

October 23, 2003

Secretary's Advisory Committee on Genetics, Health and Society

Good afternoon. My name is Dawn Allain, and I am the president of the National Society of Genetic Counselors. It's my pleasure to speak on behalf of NSGC, which represents genetic counselors worldwide and is the leading voice, authority and advocate for the genetic counseling profession.

Like others, NSGC recognizes we are entering an era where genetic services will increasingly have a significant impact on health care. Although genetic advances will benefit health care services, they will also pose challenges, particularly as they relate to access to genetic care. Specifically, many areas of the country have few, or no geneticists or genetic counselors, and many non-genetic health care professionals have minimal training in basic genetics. NSGC supports the expansion of not only the genetic counselor workforce, but also all genetic professionals. We also support increased training and education of health care providers. I would like to highlight some key areas, which NSGC believes could increase the genetic counselor workforce, as well as access to genetic services.

In regards to increasing the genetic counselor workforce, NSGC proposes three areas for consideration. First, we encourage SACGHS to support renewed passage of and appropriations for the Allied Health Reinvestment Act. If this act is renewed and budgeted for, and HRSA develops grants targeted specifically for genetic counselors, genetic counseling training programs could be eligible for grants promoting recruitment of minorities, development of didactic education and clinical internships and programs for faculty development.

Second, NSGC recognizes that access to genetic counseling and testing services requires genetic specialists to practice in underserved patient populations and/or geographical areas. Inclusion of genetic providers into federal acts and programs would enable expansion of genetic services into these areas. For example, while federal programs, such as HRSA's National Health Service Corps, specifically aim to increase access to primary care physicians in underserved populations through scholarship and loan repayment program, there are no programs specifically targeted for genetic providers.

NSGC would like SACGHS to support the development of federally funded mechanisms for enhancing clinical genetic services in underserved populations. We also urge SACGHS to promote developing network infrastructures which will allow the provision of genetic services through telegenetics and web-based modalities enhancing access to genetic services in these areas.

Third, employability of an increased genetic counselor workforce and improved access to genetic health care is directly tied to reimbursement for genetic services. According to preliminary data obtained by NSGC, many medical centers subsidize genetic counseling services because there is no CPT code for genetic counseling services and there is no

manner in which genetic counselors can bill. The NSGC is committed to obtaining more comprehensive coverage for genetic counseling and testing services. We encourage SACGHS to make appropriate agencies aware of the current problems of billing and reimbursement and support state-based licensure for genetic counselors, the lack of which limits patients' access to genetic health care.

Separate from services already provided by the clinical workforce, it is clear that non-genetic health care providers are already providing some level of genetic services, including ordering and interpreting genetic tests. NSGC believes a well-informed and prepared health care workforce will lead to appropriate utilization of genetic services. We have and will continue to play an active role in educating health care professionals about genetic counseling and testing services through the development of professional guidelines and genetic education programs.

Based upon our experience, NSGC believes that the development of genetic curriculums or educational programs should be tailored to each medical specialty to ensure that each health care provider understands the immediacy and relevance to their patient population. Education must also stress the underlying genetic component in common complex disorders, as well as single-gene disorders. In addition, educational programs must incorporate mechanisms for distance learning to help meet the needs of educating non-genetic health care providers. NSGC requests that SACGHS support the development and implementation of model educational programs.

In conclusion, genetic counselors currently provide a large percentage of direct patient care, genetic services, and education of health care professionals. Therefore, increasing the genetic counselor workforce will be critical to continuing translation and integration of genetics into routine health care. We encourage SACGHS, in conjunction with professional and consumer organizations, to continue to develop thoughtful yet practical strategies addressing issues regarding oversight for genetic testing, education of health care professionals and increased workforce.

The NSGC membership has vast experience and expertise in direct patient care, laboratory services, research, public policy and industry-based genetic services. We are available to work closely with SACGHS as you continue to address your important mandate.