of the newly formed National Human Genome Center at Howard University. She is here representing the National Medical

Association.

Toby Citrin, who is Director of the Office of Community-Based Public Health at the University of Michigan School of Public Health and Director of the Michigan Center for Genomics and Public Health. He is here representing the Association of Schools of Public Health.

Michael Whitcomb. Dr. Whitcomb is Senior Vice President of the Association of American Medical Colleges, and in the past served two terms as Dean at one, the University of Missouri Columbia, and the other at the University of Washington.

Thank you all for being here.

I'd like to open it up with a question for all of you. If you could speak a little bit to your key issues, concerns, and problems with respect to genetics education and training from the perspective of your organizations. Here, if you could in particular refer to gaps in current genetics education of health professionals.

Would one of you like to take it? Mr. Citrin?

MR. CITRIN: I'll take a stab at it. I should say initially at the outset that to my knowledge, the Association for Schools of Public Health, who I'm here today representing, has not a current survey of what the schools in fact are doing in incorporating genomics into education. But we did have a graduate student of ours do a survey based on websites of all 35 schools of Public Health to see the extent to which genomics has found its way into programs or curricula. I shared that survey with Amanda Sarata, for whatever usefulness it might have to your work.

Interestingly enough, of the 35 schools, ten of the schools have been stating that they now have genetics programs, so most of these are very research-related, as opposed to teaching related. Twelve schools are offering courses. Very few schools are identifying ethical/legal/social issues among what they are teaching. So the current scene, if that is an indication, suggests that the large majority of schools of public health really have not incorporated genetics or genomics into the content of the education of people going into public health.

This, in spite of the fact, or maybe leading to the fact that the Institute of Medicine's report on the teaching of public health that came out in 2003, "Who Will Keep the Public Healthy?" makes a strong plea for genomics being one of the eight content areas that all schools of public health should teach.

Now, with specific reference to your question of one of the barriers. The very fact that the recommendation of the IOM report is that these eight content areas should now be incorporated into the teaching of public health, rather than replacing what is now being taught, suggests an add-on to what is already seen by many in the schools as an overload of information to be taught to students.

Now, the answer to that question, of course, is integration. In fact, the "Who Will Keep the Public Healthy?" report suggests that genomics needs to be integrated into an overall ecological view of causation of health and disease. But this suggests that people who teach epidemiology, biostatistics, health policy, and environmental health and health behavior, should all incorporate genomics in what they teach. Most of the people who teach these subjects do not understand the role that genomics plays in these areas, and the field has been so fast moving, that it is hard to have people who specialize in these, what are now identified areas of public health, to keep in touch.

So most of the schools that say they are teaching genetics, these 10 or 12, have specific, discreet courses that are typically electives, so that by far, students going through schools of public health today are receiving little or no genetics education. So the ability to have people who know how to teach incorporating genomics into the broader view of causation of health and disease, this would be a very major barrier.

The issue of time to incorporate this into what is already a very busy curriculum is yet another. Of course, related to that is the fact that there is no requirement to incorporate genetics, and it was good to see that accrediting bodies are incorporated into the draft resolution that you have put together.

So these, it seems to me, are some of the barriers. I want to add another barrier with respect to the one aspect of teaching, which is the ethical/legal/social issues. The very teaching of ethics in schools of public health is a hot topic these days. Most schools do not require training in ethics as a condition of getting a masters degree in public health. So if ethical/legal/social issues related to genetics are to be part of the required curriculum, which many of us who are in this field feel it should be, this then presupposes that ethics itself is a part of the curriculum of people going through schools of public health, it since becomes part of a broader issue. So that is at least one summary of some of the issues that colleagues of ours, and people in our school are seeing.

DR. REEDE: Thank you very much.

Dr. Lashley?

DR. LASHLEY: I'm here representing AACN, which is the national voice for baccalaureate and higher degree in nursing programs across the country. The membership consists of the deans and directors of those programs throughout the country.

AACN has had a few efforts in recognizing genetics as an essential part of nursing curricula. One of the first was to incorporate some knowledge of genetics in the 1998 "Essentials of Baccalaureate Education" document that was put out by the group. What this group does is put out essentials for the different levels of education that includes core content and core competencies for nursing at the baccalaureate and at the higher degree levels.

At the masters level, there was no such content included when that document came out originally, but that is going to be revised, and provides an opportunity for getting those essentials into those curricula as well, and that would be advanced practice nursing and nurse practitioner programs, and the like.

They have also had some conferences on incorporating genetics, one in which Dr. Collins spoke to the group, and I did as well, as far as applying genetics education into nursing curricula. So the group is moving on the need for that. What some of the barriers are are similar, I think, to what all the health professions are experiencing, and those are the intensity and density of the curriculum. There are a lot of competing topics for all of us in terms of what we put into our programs, and how much time we spend on them.

The second is that there has been traditionally a lot that relates to genetics in nursing programs throughout the years. But they tend to be more in the specialized, discreet disease-type areas, rather than a broad look at the influence of genetic and genomics across the curriculum, where most of us believe that that needs to be in terms of patient education, counseling, and that those

things are not all that different for people with genetic disorders, but that the knowledge has to be integrated throughout the nursing curriculum.

Another barrier has been the lack of qualified faculty to be able to do that, and there have been efforts to address that. Summer institutes, NINR programs, in terms of building that out, but it hasn't suffused the programs, if you will, nationally. So I think those are some of our major challenges, is getting genetics through the life span in nursing education.

DR. REEDE: Thank you.

Dr. Lewis?

DR. LEWIS: Probably a nice segue from the same discipline, and I'm here today as President of the International Society of Nurses in Genetics. It is also interesting to me, having been a member of the former Secretary's Advisory Committee on Genetic Testing, to watch the continued growth and development, and I want to applaud you all for continuing along some of the lines that we felt were so important.

One of the things that I really think is important is when you talked about the lack of looking at genetics as exceptional. I think that becomes really important. If it becomes part of base knowledge, rather than considered specialty knowledge, that is very critical. I think of myself when I worked as an advanced practice nurse, and if every time I saw a patient with an elevated temperature, I called in the infectious disease specialist, we wouldn't get very far.

The infectious disease specialist certainly has a place in looking at patients who have complicated problems, but when I think we get to the point where every generalist is able to incorporate basic genetic knowledge, and those of us with specialty knowledge become like the infectious disease specialist, or the subspecialist, that that is when we'll know we've arrived. So part of what ISONG is working really hard to do is to ensure that all clinicians and all health care professionals, and in our case, we can only deal with nurses, but that people have a certain base knowledge.

ISONG has published in collaboration with the American Nurse's Association, scope and standards of practice of looking at what kind of knowledge is based on the NCHPEG competencies. But looking at what kind of knowledge we would expect a generalist to have, and what kind of knowledge we would expect a specialist to have, that model makes an awful lot of sense. And because we are a relatively small group of people who are specialists, part of our goal for ISONG is to work with our 2.7 million colleagues who are not members of ISONG, to ensure that people have basic knowledge, and that we're available as consultants and collaborators, but power is only powerful when you share it. So the idea of being able to share it is so that the knowledge base trickles down.

What are the barriers to that? The barriers are, I think the same ones that have been recognized in terms of competing priorities for all of us. But I also am old enough to remember when the new disease called HIV was discovered in the early '80s, and we got mandates to include that in the curriculum, and we sat there and argued over what was going to stay in and what was going to go out, so we could include information on HIV and AIDS. Somehow we have managed to do that, and I don't know of a health professions education that doesn't include content on HIV at this point.

So I think it can be done, it is just a matter of making sure that everybody has the will. So I'm

really pleased to see the certification and the credentialing bodies at the table, because I think that is where the push is going to come. Good will only goes so far, and mandates work much better.

DR. REEDE: Thank you.

Dr. Whitcomb?

DR. WHITCOMB: Well, from the perspective of medicine, it may surprise some of you when I say that I really don't think that the issue, in terms of being a barrier, really relates to how crowded the curriculum is. I think that the issues, as they relate to medicine, are two fundamental problems that sort of transcend all education, at least at the level of thinking about the continuum of education, including medical school, and then onto residency training.

One of those is simply how do you integrate content that should be integrated really across the curriculum in a way that makes that content relevant, important, and learnable? We are perhaps fortunate in one sense, because the movement in medical education reform, as it relates to the undergraduate, medical school curriculum for the past decade has really been to evolve towards an integrated curriculum, as opposed to the

discipline-specific sort of departmentally-controlled courses that were typical of most medical school curricula.

This is an ongoing process with many schools involved, and it takes time to do it, but I think the challenge is simply then how do you integrate within the framework of that curriculum? I think perhaps the biggest challenge as we look down the road, and I think this will apply not only to medical students, but I think it will be an issue for residency education as well, is the opportunity for the learners to have exposure to patients that will make real for them what it is they are expected to learn, and how they will then apply their learning in the patient care environment.

That is an extraordinary challenge of an increasing severity simply for education of medical students at all levels. I think that with the changes that are occurring within the delivery system, it will continue to be a major challenge as we try to figure out how to get access to patients, the kinds of patients that students and residents need to be exposed to, since more and more of that care is being conducted outside of the traditional teaching site, which is the major teaching hospitals. So I really think those are the two major barriers right now for medicine.

DR. REEDE: Thank you.

Mr. McInerney?

MR. McINERNEY: Thank you. The barriers that everyone has discussed so far, apply across the board for NCHPEG's efforts. We have more than 145 member organizations now here in the United States, and abroad as well. Certainly we have a fair number of organizations that represent physicians, but the vast majority of our members are non-physician allied health groups, commercial organizations, consumer groups, and so on.

So one of our great challenges is to address the needs of this extraordinarily diverse membership. I should say that across the board, again, the greatest gap we face is the availability of evidence and educational materials that demonstrate to our constituents that genetics makes a difference in patient outcome, and can change effectively what they do now, rather than five years from now. We need to make that case more dramatically, we need the evidence to do that, and we need the educational materials that can do that.

Another gap is providing more guidance about what to teach. You have heard referenced a number of times this morning for the core competencies, and I think they have been very effective. Lots of organizations have begun to incorporate the core competencies into the development of their own curricula, whether it is undergraduate curriculum, or continuing education.

Increasingly, we are getting questions about what should we teach then? What is the content that we should teach? I think the core competencies do a very nice job of saying this is where we would like your constituents to end up when they're finished, but what do we teach to help get them there?

This week, we're posting on the NCHPEG website a set of core principles in genetics that really are, we believe, core concepts, that most health processionals should be able to understand with respect to basic genetics. So that's another gap.

Another serious gap for us, and we're trying, believe me, we're trying, is the issue of diversity and cultural competence. How do we represent issues related to diversity and cultural competence more effectively in our programs, and how do we involve organizations more effectively that can help us do that? So any suggestions that anybody in this room has to help us do that more effectively, we would certainly appreciate.

The last gap for us, I think, is related to what I have just mentioned. That is, there may be some significant gaps in our membership. There may be entire constituencies within the health professions that we are not reaching, that we need to be reaching, and that we need to have involved in the development of our materials.

We have a membership committee that is looking at that issue now, taking a look at our membership and how it sorts out with respect to disciplines, and trying to figure out where we should place our efforts in that regard.

DR. REEDE: Thank you very much.

One of the recurring themes for many of you related to faculty, and the lack of trained faculty in genetics as a barrier. Do you have suggestions on how we could address this issue of training our faculty? Dr. Lewis?

DR. LEWIS: There are several programs that I know of that are available that might serve as models in terms of nursing. I believe one of the ELSI-funded projects was the project that Cindy Prows has out of Cincinnati Children's Medical Center that runs in two formats. One is webbased for 16 or 18 weeks, and the other is a summer, two-week intensive program that is basically designed to provide nursing faculty who have no previous knowledge, or have minimal knowledge in genetics, with what they need to infuse the curricula with genetics.

I took that a couple of years ago, and every year I get a follow-up server that said so, what did you do this year? You took this course and you used the government's money, and what have you done this year? That is one program that I know of that exists that was ELSI-funded, I believe. I may be wrong in that, but I'm pretty sure that is where the original funding came from.

Dale Lea at the Foundation for Blood Research has put out a group of modules that are available

that you can order by mail that give faculty information that they can then use and adapt to their curricula. Then there are other programs like the National Institute of Nursing Research has the summer genetics institute that is an 8-week residential program for advanced practice nurses, and nurse faculty that deal with both education and research training. That one is really to help faculty with the knowledge development, as well as the knowledge transmission role.

I think there is some really good programs out there. The problem is that at least in nursing, they are relatively small. My class last summer at SGI was 20, and we were the fourth or fifth class. So in five years, they have trained 100 nurse educators. The Cincinnati program probably has groups of 25 twice a year, so I think there are programs there. Part of it is volume, part of it is taking people and finding people who are willing to do this, and then get back to their home institutions, and then have to convince curriculum committees that this material becomes important.

So I think there are models out there, but the question is what is the best model? I think a mixed model is best. Some people learn best in web-based, other people learn best when you take them out of their environment for a couple of weeks and turn off their pagers and their cell phones. So I think it is just a matter of what works best for individuals, but there are models out there, at least that I know of in my discipline.

DR. REEDE: Mr. McInerney?

MR. McINERNEY: Yes, thank you. I wanted to comment on one of the slides you showed during your presentation, and the comment that physicians prefer interactive learning with case studies. I can tell you from our experience with the NCHPEG membership that that applies across the board to all health professionals, not just physicians. We found that that is probably the best way to go, to engage people in the genetics content.

With respect to models, we have just finished developing in conjunction with a number of colleagues from the dental community, a program to train faculty in dentistry and dental hygienics. It is creatively titled "Genetics, Dentistry, and Health" on our website. Go to nchpeg.org and you can find that.

We have developed that around case studies with the intent of trying to get dentists and dental hygienists ultimately to change practice, to think a little bit differently about genetics when their patients come to them. But again, it is focused on case studies, with some core basic genetics.

DR. REEDE: Dr. Dunston?

DR. DUNSTON: First, just to set the record straight, I am a former chair of the Department of Microbiology as of March of this year. Also, I'm sitting in for Dr. Randall Maxey, the President of the National Medical Association. I just wanted to make a comment to your first point, and then the comment on education.

The National Medical Association promotes the collective interests of physicians and patients of African descent. It is the largest and oldest national organization representing the interests of African Americans, representing more than 25,000 physicians, and the patients that they serve.

The NMA is dedicated to keeping its members abreast of the many rapidly occurring advances across the various medical specialties, and the other changes affecting medical practice. So from that general perspective, certainly the organization considers genetics and genomics of paramount

importance.

The National Medical Association was founded more than 100 years ago, and had its formation in the history of the American community. From that history, the subject of genetics becomes particularly important, because the subject concerns the inclusion of African Americans, not just as a social imperative, but the subject matter forces the inclusion of African Americans as a scientific imperative, recognizing that the subject of genetics itself is challenging to our whole concept, construct, as well as methods of teaching.

Biology. We are moving from group-based kind of analyses, to individualized. Genetics as a discipline is often equated with the prospects of individualizing medicine. So there is a particular challenge that the NMA recognizes in a science that has the potential of individualizing medicine in a society that tends to group in its approach and methodology. So genetics as a subject that deals with biological identification, and classification of groups at all levels, is particularly challenging.

The issue, as was stated on one of your slides, is what does the science of genetics have to say about our biological thinking about race, race medicine, profiling in medicine, and developing drugs for groups when you are using a science that is potentially distinct in its capacity to individualize?

The NMA is sensitive to genetics as a subject that is very destabilizing in its whole concept with regard to the community. In the evolution of the science, the organization is concerned about the apprehensions of the community to become engaged in the potential benefits because of the historical context, in which the community, as well as the particular science, has been applied.

So a major barrier is how do we engage the community in such a way that the prospects to benefit become the driving force? To be proactive for engagement, recognizing that exclusion is not an option in the science of genetics? Because the science itself deals with the fundamentals of disease diagnosis, treatment, and progression in ways that not being included at every level of the science and its application in society is critical to how help will be administered to the group as long as we are part of this American community.

So the education of the community, as well as the professionals in medicine is of paramount importance, as reflected in the meetings at the local, regional, and national level that the organization sponsors in its continuing medical education, and its outreach to community. It is outreach to the community in ways that are complemented by current focus on faith-based organizations. Again, the history of the population is one where the engagement of faith-based organizations become perhaps a proactive means of addressing a subject that tends to be approached from a fear-based perspective.

So the challenge of how do you ensure that as new knowledge is coming forth, that you are represented, that your perspective is reflected, is paramount, and is certainly underscored. I would just say as one who is in academia, the role of education about the science, as well as the application of the science, and helping the community to appreciate that, that this is a science that demands participation.

It is a science that is challenging the reference point, and is challenging definition of what is norm. Inclusion of African people brings with it the challenge of variation and diversity in biology, and needs to recognize that what one sees cannot be separated from the context and the reference point from which you are viewing. How do we begin to incorporate that in our medical

practice? That we have diversity as a strength, as an instructive commodity, not just a pathological or a basis of disease. That is my last point.

In trying to engage the community in terms of genetics and its impact, recognizing that the genome project not only led us to techniques and technologies for identifying single genes that have major effects in causing disease, but it now has brought us to an appreciation of haplotype variation, and many common genes that vary, but are not pathological, just different in their functional capacities, and that they work together to accomplish functions.

So how do we begin to change the concept of medicine when the gene is not the pathological agent, but it is a means by which we can analyze, process, and understand disease, not always as a structural defect, but a regulatory one, and understand what is regulating the expression of genes that are associated with various diseases?

Thank you.

DR. REEDE: Thank you very much.

DR. BOUGHMAN: It is because of this change in science in general that the American Society of Human Genetics has been asking the question, as if we didn't have enough questions at the professional level and the health professional level, we have asked the questions kind of on the front end.

How can we work together better to improve on our answers to several of these questions? We asked ourselves, what resources do we have, and I'm speaking now as the umbrella organization of genetics, knowing that the American College of Medical Genetics, and the other medical genetics organizations would be here and be able to say some of the same things slightly more focused, but I'll speak in the broader terms.

What we bring to the table, if you will, is human genetics resources, in the form of individuals who have a knowledge base. What we have with the other organizations here, and as Dr. Dunston has pointed out, in the general public is a set of needs and questions that are being asked. So it seems to me, anyway, that we are now at almost the point of what I call genetics readiness across the board.

People are beginning to identify genetics as interesting, as important, it is appearing in the newspaper and so on, and now they want to ask the more practical question. We, the geneticists, are saying we have some information, and it is the gap in between. The geneticists need to become more teaching ready, and the organizations and communities need to tell us more specifically what they need.

At that interface, I believe is the concept of models or materials, as Joe McInerney pointed out before. And now we have had two tries at DNA Day, and each one has been better than the former one. This year, we got a couple of very interesting responses to our survey, and some terrific ideas on how to engage second and third graders in some movement, and some cutting and pasting kinds of activities that talk about differences and similarities, and so on, in a very practical kind of way. So some new kinds of things that we think can be put out there.

Exactly the same thing would apply in public health in our work with the American Academy of Family Practice in their genetics initiative and so on where the needs and the human resources are coming together in the form of models to tell us how we can be more helpful in the development

of certain models, although we don't have the expertise to actually translate and put those onto the CD-ROMs. We are going to need the resources together to get that activity and bring the other professionals in that need to focus on that. But I think we have the major portions covered, and now we just need the impetus to put it together and build the rest of the model together.

DR. REEDE: Thank you.

Ms. Allain?

MS. ALLAIN: Jo actually very eloquently said much of what I think NSGC's perspective would be on this. I think we are bringing to the table the human resources, we are at a number of tables now, along with ASHG and NCHPEG, and other organizations. Primarily NSGC has been focusing on in the last year, the allied health professions, by joining the Health Profession Network, which is an organization of allied health provider professional organizations, as well as joining the Association of Schools of Allied Health Providers. So trying to be the resource to integrate genetics curriculum into allied health provider education, as well as ongoing education for those professionals.

But as Jo pointed out, we have the resources, they have the interest, but it is getting the evidence-based activities, developing case studies based around those specific disciplines, in order to integrate those into their curriculums and daily activities.

DR. REEDE: Mr. Citrin?

MR. CITRIN: For the schools of public health, I should note in terms of your question of what actions are necessary in order to train faculty, I should note the role that the Centers for Disease Control and Prevention has been playing in moving genomics more into the forefront of both research, particularly teaching, and practice connections with the schools of public health.

The Center, and of course, Dr. Khoury, is the resident expert on this program, and your committee, and nationally, has been funding three centers for genomics and public health, of which Michigan is one, and North Carolina and Washington are the other two. Part of our role has been, up to now, to advance knowledge of genomics in public health, and to further the interaction between the schools and the world of public health practice around genomics, and the integration of genomics into public health practice.

I should say one of the facilitating factors here is that at the same time that the schools of public health are increasingly trying to develop closer relationships with public health practice, genomics being in an early stage of expanding in public health practice, presents a wonderful model for the schools on how to connect with practice. Because the schools and practitioners can be learning about integration and expanding knowledge in the field at the same time, and can be keeping pace with each other, and performing the usual loop of research applied into practice, practice being studied by researchers. Genomics is just a wonderful model of how to do that.

It seems to me that the associations, and here in our case, our own association of schools of public health, can do a lot to facilitate the linking up of people within each of the schools who are carrying out these roles within the schools of expanding the teaching of genomics.

CDC and their centers program have certainly been supporting this, and they are about to expand their program of centers. They may not all be in schools of public health, but they're all going to be involved in public health teaching and practice, and sharing education.

All of what has been said about the increasing resources that are available for teaching needs to be paralleled, it seems to me, by advocates within the institutions of learning who not only carry out the roles of spreading out the need for teaching in their own schools, but need to be able to connect with each other. Here is where the associations can do an awful lot to form committees that connect people across, in our case, the schools of public health who are trying to advance teaching of genetics in their schools, so they can be sharing lessons learned, the barriers, and how to overcome them.

DR. REEDE: Thank you.

I'd like to open the questions up to the committee now.

MS. ZELLMER: Does anyone have any comments on ways that practitioners, not students, that we can get the word out to them? I mean, I'm the parent of a child with a genetic disorder, and the frustrations in dealing with medical professionals, it seems like medical students, nursing students, you've got a captive audience, and that's probably the easier question.

You can teach them, and my experience was I've got a husband who is a physician, and I have got a father who is a physician. We saw four different physicians. The first time we were recommended genetic testing was by a resident. I think the problem I see is how do you get the people that are already out there practicing to realize the importance of genetics?

At least I would guess with continuing education, it is strictly voluntary. I mean, they are going to go to the things that they want to go to, and I think probably most physicians don't understand the importance of genetics. How do you encourage them, or force them to learn what they need to know about genetics?

It seems we have the materials, but how do you get them to use them?

DR. REEDE: Dr. Lashley?

DR. LASHLEY: I would make a comment in regards to nursing in that regard. In some states, continuing education is in fact a part of relicensure, or for recertification for specialists, depending on your specialty. But I think the aspect that we briefly touched on before, which his requiring a certain amount of genetic knowledge, much in the same way that HIV knowledge is part of mandated, continuing education in many states would be one way to unfortunately, one has to look at driving curriculum sometimes by licensure and certification aspects. That is one way to do it.

Another way is to go through the specialty of continuing organization's genetics in each of their programs, whether it be as a feature by itself, or integrated within such things as MI, if it is a cardiology conference, updates in that, or whichever way that goes.

DR. REEDE: I'd just like to acknowledge that Dr. Reed Tuckson, a member of the committee, has now joined us. Welcome, Reed.

DR. TUCKSON: I'm listening carefully, and I will chime in if I get a chance. Thank you.

DR. REEDE: Dr. Boughman?

DR. BOUGHMAN: Let me put on a slightly different hat for just a moment. For the last 14

years, I have been a representative from the American Board of Medical Genetics to the assembly of the American Board of Medical Specialties. There have been two or three things that have happened in the last five years or so in that organization. Coming back to the comment that Dr. Lewis made earlier about statements and accrediting bodies being extremely important.

One of the things that has happened is the shift in continuing medical education to required maintenance of certification. This is a formal shift, this is a difficult shift for many of the specialties to make that once had the attitude, once I pass my boards, that's really it.

So we do have a window of opportunity here to in fact include genetics as at least recognizably new information. Our challenge is to make it the most exciting among the various kinds of continuing medical education courses, or whatever, that individuals can take. So it is a two-way street there, certainly.

One of the other comments that I would like to make is that as the genetics representative to the process of creating the principles of practice in training and in maintenance of certification, I think it was the approach of the geneticist and our tradition in number one, looking at family units, and number two, fully recognizing and addressing cultural-specific issues and the need for cultural competence in every clinical situation.

I think our experience in that helped bring that to the fore, and I think that may be the results of the way, if you will, geneticists kind of look at the world at the same time we're looking at individual patients. But we do have a window of opportunity here in maintenance and certification for physicians.

DR. REEDE: Dr. Lewis was next.

DR. LEWIS: One of the things that we've been working at really hard with ISONG is to make people with specialized knowledge available for professional meetings. For example, I'm speaking with three colleagues, one of whom I believe became interested in genetics because she has a child with a genetic condition, and the nurse from NIH who is her research nurse, and another colleague and myself, the four of us are presenting at the American Nurse Association, which is probably the biggest generalist nursing organization.

Dr. Lashley is presenting there too this year, and so we're working really hard to present at non-genetics conferences, and to be able to work with our colleagues. Now obviously when I'm speaking, I'm one of 27 break-out sessions, and how many people are going to choose to go there versus retirement planning, versus how to take care of the patient in the intensive care unit? That becomes a hard issue.

I think part of what happens is that as people are exposed and learn from people like you, because I learn most of what I learn not just from books, but from the patients that I see every day. So as I interact with people like you and your family, that hopefully will pique my interest in that this is an area where I need more education. So when I go to my professional meeting, I'm going to choose the genetic session over the retirement planning session, or whatever.

So that I think it is a two-way street. But to forget that patients are probably our most valuable source of education, and that is not helpful as a patient when you're going in to realize that you're as responsible for educating the clinician as the clinician. So if you look at it as a partnership, I think sometimes that becomes real helpful, too, and that each of us has an opportunity to help educate folks.

I'm sure that the folks that you and your family dealt with learned as much as you did, it sounds like, but that becomes an important partnership, I think, too.

DR. REEDE: Mr. McInerney?

MR. McINERNEY: Yes, thank you. Professional societies are an extremely important vehicle for reaching out to health professionals. I'll give you four concrete examples, one of which Ms. Allain can describe better than I. But the National Society of Genetic Counselors worked a couple of years ago with the Endocrinology Society to integrate genetics thoroughly into its annual meeting. I don't remember how many members of NSGC were there, but I think there were at least 20 members of the society who were at that meeting.

They actually constructed genetic counseling sessions around a particular genetic test for the endocrinologists, so they could come in and do hypothetical genetic counseling sessions. The point here, and you'll hear it again, is to work with the professional societies so that you are meeting their needs.

NCHPEG will be working with the National Black Nurses Association to develop a half-day workshop on genetics for its annual meeting in 2005. Beginning this year in October with its annual meeting in Orlando, the American Academy of Family Physicians will begin a year-long clinical focus on genetics, and there are lots of organizations involved in this.

The Genome Institute, I think CDC is involved in one way or another, and that will continue for the year. But again, we worked with the society, the Academy, to determine what their needs were. I thought it was very interesting, when the group of geneticists sat down to develop 12 modules, one per month for the clinical focus, when we looked at it, it was what geneticists would come up with.

When we looked at what the interest of the family physicians were, there was almost no connection, except for the fact that each of the diseases, and they were all disease oriented, each of the diseases has a genetic component. But the importance is to work with the professional societies to build those programs. So there will now be one module a month rolled out by the American Academy of Family Physicians in conjunction with a number of us around this table, to bring genetics to family physicians once a month over the year.

We have also just finished working with the American College of Clinical Pharmacy to develop a new continuing education program on pharmacogenomics. And again, they came to us as a genetics community, and we have been working with them now to bring the genetics that they need to that program for their members. So professional societies are extremely important.

DR. REEDE: Thank you very much.

I have a general question. As I'm hearing about these various forms of curricula, the cases, the different materials that are being developed, is there a mechanism in which those can be shared? Part of my concern is everyone is starting from scratch every time.

MR. McINERNEY: If I may, that is why NCHPEG exists. If you come to our website, you'll see a list now of about 55 different educational resources in our database, about ten of which we've

had reviewed. Two reviews usually, one by a member of the profession for whom the materials are intended, and the other review by a practicing geneticist.

There are also lots of other resources on our website, but that's why we exist. If you have materials that you would like to bring to the notice of the community, please let us know, and we'll link to them, or we'll put them on our website.

DR. REEDE: Thank you.

Dr. Felix-Aaron, you had a question?

DR. FELIX-AARON: I didn't have a question, I had more a comment on what Kimberly said in terms of trying to reach practicing providers. Somebody said earlier in terms of the window being open, I think that is right. But I think in addition to the window being open, sort of being strategic about the types of providers you engage, would be something that would be important for this group to consider, if indeed that was the direction that it wanted to go forward.

So I think it is important that the family physicians are coming to this issue, and they have that particular focus. But I think there is also a role for the committee in terms of understanding the science, and understanding the progression of the science, and with the progression of the science, which types of providers, whether they be physicians or nurses, are at the forefront of the evolution of that science? Which organizations we need to target as a committee, and which professional groups that need to be targeted as a committee.

So just to summarize my main point, is that clearly there is a need for targeting in terms of the providers that are on the forefront. I would imagine that the cardiology is important to engage the cardiologist, that the pediatricians, I mean, the state of the science is such that engaging the pediatric community would be much more of a priority than say engaging someone with subspecialties.

DR. REEDE: Thank you.

Dr. Leonard?

DR. LEONARD: So on a national level, CME is, I think, directed on a state level. Is there a national mechanism to mandate CME in, or continuing education? I call it CME because I happen to be a physician, but continuing education, professional education, for all groups at a national level, rather than doing it state by state, or organization by organization?

DR. REEDE: Dr. Whitcomb?

DR. WHITCOMB: The simple answer is no. Licensure is granted by states in medicine. As a matter of fact, not all states even have requirements for any continuing medical education. About one-third of the licensing authorities do not, and of the states that do have requirements for licensure, or relicensure I guess I should say, very few of the states mandate any specific content that needs to be covered as a part of the relicensure.

There are some that do, but as a general rule, the answer is no. But if one wanted to think about this across the country as a whole, the answer is there is no mechanism in place to accomplish that.

DR. REEDE: Brad?

MR. MARGUS: Thanks. So the people in this room obviously, I think, all concur that genetic education is important. I feel a little bit like in several other meetings, too, everyone is preaching to the choir, there are all these reasons why science is changing, and people need to be kept up to date and all that.

I'm a little unclear about what genetic education means. If it is how genetics works, so that a physician, nurse, or counselor has to be able to explain Mendelian inheritance, or what the risks are of a particular test they're going to have, or if they are supposed to, as in Kimberly's case, know the catalog of all the rare disorders and be able to help in diagnosis, that is a completely different and much more challenging thing. Or is it the ELSI part that we always hear about?

But either way, it is pretty clear, and our resolution is going to say that education is really necessary, it has to be coordinated, and all that. I think, though, because if this committee is really going to have any impact, it is kind of like the Genetic Discrimination Act, which is we're going to have to tell the Secretary that something is definitely broken.

I'm not really hearing that something is broken, so maybe things aren't broken, and certainly if you look at diversity among genetic counselors and things like that, we can go down there. But is there something that you can point to that it is really broken? Can you bring a large number of patients or families in front of us, or in front of the world and say, these patients were mistreated because their physician was clueless about genetics, or got it wrong?

I haven't heard any of those stories. I have only heard that kind of like we're anticipating that this is all coming, and we'd better be ready, and we only have one genetic counselor for millions of potential patients who are all going to be screwed up if we don't have more educated people out there. But today, is anything really broken? If it isn't, it is going to be challenging to get more funds in the things that we're asking for?

So if the people who are going to continue to make comments could just highlight for me anything you can point to that is really, really broken, it would be really helpful. Again, if part of the genetic education and continued education is things like knowing everything about rare diseases, I know from my experience as an advocate, I could bring forward thousands of families who, like my family, spent a year and \$60,000 of needless tests to find out what the real disease was that my kids had, because the physicians at world class medical centers and the geneticists didn't think of the right disease to test for.

But other than that, other than knowing that kind of information, which I'm afraid maybe it is always going to be a challenge with rare disorders, all the other things that we're talking about is part of genetic education. Is it so bad right now that things are really broken?

MS. ZELLMER: I just want to make one comment, though, Brad. I certainly don't expect every physician to know every rare disorder, and I think you're right, that would just be a useless resource. What I was looking at more is just the fact that a physician should recognize that there could potentially be some genetic basis for the problems that the child is having.

Certainly my child's disorder is rare, but if you look at the symptoms that she was having, in looking back on it now, I think it should have been something very obvious to a physician that genetic testing should be recommended to us, that there were potentially genetic bases for the problems, and certainly not that she had this specific disorder.

I think that it was very clear to a resident who saw her for one time, well, you know, have you ever had genetic testing? I think something is broken when you have several doctors, and it takes them two years to even recommend genetic testing for a potential rare disorder. Not that they know the specific rare disorder, but that genetic testing is even recommended as an option. That would be my recommendation. I think something is broken if it takes two years to even have genetic testing recommended.

DR. REEDE: Mr. Citrin?

MR. CITRIN: Let me suggest, and I'm delighted that question got put on the table, because one of the comments when we got around to any specific comments on the draft resolution, one of the comments that I was going to make was that the resolution could carry more of a sense of urgency to get on with this activity.

Let me suggest three areas where it is not so much that things are broken, but that things are, at this point, moving towards what could be very significant crashes. One is in the area of costs, that when you look, for instance, at genetic testing, here is an expanding technology as to which the corporate sector, the

profit-making sector has an incentive to get more and more tests used, far beyond what the scientific sector is able to demonstrate is effective, valid, and cost-effective.

So the ability to teach people who are professionals on how to assess and evaluate the worthwhileness, the validity of this expanding technology, is absolutely critical. If people, whether they are medical professionals or public health professionals, don't have this ability to assess the worthwhileness of this vast array of exploding technology, what we'll end up with is an enormous wasteful use of health care resources.

Secondly, there is this whole matter of distortions that are occurring in the public's view of genetics, as the result of where the public is getting most of its information from. The public, of course, is getting most of its information on genetics, as well as it does other subjects, from TV, from media generally, relatively little from health care professionals, and almost none from public health.

The messages coming to the public now are both deterministic in terms of media hype on genetics controlling her conditions, which it really doesn't, as well as an item which is on your agenda, fortunately, and that is the direct-to-consumer advertising, which will further confound the public's view of what it means to have this or that gene.

And so here again, it seems to me we need a cadre, an increasing cadre of professionals who understand how to inform the public about genetics. This is a particularly critical role for public health people, because we see ourselves as having a role of public education, and here again, this happens to be one of the major things that CDC has been emphasizing in their new announcement of funding of genomics centers, this role in trying to correct distortions in the public's mind.

The third area where we could be heading toward a serious crash is one that is directly relevant to what Dr. Dunston, at my left, was talking about. That is the fact that we have here an expanding science that has the potential to exacerbate health disparities, at the same time that it has the potential of reducing health disparities. It is uncertain at this point as to which direction it is going to travel.

How our professionals learn about genetics, how they use that learning informing practitioners how to practice genetics, and how, again, they inform the public about what is the meaning of genomics, will have a lot to do with whether this new technology is going to create further gaps between the haves and have nots, further stigmatization of groups that have already been stigmatized too much, or whether genomics as a new, powerful tool to address some of the diseases that are responsible for which genetics has a component, and diseases that are responsible for health disparities, whether this very powerful tool will be used to reduce disparities.

So this, it seems to me, would suggest at least three areas where action is absolutely essential if we are not going to see this science lead to crashes in the future.

DR. REEDE: Dr. McCabe?

DR. McCABE: I want to make several comments about several of these points. First is one that I don't think I have heard here, and if I did, I missed it. That is in preprofessional education, and I'll focus on premedical education, since that is what I have more experience with, and the whole concept that we should really equip our professional students when they arrive in professional school with some background in this area.

The topic that I find particularly appalling in premedical education is the fact that we still require organic chemistry. I quite honestly have not formulated a medication once in my career. It is simply there as an energy barrier to premedical students, and yet, something as important as genetics, or one could pick another topic that has relevance to 21st Century medicine, is not required.

I would urge that in each of these areas, that we begin to look at what the prerequisites are, so that our students come understanding the importance of these areas. With respect to the integration of content that was mentioned, I think it is important to note that some of our revamping of medical school curricula are treating genetics as a threat that runs throughout the medical curriculum, not as a specific topic.

I think it is important that we make it fundamental and exciting, and case-based on all of those topics. The degree with which we are successful does have to do with the politics of curricula, and arguments about crowding of the curriculum. So again, to the extent that organizations such as the AAMC, or other professional organizations, can encourage that this be a part of the curriculum, that will help those of us who do have to deal with the realities of fighting for space in the curriculum.

I think it is also important to note the cost benefits of genetic education. It does prevent the diagnostic odysseys that have been mentioned, which in fact are cost-beneficial. Off site, several examples with which I'm familiar where these diagnostic odysseys have occurred with delay and treatment of management of patients.

PKU, the classical newborn screening test, screening of screening, not every child will be identified, and those that are missed frequently go on for years before somebody suggests that the appropriate test be done. There are numerous examples of hemoglobinopathies, sickle cell disease, and thalassemia.

Again, relatively common disorders, and certainly quite common in specific communities in this country, that are not understood really by practitioners. Cystic fibrosis is another case where

individuals can go on for years and years before they are identified.

Finally, we need to make sure that all of our professional students understand that this knowledge will prevent medical/legal mistakes, and medical misadventures. There is a big focus on medical errors these days. We talk about drug errors and all of those things, but errors of omission, errors of lack of diagnosis, or misdiagnosis, are also extremely important, and we have to recognize that not only are those cost inefficient for the families, they lead to tragedies where diagnoses are not made, or made too late. But ultimately, they also cost society, both in productivity, as well as in real dollars for those diagnostic odysseys.

So I think that there are a number of ways that we can approach this. If we don't do this in the health care professions, then our colleagues, some of whom are sitting around this table in the legal profession, will force us to bring this to the fore in health profession education. They will point out the misadventures, and the costs of those misadventures will become even higher with medical/legal actions.

Thank you.

DR. TUCKSON: Can I get put on the list, also? This is Reed. Thanks.

DR. REEDE: Reed? Go ahead.

DR. TUCKSON: Oh, okay. One of the things I also found valuable, the phrasing of the question -- can you hear me okay?

DR. REEDE: Yes, we can.

DR. TUCKSON: I thought it was valuable, the phrasing of the question around what was the problem, what was broken, what do we fix? I think two things. One, based on what Ed McCabe just said, that the Secretary of Health has a new initiative around health information infrastructures. I would wonder whether or not we might be able to have some relationship, or propose some initiative with that new health information infrastructure task force to find ways in which we can support the availability of the best evidence-based science, as it is continuously updated, in an easy and accessible way for a clinician.

Obviously, nobody could possibly keep up with all of those permutations of information and knowledge in this field. So what I'm hoping is that somehow, one of the solutions may be that we could find a way for the Secretary to use this information task force as a potential solution to the availability at the point of care for people as these information systems are standardized, for both the outpatient, as well as the inpatient environment. That might be an idea.

Secondly, I think that the point made earlier about the maintenance of certification is exceedingly important, because at the end of the day, it is what you hold clinicians accountable for in terms of their criteria for certification. I think they, like the MS, is an essential group of people that we need to bring in.

Lastly, I would hope that maybe we would discuss later in this meeting, some things on HRSA. We will get to the idea of performance assessment. When you hold people accountable for their performance, that becomes perhaps that national unifying standard that someone asked earlier about, for getting their attention. So that as we start to get to performance assessment and it starts to get into the area of the use of technologies for genetics, then I think you provide a fertile

environment for people to want to access the best appropriate evidence-based information, and then apply it. That provides, I think, a stimulus to go forward.

Thank you.

DR. REEDE: Thank you very much, Reed.

Sarah, do you have some comments on the committee that Reed was referring to?

MS. CARR: It's just to point out that this would be a very opportune time to make a suggestion to the Secretary about that. The President has actually asked for a strategic plan on the use of the improved use of health information technologies. So it would be an opportune time.

I do think that the more specific the committee can be about how that technology and genetics would dovetail, I think the better. That would be very helpful to the Secretary, I think.

DR. REEDE: Thank you.

Ms. Berry?

MS. BERRY: I'm not trying to stir anything up here, but I was curious in reading the different comments on this issue of education and training of health professionals, I was wondering whether there is any disagreement about who does what?

The reason it is a concern to me is because in the area of coverage and reimbursement, which we're going to talk about later, I know who does what will have some impact on whether an insurer, or whether a federal health program, will cover and reimburse for a particular service.

So I didn't know if we needed to go down this path or not, or whether everyone just prefers that we ignore it and have everyone sort it out amongst themselves. But that was an issue that popped into my mind, and I would love to hear your thoughts.

DR. LEWIS: I just want to speak briefly. Back before when we were talking about credentialing, and you basically said there were no national standards in medicine, that's not necessarily true in all of the disciplines.

Any advanced practice nurse is required to recertify every three years, and the recertification usually has both an educational and a clinical practice component. While I may not be required to do mandatory continuing education for the State of Virginia to keep my license, one of the things I have to do as an advanced practice nurse is I have to maintain credentials as a certified nurse, and that requires me to have 45 hours of continuing education every three years, and a practice component that is at least equivalent to a half a day a week of patient care, depending on my particular discipline.

Some states, Massachusetts, for example, requires 15 hours every three years for all nurses to maintain their licenses. So I think that there is variability among the professions, but to look at the fact that there are windows of opportunities, at least for some disciplines to start to look at the fact at, at this point, for example, as a women's health nurse practitioner, of my 45 hours, 30 of those have to be core, and 15 of those have to be supportive, but 30 of the 45 hours have to be clinically based.

So that there are opportunities in some disciplines to produce programs that would be attractive to people, and have them out there, and it may well be variable. Even though people are licensed by the state, in nursing, the credentialing is national.

DR. REEDE: Thank you very much.

Dr. Khoury?

DR. KHOURY: Thank you very much for all your presentations this morning. I may be a bit out of sequence, I have been gathering my thoughts for a little while here. I have a couple of comments, and maybe a question of the group.

We all talk about education and training, and I think many of the issues I heard this morning are right on target. There is sort of a two-prong approach to this, at least in my own mind, and I may be saying those same things tomorrow morning when I talk about the public health approach to genomics.

The first thing to keep in mind is the issue of genetic diseases, and the rare conditions that individually may be rare, but in aggregate, may affect about 5 to 10 percent of the population. We have heard about the diagnostic odysseys that cost money, cause anxiety in families, and destruction of the social and familial fabric, but also sometimes leads to medical issues.

Dr. McCabe mentioned cystic fibrosis, and I can count a number of other conditions where there are interventions. One example comes to mind, that is familial hypercholesterolemia, which is an LDL receptor defect that leads to premature heart disease, and people die in their 30s and 40s from heart attacks. That is about 1 in 500 disease, about a million people in this country may have familial hypercholesterolemia, and there are data from population surveys that about half or more of these patients are missed by the medical system, because there are so many people with high cholesterol levels due to other more polygenic or multifactorial causes of high cholesterol levels, that people with LDL receptor defects may be missed completely.

So if not for anything else, we need the kind of red flag raising. We are not trying to get everyone to become a geneticist obviously, but it sort of raises a red flag so that appropriate follow up can be made.

But coming back to what I heard also throughout the committee, and I think Dr. Whitcomb and others mentioned the issue of relevance today. Because for most practitioners, these kinds of incidents may be too far and too few in-between, I guess, they may not be seen by one single practitioner on any given day, week, or month. So what else is going on? I want to paraphrase Judith Lewis' comment about the fever.

What is the equivalent of fever, a febrile episode in genetics? I mean, you made the analogy of the infectious disease specialist, so okay, you've got the patient with fever, and you're not going to refer everyone who shows up with a fever to an infectious disease specialist. Fever is a very common occurrence in the population. So what is the equivalent of that in genetics? To me, the equivalent of that in genetics is the occurrence of something in your family.

We have plenty of data that shows that at least the major killers, heart disease, diabetes, and cancer run in families. If you have at least one affected relative, you are at increased risk of these conditions, and they may not be due to a single-gene disease, and you may not have to refer every single patient with a family history to a geneticist. And yet, it is the equivalent of a fever,

because half the population may have a family history of something, and that becomes sort of the run of the daily practitioner. Therefore, the relevance of genetics/genomics/family history becomes of urgency to the general practitioner, in addition to the issues of rare single-gene diseases.

I'll talk tomorrow about the public health approach to family history we started, but I'm curious to see what the various organizations are. I know some of them have done a number of things in this area. I'd like them to expand on the equivalent of fever in genetics, things like family history and the development of tools that everyone can use today, and we don't have to wait 10 years to show relevance of genetics in practice.

DR. REEDE: Would someone like to respond to that question? Mr. McInerney?

MR. McINERNEY: Yes. NCHPEG develops, three times each year, a family history newsletter that is devoted to exactly the issues that Dr. Khoury is referring to. This actually was a bit of a retrenchment for us. Originally, we were supposed to develop a generic family history tool for use by all health professionals, and it simply proved to be impossible with the time and the resources we had available, so we backed off on that a bit. Our family history working group spent a fair amount of time on it, but concluded that it was an impossible task.

What we do now, however, is develop this newsletter that we put online three times a year, devoted entirely to the issue of the family history in health care. It has articles about family history, but it also refers to tools that other people are developing, such as the tool being developed by the American Society, the Genetic Alliance, and NSGC, and the tool that CDC is working on now.

So in fact when we talk with our colleagues in the health professions, we refer to the family history as the first genetic test. It is inexpensive, and it is relatively easy to do. We are also building an extensive section on family history into our new CD-ROM on the genetics of common, chronic disease, which will be out later this year, and that is intended for primary care providers and public health professionals.

At some point, I would like to respond to Ms. Berry's question about is there an agreement about who does what, and who is going to pay for it. But I'll come back to that, perhaps.

DR. REEDE: Thank you.

Dr. McCabe?

DR. McCABE: Well, I just wanted to respond with an anecdote about the family history. In retooling our medical school curriculum, we had a laboratory in how to take, and how to interpret a family history. We were told by the organizers of the curriculum that that was not interesting, and was something that we really needed to completely rethink the next year.

On the other hand, I would point out that I'm Chair of a Pediatrics Department, I attend morning report whenever I can when I'm in town, and I'd like to think that our residents are more sophisticated in a family history now than a few years ago. They used to say, is there any family history? And now if one of them says that, the others will chime in with specific questions about what that is, rather than just do you have a family history of anything, which used to be the question, which the usual answer is no, or something completely irrelevant.

So I think that it is somewhat analogous to taking the temperature, but it requires a little more sophistication than simply taking a temperature. And yet, to many non-geneticists, it is considered boring, trivial, and uninteresting.

DR.. REEDE: Thank you.

Dr. Felix-Aaron?

DR. FELIX-AARON: I just wanted to elaborate a little bit on the Department's health information technology. AHRQ, the Agency for Healthcare Research and Quality, is leading part of this effort. We funded this year, \$60 million dollars in grants, specifically to do two things. One, to build the infrastructure on IT in small community hospitals, as well as in rural settings, and the other is to demonstrate the value of health information technology to health care.

So I think we have the opportunity to look at this really closely and to see where the opportunities are between what is going on in genetics/genomics, and what is going on in IT. If this committee was interested in that, I'd be happy to go back to AHRQ and look at the portfolios we have, and whether there were any grant projects that specifically looked at genomics, and I'd be happy to report to the committee on whether they were interesting programs, or interesting projects that was directly relevant to the work of this committee.

DR. REEDE: Thank you very much.

Dr. Guttmacher?

DR. GUTTMACHER: I'm just going to state the obvious. I think in terms of linking the number of the comments that we've heard, one, the range of comments about the importance of focusing on those areas of genomics that are actually usable and useful today to the provider. Two, this calls for thoughts about how we might feed into the Secretary's Committee on Health Information Infrastructure, and three, the importance of family history.

That really is the genetics tool that we can offer today that doesn't add cost, but in fact we think it is of some benefit, that reminds the practitioner of why genetic factor is important in health, and can be used as the basis for a lot of things. There is work that CDC is specifically doing, but others are doing as well to really further the idea of coming up with instruments and other kinds of things.

It seems to me it would be useful for the committee to call attention of the Secretary and his other committee to the potential use of family history, and the electronic medical record particularly. If we could establish the idea that everyone deserves a good, relevant family history and/or electronic medical record, we will have done a good thing for patients, but we will also have established a template for providers to continue to think about other more sophisticated genetic testing and those kinds of things once they do become more broadly available and useful. So I would think that would be an obvious sort of first step to take.

DR. REEDE: Thank you very much.

Dr. Winn-Deen?

DR. WINN-DEEN: I think I greatly agree with the comments that Alan just made. I think one of the issues that keeps coming back to me about genetic testing, and I'm not talking about

diagnostic genetic testing in the context of signs and symptoms, as much as presymptomatic testing, or maintenance of information about carrier status.

A lot of this information might be lost between the time a test is done, and the time the information is actually needed at some future date. I think it is very important that we, as we start to consider moving into the electronic age and doing electronic medical records, and having an IT infrastructure for that, that we have family history, we have a mechanism for recording any once in a lifetime genetic test that someone is given, so that that information is there. I'll say that extends to something as simple as blood type, and to things as complicated as pharmacogenetic drug metabolism enzymes that might be useful at multiple times in a person's lifetime.

So I would be very interested as a committee in hearing from this other group what they are doing, and how we could integrate these things together, because I think the combination of those two activities will help us to integrate genetics into the practice of medicine.

The third point that we have to lay on top of that is that there still are concerns, and Agnes mentioned this to me at the break, about having genetic information in your medical records, that some institutions still maintain your genetics record as a separate parallel file from your actual patient record.

So we need to deal with that issue. Why is that done still? Is it still an issue of fear of discrimination in some way in insurance, health, life, or employment? Or what is the reason that that is still happening? That is clearly a barrier to having a really fully integrated lifetime electronic medical record that can bring you the full benefits of a genetic test, rather than having to sort of hide that information, and then have it redone every time you need it.

So that won't deal with the situations where there is no family history, and we still have to train medical professionals to recognize in the absence of family history, which is what happens in a lot of rare genetic disorders, the probability of two carriers coming together is low, and so quite often they don't have any family history, but then they end up with affected children in recessive disorders. So I think both of those things are very important for us to keep in mind.

DR. REEDE: Just a question as you talk about this information, and are there questions with regard to confidentiality and sharing of information, it reminded me somewhat of some of the comments from Dr. Dunston, and the public's view of this information, how it gets shared, and concerns from special populations in terms of how this information gets shared. Could someone speak to that, please? Dr. Lewis?

DR. LEWIS: It's real interesting in terms of what people want in their medical records or not. I know when I deal with the women that I work with, for example, lots of folks don't want their sexual orientation in their official medical record.

So I think when we start to look at information that is different information that is potentially labeling, it is genetics information, and it is a whole lot of other information, too. I'm not sure all of the privacy protections that we have in law that are so challenging to implement, necessarily help people in terms of the fear of what is in their record, or what is not in their record.

I guess I worry about the fact that we have a system that has created the need for people to want information to be excluded from their medical record. I know several years ago when I went to Iceland and was sitting and talking to the President of Iceland about the issue of privacy and confidentiality, he basically looked at me and said, you know, that is not an issue in our country,

because we are a democracy, and people trust the government.

I thought, wow, how unique and how wonderful. For whatever reason, we have created a climate of distrust in this country. Not us sitting around the table, but the system has created a climate of distrust, and of people's need to keep private information private. So I think the problem is even more than genetic information, I think it is an information of the fact that people have been treated badly.

Once people have been treated badly, or groups of people have been treated badly, then we have a lot of work to do, because once trust is lost, it becomes twice as hard to regain. So I do worry about people who have concerns about keeping information out of their medical record, and why.

DR. REEDE: Thank you.

Dr. Hans?

DR. HANS: Thank you. I just wanted to extend some of the ideas that have been put forward around where this committee may want to consider interfacing with the Secretary's Health Information Technology Initiative. From the lessons of a department that has an integrated health information system, electronic health records available at the bedside for patients, some of the issues that you may want to consider along the following lines.

One is certainly proposing what elements of genetic knowledge should be part of the basic components of the electronic health record. That is one of the decisions going on across the agencies at this time. Family histories could certainly be something that is considered, if you are out there as a technology developer, you should certainly put that capability into whatever system you are developing.

I think it would also be helpful to look at the other kinds of tests and knowledge that should be part of the basic record, and part of the recommendations that this Department and others are looking at at this time.

In addition, in a more future looking perspective, to think about once folks have records at the bedside and have the interactive capacity with those programs, what sorts of prompts and guidelines on a daily basis would be helpful for the practitioners gets a little bit at how much knowledge does every practitioner need to have?

If you can build in some of that knowledge and reminder to the automated system, then you don't have to make all the effort to make sure that every practitioner knows every bit of information. But if certain diagnoses and conditions come up as they are put into the record, if there is an electronic prompt that then says what about this, or consult a genetics expert, you may want to consider this, that would be helpful in helping this entire enterprise around health information technology begin to map out where they may need to put that kind of information into the records over the next five to 10 years I think would be extremely helpful, particularly from the professional societies.

Certainly that is the role many other professional societies are playing at this time in that arena, as providing information and guidelines that then can be incorporated into these electronics systems.

And finally, an area that I think both for genetics/genomics, as well as the rest of the fabulous knowledge that is coming out of NIH at this time is how do you incorporate knowledge

management systems into a desktop electronic medical records system?

What do I mean by that? Well, you can't overwhelm a practitioner with all sorts of prompts and guidelines. We certainly found within the VA that after sort of a certain number of prompts, that physicians start to turn off the prompts. So in any one visit, you can't have too many things coming up on the screen at the same time. But you can think about a way where when you have a particularly difficult case and you're not able to diagnose what is wrong with the patient who is in front of you, if there is access on that desktop to information, ability to query based on the diagnosis in front of you, it can help physicians and other practitioners seek out information, and perhaps assist them in understanding sort of the conditions of the patient that is there in front of them.

So those are just some ideas that the committee may want to consider in this interface with the Secretary's committee.

DR. REEDE: Thank you very much.

Dr. Feetham?

DR. FEETHAM: Thank you. I have a number of things, and some of it goes back to the broader issues brought up in the original presentation, which I'd like to commend that you looked at what is common across the disciplines, because this is truly an interdisciplinary issue, and that we're really talking about quality of care and access. The way your report was framed, I think that comes forward as very important.

Many of the things that you brought forward are consistent with a report with recommendations we'll be taking to Dr. Duke, the head of HRSA, in just a few weeks, after doing an analysis across all of our agency about genetics activities.

But what I'm hearing is a key issue of communicating what is available to support the integration of the genetics to practice research and education. Again, part of what I see in the role of HRSA in working with our other federal and non-federal partners, is that we can facilitate, and we do have some mechanisms that we can help in moving forward with that.

Art even mentioned several activities, including we do fund the GeneTools with a contract with the University of Washington and Dr. Wylie Burke. This does emphasize current clinical labacobility as one example. Also, the Genetics in Primary Care Program we have had for several years is the focus of that, is getting that into practice, and I can give you several other examples. But the issue is how do we disseminate that? How does that get brought forward across all the disciplines, whether you are an active clinician or an educator? I think that is a key issue that perhaps this committee can look at in the future as an issue of the next steps of where we go.

Also in stepping back, some of the activities and current mechanisms we have within HRSA are we have programs that can look at cultural competency, and we have funding streams and programs in the Office of Minority Health, and other parts of HRSA, that that may be a help in what you're talking about.

We also have responsibility in workforce diversity, and have programs within our Bureau of Health Professions that again, can be tapped into perhaps, and informed to move in this direction. Also we have programs looking at the pipeline for the workforce, whether it is a genetic

specialist, or the generalist.

So again, just as a reminder, we do have some structures within our agency in working with our federal and non-federal partners that perhaps we can address some of the issues that you brought up in your original report.

We just had a meeting that Dr. Hans was at on Thursday, looking across information system capacity in our health centers. As you may know, we served 12.5 million patients in 3,500 sites in our federally-supported health centers, although we're only on average 25 percent of the funding for the health centers. We can influence some of the direction, and one of the things we're working on within our health centers is the integration of the genomics into the latest science, which we do through our Health Disparity Collaboratives, which again, that has the patient registry with some of the prompts and activities that you have been talking about. So again, I think we can help facilitate in a variety of ways, some of the issues that you have brought forward with the review earlier.

DR. REEDE: Thank you very much.

Dr. Boughman?

DR. BOUGHMAN: I urge the committee in its deliberations to, and I'm quoting from a conference I was at recently, "don't let the perfect get in the way of good."

As far as Cynthia Berry's question on who is going to do this, and are people getting in each others' way, and are we stepping on toes. At this point in time, it seems to me that there is so much to be done, and there are in fact from the genetics point of view, so few of us to continue to do it, workforce issues being one of our issues, that from the educational point of view, that is not our primary issue.

It will be an issue if the question is, who is responsible for all this education without dedicated resources to get it accomplished? So as long as we can continue to generate possible resources from federal agencies, or from within institutions, then I think exactly who is going to do what is not our basic question. I think we have generated several models where we're working in concert with each other, and I hope that certainly continues.

The other point that I would make, and we have gotten some very sophisticated comments back about family history in the medical record, and specific prompts and all of those things, but I would simply remind folks that the approach that the Genetic Alliance, the National Society of Genetic Counselors, and the American Society of Human Genetics have taken in the development of a generic family tool as to remind people that it is the consumer's information, and it is the consumer's responsibility to gather that information to provide it to the provider, no matter who it is.

There is no blood test, there is no fingerprint, there is no way that any provider can get the information without engaging the consumer themselves. So in fact, the approach that we have kind of built our strategy on is let's get the consumer, let's get the general public excited about their own family history and information, some of which at least may be medically relevant. As they bring that to their provider, whatever the provider's credentials are, then in fact they will initiate and engage the provider.

If the provider, once again, has gone through their genetics readiness training, they will be much

more able to accept and interpret that information correctly. But we have in fact not directly addressed this most perfect genetic or family history tool, and we are working with other organizations to try and get down to the basics.

In many situations, we would take almost any information that we could get as a starting point, and I only need refer or remind people that many of the best genetic studies have gone back to family bibles, and the information that the family had to begin with to in fact garner our information, which would be considered the geneticist information.

DR. REEDE: Thank you very much.

Mr. McInerney, you had mentioned earlier wanting to make a comment in regards to who should be doing what. If you could speak to that, and also in some of your written comments with regards to the recommendations, you had mentioned promoting public education that provides knowledge and skills to consumers, with requirements to participate effectively with health professionals in decisions that informed genetic prospectus, which I think follows very nicely from the comments just made by Dr. Boughman.

If you could speak to both of those, please?

MR. McINERNEY: Yes, thank you. Well, Dr. Boughman really covered the first point that I was going to make, but I will tell you just a quick story. That is when we first published the core competencies in January of 2001, we heard a lot of complaints from people in the genetics community, that these competencies were trying to turn all health care professionals into geneticists.

I suspected that that was not likely to happen, to begin with. And in fact, it hasn't played out that way. I will say that the competencies are challenging, and we ask a lot of health professionals in those competencies. But what we've heard in the subsequent three and a half years roughly, is that health care professionals are quite sanguine about their own limitations, not only their own knowledge, but their own limitations in practice. They want to know how much they need to do to incorporate genetics effectively into their own practice, and when it is necessary, then hand that off to somebody else.

What we found is that people are using the competencies in that way. They are thinking carefully about how genetics manifests itself in their own practice, and then picking and choosing the competencies appropriately. So I think that issue has resolved itself, perhaps only for the moment, but I think it has resolved itself now. The issue of who pays for what, who delivers genetic services, that's an entirely different issue, and one that I'm not even remotely qualified to address. But from an educational standpoint, the other stories should serve, I think, as a helpful guide.

With respect to my proposed recommendation, or proposed addition to the recommendation you want to take to the Secretary, it just strikes me, as I said to the committee when I testified here at the last meeting, that we can't think about education of health professionals in the absence of education of the public, particularly if the assumption is that genetics ultimately is going to move health care more and more towards a prevention-based paradigm. That is something we have all been hoping for for a very long time, and for me, the notion of prevention always has implied a partnership between patient and provider.

If we are going to have an effective partnership, both of the partners have to be well educated.

The education, I think, for the public, has to proceed from the same conceptual base, the same set of assumptions about genetics that we use for health care professionals. The details will differ, but I think the set of conceptual assumptions has to be congruent with that for health care professionals.

DR. REEDE: Thank you very much.

Dr. Dunston?

DR. DUNSTON: Yes. I wanted to underscore a point made earlier, too, about the importance of getting the consumer involved as part of this transition. But I wanted to preface my comments by saying that I thought it was very instructive that this committee is genetics, health, and society, and not genetics, disease, and medicine.

Instructive in the sense that I think that engagement of the consumer in why they need to be engaged in understanding the knowledge, participating in the research is a challenge that is part of what I like to call, the very positive potential of genomics. In that this seems to be a time where the genomic technologies offer an opportunity to understand disease at the biological level that requires the participation of the consumer, participation of the non-patient, and family histories must engage those who are not coming to the attention of the physician because of the disease.

The absolute necessity of public education, so that we can get participation in research to really utilize the power of genomics, and understand the biology of disease, is a challenge that I think is putting public health in the forefront. The necessity of the consumer, and the population, both those affected and non-affected with disease, are integral to understanding the biology of disease in ways that the challenge to me would be to take everything that we have learned on the negative side, if you will, from genetics with disease and medicine, and ensure that laws are put into place now that would at best, minimize the exploitative and manipulative, and the issues that would keep the public from participating in the research that is absolutely necessary to really use the power of genomics today to understand biology.

So on the one hand, we can take what we have learned during the era of genetics that may serve as the basis for the public being fearful, and look at the laws. I loved the beginning of this meeting with the emphasis on the Nondiscriminatory Act. We can ask, what are the things that were wrong with the way we used genetics before? And what do we need to put in place to minimize that occurring so that the science can move forward in a way that the public will want to participate?

I really underscore the importance of research that engages the public, engages the non-affected, as well as the affected as essential to getting the benefits of how we understand our genetics today.

I think, lastly, that for the public to understand that the power of genetics now, or genomics, large scale, high-throughput, information technology driven science, to tease out the underlying biology that is related to disease, requires public participation. So the question becomes what do we need to put in place with our laws, policies, and education, that will ensure that we do a PR job for what the potential of genomics is is one that we are not concerned about a whole battery of things to present discrimination. But what do we need to do to protect our privacy? To protect confidentiality?

Those are issues driven more by how do we get the public excited about the power of science

today to help us understand disease in a way that gives us whole new approaches to prevention and promoting health.

DR. REEDE: Thank you.

Dr. McCabe?

DR. McCABE: I think that's a terribly important point, because if we are to really utilize the power of genetics, then we will need large population studies, and we'll be talking about that more. But given that the unique genotypes, whole genome genotypes, that individual patients will have will be relatively rare, if we're really to develop the correlations, we will need those large population-based studies.

I think it is also important that you tie it to the Genetic Nondiscrimination Act that was discussed at the beginning of this by Dr. Boughman, because until our patients feel that they can be safe with genetic knowledge in their medical care, they're not going to feel safe in the research arena.

If they understand that the research is to improve their care, and not to be used in a discriminatory fashion, because that is outlawed, then I think that they will feel far more secure in gaining that knowledge about themselves. So I agree wholeheartedly with your points, Dr. Dunston.

DR. TUCKSON: This is Reed Tuckson. I'd like to get on the list also.

DR. REEDE: Reed, go ahead.

DR. TUCKSON: Thank you. Two things. I think it was very helpful to hear those last comments. One of the things I have been impressed by, particularly by certain people on our committee, and many of the people that have testified, is how specific they are of families who are going through the experience of genetic disorders and diseases, how quickly their learning curve reaches fairly impressive levels.

With that as a hopeful sign, I am also, though, faced every day with the reality of just how tough it is to get any level of understanding about health and disease in the general American population. If you even just take an example like obesity, it is a devil of a time trying to educate people in our country about the etiology and other therapeutic issues regarding something that is commonplace as that disease and disorder.

If you think even of the number of people who are currently appropriately getting diagnosed for hypertension, my point is that I think that while this is an important area that we have underscored, I think this committee is going to be challenged by trying to figure out what the priorities are in this area.

We obviously cannot reorder all science literacy in the country. In fact, if you look at the science literacy of the American population, it is staggeringly low. And so I wonder whether we might start to, as we continue to discuss, drill down to the key priority areas that we think we can meaningfully through the power of the Secretary, actually do something about.

Secondly and finally, I just wanted to briefly get at this idea of who does what, and what those competencies are that Joann talked about, and others. I hope that we can also get to this idea of defining what needs to be done, and then start to figure out the whole range of comprehensive tasks, and then start to determine what is the interrelationship between different parts of the health

care system, and the various professional, and maybe even non-professional disciplines that have an opportunity then to play a role in that. I think if we talk about it, we can get more specific.

Thanks.

DR. REEDE: Thank you very much.

In the interest of time, if there are any comments or questions with regard to the recommendations for resolutions? Additions? Mr. Citrin?

MR. CITRIN: Well, the recommendations that I had as comments relate to a couple of my earlier comments, but just to be quick. One is that while public health is mentioned in page two, there are references in page one to clinical medicine that could be broadened out to make clear that they relate to public health as well. There may be some more generic terminology. I still get the sense that there is more of a clinical/medical focus than there is a broader focus on all health professions and education, including public health.

Secondly, it seems to me that the ethical/legal/social implications, the ELSI, ought to be referred to specifically somewhere in the resolution. It is interesting that in the Institute of Medicine's report that I referred to on the teaching of public health, a good deal of the language in the recommendations on the genomic competencies that all public health professionals need, related to the ELSI dimension.

It isn't automatically evident in reading the resolution that this is a component of the education, that this committee particularly ought to see as essential since it is so much at the heart of what this committee is all about.

Then in terms of the preamble, and I guess this relates to the question that was put on the table earlier about what is broke, that it would be helpful, it seems to me, in gaining attention to the resolution if some content were put into the preamble to suggest some of the really compelling reasons why it is urgent that increased attention be given to the education of health professionals in genomics because of concerns of what will happen if the pace of development of technology goes far beyond the competence of professionals to make use of the technology, or to inform the public adequately about the implications of the technology.

Thank you.

DR. REEDE: Thank you.

Dr. Lewis?

DR. LEWIS: My only comment is on your points in terms of the recommendations on number five. I'm not sure who is going to decide what is adequate knowledge in human genetics and genomics, because that might depend on where you sit.

So to use something that is either to take out the adequate, or to determine how it is going to be measured would be helpful, because I think that having that be left to interpretation may be problematic.

DR. REEDE: Dr. McCabe?

DR. McCABE: I just wanted to follow up on Mr. Citrin's comments about the ELSI. Not only are they important, but also they are engaging to the students. Perhaps even more importantly, however, while the technologies will change, the ethical, legal, and social implications of those technologies will remain somewhat constant. So I think it is important to cast a lot of the teaching in those, because they are engaging, and they are important. But they also will be somewhat longer term issues than whatever is the technique de jure.

DR. LEONARD: This is a rather specific point, but in recommendation number five, "Encourage accrediting licensure and certification bodies to condition accreditation licensure and certification among demonstration of taking out adequate knowledge in human genetics and genomics." Can this be specified to refer to health care professionals?

Laboratories that do testing are also accredited and licensed, and I don't think you were referring to laboratory or testing accreditation and licensure. You are talking about accreditation and licensure of health care professionals. It raises a measure of concern among those of us who do laboratory testing, because there aren't a lot of people out there who are accredited and licensed in genetics, such that if we are limited to hiring only people who are accredited and licensed, we won't have a workforce.

So while I agree that we should encourage accrediting licensure and certification of health professionals, it shouldn't include laboratories.

DR. REEDE: Any other comments? Dr. Felix-Aaron?

DR. FELIX-AARON: Yes, a couple of points that came up in the conversation today. I don't see them represented in the points in these documents. I want to build on Dr. Whitcomb's point, the question around building the evidence. So that not only relates to Dr. Whitcomb's point, but also to what Dr. Tuckson said about the what to do in terms of building the evidence base for genomics and its implication, not only for practitioners, but for medical education. So I don't see that reflected in the resolution.

The other point I would like to make is also related to this issue, but how to integrate content. I'm not sure what I'm about to say has implications. Well, it is something you would try to implement in this document, but I think it should be captured, and the committee may want to consider it in terms of how to integrate genomics into medical education.

I think we may want to study what HRSA has done with the disparities collaboratives, and how they have used a collaborative and improvement model to get changes in practices. So I offer this as a model that we could use, or at least study to see how you get change in medical curriculum. So it is an area which I think is right for a pilot.

You have best evidence, you have tools, you have people in small pockets doing best practices, and you could use that, and develop a model for getting that kind of curriculum changed into medical schools, schools of public health, and nursing schools. So I think it is something that I would like to put on the table that if the committee was interested in looking at.

It is something you could comment on sort of what the health centers have done, and how they have used a collaborative learning model, coupled with an improved model to change practice. I come from the Agency for Healthcare Research and Quality, and we think a lot about integration and trying to change practice.

We struggle with the issue of overburdening not only teachers and practitioners, but really trying to give people the tools, give them the tools, give them the setting they need to support and foster change in their practices.

DR. FEETHAM: I mainly would like to say I had written that down earlier that they, again, the collaborative or breakthrough series type of model may be something that, again, various disciplines could come together and make application to the Bureau of Health Professions to look at this as -- because system changes really are a major piece of what we're talking about. Not only within the academic institutions, but in the practice and providers.

So again, I would just encourage our community to be thinking of something innovative that you might look at that type of a model for coming in for funding from the various federal agencies to build off of that idea. Again, I can give people information about our website if you want to know more about the breakthrough series, and that type of learning model. But I do think we need to look at this within the context of system change.

DR. REEDE: Mr. Gray?

MR. GRAY: Yes, thank you. I'm sitting in for Commissioner Miller, who wanted me just to raise this one point, and I guess it relates to point number six. That is that we're talking about issues relating to diversity that we keep in mind diversity within the disability community. Cultural diversity should include that segment of the population as well, and we should just bear in mind that within the disability community, there is a wide range of interests, concerns, and differences among persons with disabilities. So that should be something that we should focus on as well.

DR. REEDE: Thank you.

Ms. Masny?

MS. MASNY: Yes, this is a comment, and then just a suggestion for one of the resolutions. In reviewing the papers from the responses from all the professional organizations, I do believe that almost every single one of the professional organizations did mention NCHPEG, and what the core competencies meant for them, and how that was one of the pieces that they were able to integrate into the work that they were doing to integrate genetics into practice, in genomics into practice.

One of the comments that we received from Dr. Jean Jenkins was to actually recognize NCHPEG and the work that they have done in part of the resolution. I think that it would fit very well into the second recommendation regarding the partnerships and the cataloging of information, and sharing information to actually mention NCHPEG there, both to hopefully get more visibility for NCHPEG, and maybe future members, as well as to see it as one of the models for partnership.

DR. REEDE: Thank you very much.

I want to thank all the members of the roundtable and the members of the task force for their work on this, and we'll use this in further deliberation. Thank you.

DR. McCABE: Thank you very much, Dr. Reede, and all of our invited guests for sharing with us the work of your organizations in advancing the education and training of health professionals in genetics and the insight on how to encourage more of these efforts.

Your responses, and all of the responses we've received to our information request and this roundtable discussion, are immensely helpful to our exploration of private sector efforts in genetics education and training, and certainly it will be very useful to us as we further develop our resolution to the Secretary on this important topic.

With that, we will be discussing the draft resolution during a working lunch, and so to all committee members and ex officio members, box lunches are available for you out in the hallway. Please take a few minutes -- literally a few minutes -- to gather your lunches.

For members of the public, lunch is available in the hotel restaurant, which is on the way to the lobby.

We will reconvene in about 10 minutes.