Public Comment Session
October 22, 2003

DR. McCABE: Well, thank you, everyone, for reassembling on time. At this point in our agenda, we will take time to hear from members of the public. One of our functions is to serve as a public forum for deliberations on the broad range of human health and societal issues raised by the development and use of genetic technologies. So we greatly value the input we receive from the public. We set aside time each day during our meetings to hear from the public, and we welcome and appreciate the views that you all share with us.

We also have received a number of comments. I mentioned before that we received 20 comments in writing in response to a more targeted request regarding genetics education and training. Most of those written comments are in Tab 1 of your briefing book, and there are several additional ones in your table folders.

I have three individuals who we will be hearing from this afternoon. We would ask each of you to please try to keep your remarks brief, under five minutes. I would prefer that they be more like two to three minutes with time then for us to discuss them around the table. We will confine this to a period of 20 to 30 minutes maximum because then we want to move on to discuss what we've heard today and how that begins to help us set the agenda for the committee in the future.

So the three individuals I have in the order I have them, just so you'll know when you should be ready to speak, is Dr. Shirley Jones from ISONG, Dr. Veronica Feeg from the American Academy of Nursing, and Dr. Fred Ledley from Mygenome.

So we'll start with Dr. Jones, and if you could come to the podium please, up front here.

DR. JONES: Good afternoon, Dr. McCabe, and members of the Secretary's Advisory Committee on Genetics, Health, and Society, fellow colleagues and concerned public. I am Shirley Jones, a founder, past president, and current member of the Ethical Issues and Public Policy Committee of ISONG, the International Society of Nurses in Genetics. ISONG is a nursing specialty organization dedicated to caring for people's genetic health through excellence in the provision of genetic health care services by fostering the scientific, professional and personal growth of nurses in human genetics.

The more than 350 members of ISONG reside and work throughout the United States as well as in Canada, Britain, New Zealand, Brazil, Israel, Greece, and Japan. On behalf of ISONG, I would like to offer the following comments in consideration of tomorrow's session on genetics workforce education and training.

Nursing is the prevention of illness, the alleviation of suffering, and the protection, promotion, and restoration of health in the care of individuals, families, groups, communities, and populations. Nursing practice encompasses the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation.

The hallmark of nursing education at both the undergraduate and graduate levels is the acquisition of the knowledge and skills necessary to continuously integrate and apply scientific and technologic advances into the science and art of professional nursing practice. As such, nurses are well-grounded in the skills requisite to the integration and application of new knowledge.

A genetics nurse is a licensed professional nurse with advanced specialty education and training. Genetics nurses help people at risk for or affected by disorders with a genetic component achieve and maintain health. Genetics nurses perform risk assessment, analyze the genetic contribution of disease risk, manage genetic information, and discuss the impact of risk on health care management for individuals and families. Genetics nurses also provide education and conduct research in genetics. Recognition of this expertise may be obtained by acquisition of the advanced practice nurse in genetics credential or the genetics clinical nurse credential through the Genetics Nursing Credentialing Commission.

In support of the importance of the integration and application of genetics knowledge into the professional practice of nurses, ISONG developed, in collaboration with the ANA, the statement on the scope and standards of genetics clinical nursing practice. This document identifies and describes the integration and application of genetics at both the basic and advanced levels of nursing. ISONG has authored and adopted multiple position papers that address the diversity of issues that confront the role of the nurse, including informed decisionmaking and consent, privacy and confidentiality of genetic information, genetic counseling for vulnerable populations, and most recently access to genomic health care.

ISONG members are at the forefront of efforts to assist their nursing colleagues in the integration and application of genetic knowledge. Most notable are four well-established programs: the Genetics Program for Nursing Faculty and the Web-Based Genetics Institute led by Cindy Prows at the University of Cincinnati; the Summer Genetics Institute through the NINR, led by Drs. Mindy Tinkle and Francine Nichols; and the Practice-Based Curriculum for Nurse Educators developed by Dale Lea at the Foundation for Blood Research.

Annually, ISONG hosts an educational conference that is well attended by not only the members of the organization but also by nurse clinicians, researchers and academicians who reside in the geographic region in which the conference is hosted. The 2004 ISONG conference is dedicated to the assimilation and synthesis of the state of the science for genetics nursing and the establishment of a research agenda that will be strongly focused on the delivery of and access to genetic health care services for or by individuals, families, groups, communities, or populations.

However, there is a significant lag in the time it takes to move knowledge to practice and apply scientific advances within the health care setting. As a consequence, there is inconsistent and irregular availability of genetic health care services as they become clinically valuable to the public. It is daunting to consider that at the present time there are 2.7 million individuals currently licensed as professional nurses in the United States who are in need of this knowledge. Therefore, it is critical and necessary that current programs continue to be supported and new initiatives identified and implemented to reduce the genetics knowledge to practice gap among the largest and most omnipresent group of health care providers, nurses.

At present, there is a national effort led by Dr. Judith Cooksey and her colleagues to identify and describe the issues confronting the development of an appropriately educated genetics workforce. The profession of nursing is the focus of the 2003-2004 effort. ISONG is actively involved in this effort, with many of its members serving on the advisory board of this federally-funded project. ISONG supports activities such as this and strongly urges the Secretary's Advisory Committee to recommend support for the identification, development and funding of such efforts so that the gap between identification and transfer of new genetic knowledge is significantly and uniformly reduced. Such action will strongly benefit those to whom we responsibly provide care.

On behalf of ISONG, thank you for the opportunity to provide public comment and for your

courtesy in receiving these remarks. The International Society of Nurses in Genetics is eager to continue dialogue with the Secretary's Advisory Committee as you investigate and develop recommendations about these important issues.

Thank you.

DR. McCABE: Thank you for your comments.

Any questions or comments from members of the committee? Any of the ex officios?

DR. WINN-DEEN: I understand you're asking sort of generically for our support, which I could probably say on behalf of the committee you have. But is there anything specific that we could do to help move education through the nursing workforce in a more expeditious manner?

DR. JONES: At the present time, we have identified several programs that are doing very well in training nursing faculty, but there is limited resources to getting those faculty to the programs. So if there is a mechanism to provide funding and opportunity for the faculty who are going to be our principal way of reaching the most individuals, that would be especially important.

Additionally, I think it would be helpful to take a very serious look at the programs that are attempting to train not only nurses but all health care professionals who are in the practice level, not in academia or research, and see what has worked, what hasn't worked, and why it's not working. It is unsettling that we still have nurses who feel that their competency and confidence in providing genetic health care is lacking.

DR. McCABE: Emily, did that answer your question?

DR. WINN-DEEN: Yes.

DR. McCABE: Any other questions or comments?

(No response.)

DR. McCABE: Okay. Thank you very much.

Our next speaker is Dr. Veronica Feeg from the American Academy of Nursing.

DR. FEEG: Mr. Chairman, members of the committee, and distinguished guests and colleagues, I'd like to also focus your attention for the next five minutes on education and workforce issues that will be covered much more in depth tomorrow. Thank you for the opportunity to present public comment on behalf of the American Academy of Nursing Expert Panel on Genetic Health Care, whose members are recognized nursing leaders. The Academy's mission is to transform the health care system to optimize public well-being. Members of the panel include nurse researchers, educators, and leaders in health policy related to genetics.

Education of the public and health care providers regarding implications of genome discoveries is an important priority for nursing. Nurses educate patients and the public on ways to protect and maintain their health. It is difficult to imagine any segment of our population who does not receive education on health-related topics from a nurse.

Nursing recognizes the need for basic and ongoing genetic and genomic education of the nursing

workforce in order for professional nurses to fully integrate their knowledge into the nursing care provided to individuals, families and communities. The nursing profession is partnering with other health care disciplines to address workforce issues and nursing education regarding genetics and genomics.

Let me first address undergraduate education. Three documents provide standards for nursing education regarding genetics and genomics for entry-level baccalaureate nurses. You've heard from ISONG; you can also read in the document from the American Association of Colleges of Nurses, who recognize the importance of genetic knowledge for nursing practice.

Several associations also have produced documents. The Association for Women's Health, Obstetric and Neonatal Nursing, and the Oncology Nursing Service have issued position statements that describe the responsibilities of members of these organizations regarding nursing care for persons considering genetic testing. Educational programs and articles in nursing journals provide the members to fulfill these responsibilities.

Comprised of organizations representing the health professions, NCHPEG, the National Coalition for Health Professional Education in Genetics, with a membership of over 120 organizations, includes 16 nursing organizations. In 2000, NCHPEG issued core competencies for health professionals regarding genetics, and again you heard before from the previous speaker and will hear tomorrow more information about NCHPEG core competencies.

For over two decades, nursing educators have received funding from HRSA for the education of nurses in genetics. A recent example of this is also the program that is now web-based from the University of Cincinnati and has reached over 230 nursing educators throughout the United States.

Let me turn to advanced practice education for nurses. A second goal of nursing is to assure that advanced practice nurses apply an understanding of the influence of genetics on health care in their care for specific populations. Pediatric nurse practitioners provide primary health care to children and manage the health care of children with chronic diseases. Content regarding inherited factors that influence reproductive decisions in families is a component of family nurse practitioners and pediatric nurse practitioner competencies as defined by the organizations I've mentioned, as well as the National Organization of Nurse Practitioner Faculties, known as NONPF.

An innovative interdisciplinary program to educate faculty on genetics topics is ongoing at Duke University. The genetics education program is providing genetics education to 25 teams of educators who teach nurse practitioners, nurse midwives, and physician assistants across the U.S.

Let me focus specifically on education of advanced practice nurses with specialties in genetics. Advanced nurses in genetics provide nursing care to people who have genetic conditions or health disorders that have a genetic component. These nurses complete graduate-level education and training in Master's degree programs. The scope and standard document also defines the parameters of advanced practice nursing in genetics.

Now, what do nurses in practice do? Application of genetic knowledge into practice occurs in a wide range of health care settings. Nurses include a genetic family assessment when they conduct a health assessment for women who are anticipating pregnancy or who are seeking prenatal care. Nurses provide education on healthy lifestyle practices prior to and during pregnancy, and education regarding genetic testing options. Nurses use genetic information in

identifying persons at risk for inherited forms of cancer, and then use the information for promoting adherence of at-risk persons to surveillance and treatment plans. Nurses monitor the impact of genetic information such as genetic risk status, follow predictive genetic testing on the health and well-being of individuals and their families.

Let me speak very briefly to the development of scientific knowledge regarding genetics and health. The development of knowledge regarding the application of genomic discoveries to clinical practice requires a cadre of scientists whose research is based in the nursing and genetic sciences. As you heard, the National Institute of Nursing Research has hosted for several years a summer genetics institute that has produced 66 genetic nursing research scholars. Products of nursing research on genetic topics will increase the understanding of the impact of genomic discovery on aspects of health such as decisionmaking, psychosocial coping, relationships between ethnicity and risk for inherited diseases.

Let me summarize on behalf of the Academy. As a component of this mission, the American Academy of Nursing has taken a leadership role for several years in assuring that genetic content is integrated into baccalaureate and advanced nursing education. Last year their position statement integrating genetics competencies into baccalaureate and advanced nursing education was adopted with a statement that follows: "It is the position of the American Academy of Nursing that organizations or institutions that are responsible for curriculum development, curriculum standards, approval or certification of basic and advanced programs, and those that accredit hospitals incorporate and include NCHPEG core competencies as part of their continued competencies for health professionals, including nurses; and that jurisdictions that license registered nurses establish policies that acknowledge nurses with competencies in genetic care."

I'd like to conclude with the statement that nurses are increasing their ability to include genetics education in undergraduate, graduate, doctoral, and continuing education programs. This reflects an important contribution by the nation's 2.7 million nurses to clinical practice, public and health professional education, basic and applied research, and health policy in order to assure the genetic health of the public.

Thank you.

DR. McCABE: Thank you, Dr. Feeg.

Any questions or comments? Reed?

DR. TUCKSON: Yes, just a brief one. We'll hear more later around genetic counseling and the adequacy of resources for genetic counseling. Is it your position that nurses ought to be supported in an educational way to be able to help fill that gap in a particular way, or do you see that as being one of the competencies of the nurse of the future?

DR. FEEG: I believe I can safely say that the Academy's position recognizes a distinction but acknowledges that as first responders of sorts, nurses are asked questions and need to understand the limitations of their knowledge and when to refer. But I think that it requires the support of continuing education and support for programs that develop those competencies to know the distinctions. If your question is related to are they the same thing, I believe the answer is no, but I believe that there's a way of combining the clinical skills.

DR. TUCKSON: Then the other question would be if you do not specifically single out the counseling function as a special competence, what are the kinds of -- Huntington sort of asked

these questions a bunch of times today, and I think if I understand his question, it gets to this idea that genetics is ultimately, if you transport to a few years from now, it's medicine. It's how medicine is practiced, just like everything else in medicine. So at the end of the day, what do you sort of see as being what it is that a nurse would be doing in the genetic era that would be particularly different than what they do today?

DR. FEEG: I think if you're asking the who does what when, and if in fact changes on the horizon would change roles, I think the answer would be, to fast forward, that would depend. I think that the statement that the Academy would support is that nurses are in fact involved with health discussions. Whether you want to relegate those to specific counseling activities, I don't think I would be prepared to say they would become the genetics counselors. But I think they acknowledge that the role encompasses a broader frame of interactions with patients. Does that help?

DR. TUCKSON: Thank you.

DR. McCABE: Brad?

MR. MARGUS: I understand, and I think we all agree, that we'd like to have the millions of nurses be extremely well-educated on genetics in the frontline role they play, and I understand you were saying that there are already steps being taken to incorporate genetics into curricula at different levels, but what I don't have a feel for, and hopefully you can answer safely, is is it really inadequate right now? Is it pretty good? You would know this and we won't, so is it really a real problem right now, something outrageous, or it's getting up to speed and you'd obviously like us to support it and funding to be there to continue it?

But how bad is it out there? Have there been any kind of tests or studies or surveys done? I've heard of some with physicians that kind of try to measure that. But what's it like out there?

DR. FEEG: Well, I can say that through the NINR support, there are ongoing studies for the roles that nurses play in assisting with decisionmaking and in -- I don't want to call it counseling but in other psychosocial issues. So I know that the research is ongoing.

To answer your question safely, I think that the position would be that in the best world, where there were additional funding available, we certainly need more and need to do better. In general, I think we've established a track record of core competencies in those expectations of what every nurse should have and what those who are specialized in genetics should have, and I think we'd look for the kind of support the committee would give us.

MR. MARGUS: So if you made up a test, just a basic test of what you think or what we all would agree or what you would decide is adequate to acknowledge today -- and I understand the field keeps changing and you want to keep continuing to educate people, but today what you'd want a nurse to know about genetics, would most nurses pass that test today?

DR. FEEG: I think I'd have to say as a nurse researcher myself, that's a tough question to answer without any kind of information to support what I might ask you back, in what aspects do you mean in the different roles that they would play? I think in some fronts they're extremely well prepared. I think in others, as the previous speaker mentioned, there are adequacies that need to be brought up to speed.

DR. McCABE: Brief comment, Hunt.

DR. WILLARD: Very brief, because I just want to make sure I understand from your perspective what role you anticipate or hope for in the nursing community. Is this any different than your approach to kidney disease, for example? Obviously your hope is and we trust that the nursing community actually has been educated about the kidney and how to recognize symptomology that's related to kidney malfunction and how one might counsel, in the lower-case sense of the word, patients who have kidney ailments. Is this different from that, or is this simply as if we'd just discovered a new organ and it's called the genome, and the problem is that nurses in their education, because we hadn't seen the genome yet, were never really exposed to that?

DR. FEEG: I think that your analogy of being an organ or a disease is what makes this different. I think genetics, as we've heard today, presents different kinds of issues. So I think I'd have to say that this is somewhat different. We've always looked to try to supplement education in whatever new things, in whatever diseases, or perhaps particular interests that large constituencies might want us to focus on. But the genetics changes that happen every day I think are presenting a situation that is different. So in looking for support for education for a workforce that would be competent, I think it's somewhat different.

DR. McCABE: Thank you very much.

Is Dr. Ledley here?

(No response.)

DR. McCABE: Okay. Perhaps he's coming tomorrow. I would point out in the packet that was at your place today, there's an article by Dr. Ledley from Nature Biotechnology, August 2002. There are copies out on the table outside talking about a consumer charter for genomic services. I think it would be important for individuals to look at that.

With that then as a background, I want to thank the speakers, the public for both their written and verbal comments.