

March 2, 2004

Secretary's Advisory Committee on Genetics, Health and Society

Good morning. I am Dawn Allain, President of the National Society of Genetic Counselors. NSGC represents approximately 2000 master-level genetic counselors who practice in a variety of medical specialties, research centers and biotechnology companies.

NSGC recognizes that in order to realize the full benefit of genetic technologies, clinical genetic services must be integrated into current health care delivery models. This morning, I will present two issues that must be addressed to achieve this goal as well as to facilitate improved access to genetic services for American citizens.

First NSGC feels that inadequate coverage and reimbursement for genetic services is a significant economic barrier to providing adequate genetic health care. This is a direct result of four factors. First is the failure of third party payers to recognize clinical genetics as a subspecialty in routine health care services. Although the American Board of Medical Subspecialties formally acknowledged medical genetics as a subspecialty, many health plans and payers do not provide a listing of genetic practitioners within their plans. This suggests that genetic services are not yet appreciated as standard or routine medical care.

Additionally, some third party payers continue to deny coverage for genetic services by claiming that they are experimental or because counseling services are deemed non-essential. Third, CMS does not currently recognize genetic counselors as allied health care providers. This prevents facilities from billing for genetic services that are rendered by a board-certified genetic counselor. The combination of these problems frequently results in greater out-of-pocket costs for consumers or consumers forgoing services entirely.

Finally, while progress has been made in developing current procedural terminology or CPT billing codes for genetic diagnostic tests, as pointed out yesterday, CPT codes are still lacking for the genetic counseling and evaluation services that precede and follow most genetic tests. This system shortfall continues to make it extraordinarily difficult for genetic clinics to bill for services. As a result, genetic counseling services are frequently considered to be non-reimbursable and there is growing concern among genetic professionals that genetic services will be reduced unless the financial impact of providing services can be mitigated. If genetic service providers' positions are eliminated due to inadequate or non-existent reimbursement, this will only serve to worsen access to genetic services, particularly for clients in underserved populations.

NSGC is currently funding a research study to analyze the cost-benefit ratio of prenatal counseling services. We encourage SACGHS to identify and promote additional companion research that will add to the evidence-based outcome data necessary to tackle billing and reimbursement issues. In addition, we encourage SACGHS and CMS to work with genetic professional organizations and the AMA to establish CPT codes for clinical genetic services and to recommend to administration and Congress that genetic

counselors be incorporated into federal statute and recognized as allied health care providers.

Second, NSGC recognizes that additional genetic training for non-genetic health care professionals and specialty training of genetic specialist is critical. AS NSGC has testified previously, there are only about a 150 genetic counselors graduating from master-level programs annually. There are even fewer medical geneticists whose training numbers have dropped in recent years and even fewer advanced nurses in genetics. With the demands for genetic services on the rise, this training pipeline is inadequate.

In addition, the lack of basic competencies in genetics of health care professionals is a barrier. Numerous peer-reviewed studies indicate that many non-genetic service providers lack genetic knowledge, expertise and confidence in their abilities to provide these specialized services. An inadequate genetic workforce poses several hazards, including the potential to miss critical opportunities for preventive medical strategies. Furthermore, inaccurate genetic information given to consumers may raise undue alarm and/or prompt ill-advised and costly medical decisions, testing or interventions.

If consumers are to benefit from the many advances in medical genetics, steps must be taken to ensure access to a well-trained health provider workforce that is large enough to handle the public demand. We encourage SACGHS to identify novel methods to increase the number of qualified providers through genetic counseling training programs, medical genetics residency program and genetic nursing programs, as well as continuing to support the educational efforts targeting primary care providers and allied health professionals.

As an organization that is currently developing a strategic plan, the NSGC understands the challenges that face this committee as well as the difficulty of maintaining focus on the bigger picture. The scope of this committee's charge includes assessing how genetic technologies are being integrated into health care and public health. The top priorities you have raised both begin and end with access.

Therefore, NSGC strongly encourages this committee to evaluate achievable goals in a manner which will consistently move forward the ultimate objective of improved access to genetics as part of a global health care program. NSGC is available to support SACGHS in this endeavor. Thank You.