NSGC Foundations—Then, Now, and Tomorrow

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It is a great honor to serve the National Society of Genetic Counselors (NSGC) as President in the upcoming year. This year, NSGC celebrates its silver anniversary—a mere 25 years ago our society was founded to promote the profession of genetic counseling. We have gone from a fledgling group of genetic counselors to over 2000 members nationally. NSGC is (and has always been) filled with hardworking, intelligent individuals who are excellent communicators, flexible in our roles and able to communicate our expertise in various areas. More than any other genetics profession, ours has demonstrated flexibility in adapting to the new areas of specialization. We, as genetic counselors, have demonstrated that we play a key role in health care, and after having worked so hard for recognition those 20+ years ago, we are recognized as experts with a significant contribution. As importantly, the NSGC is—without question—recognized as “the leading voice, authority and advocate for the genetic counseling profession.” Today, I want to talk briefly about where NSGC had been in the past, to reflect on our current status as a professional society, and to envision the future and how we can work together to get there.

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At the start of our society, individual members played a driving role in every professional activity that NSGC conducted; the success of the society was intrinsically related to the vision, dedication and leadership of these early leaders and their grassroots efforts. During my President elect year, I spent some time at the executive office, digging through some of the archives. It reinforced for me just how visionary our society’s founders were—it may astonish you, as it did me, to learn that almost 20 years ago our founding members were discussing issues of specialty training, as well as the need for licensure and reimbursement. Rather than being disappointed by the fact that we are still working on these critical initiatives, we should take heart that our founders had such vision (in fact vision beyond their time), and that their thoughtfulness and hard work provided us with a strong direction for our future. As Henry David Thoreau said, “If you have built castles in the air, your work need not be lost; that is where they should be. Now put the foundations under them.” Those foundations may take years to build before we finally see the castle before us, but the success of NSGC in the past 25 years is a result of the combined vision, the development of a strategy to achieve the vision, and the focused hard work of our members. NSGC’s goal today is to both maintain the strong castles we have worked hard to develop, and also to imagine new castles, and to lay the groundwork for the next 25 years.

Each of NSGC’s current strategic initiatives are driven by our mission, “to promote the genetic counseling profession as a recognized and integral part of
health care delivery, education, research and public policy.” As you have just heard from Dawn Allain and Bea Leopold, the past year has further solidified our society’s foundations. We have made great strides with regards to prioritizing billing and reimbursement in a stepwise manner, starting the process of defining a scope of practice for genetic counselors, and assessing various genetic service delivery models. We have achieved licensure in our third state, and the Journal of Genetic Counseling received indexing in Medline! NSGC has worked hard to ensure that we are well positioned externally to achieve our mission through these initiatives, and we will continue our efforts in the upcoming year with the momentum we’ve already developed.

To continue the strong forward movement of our society, it is critical that we remain focused primarily on the strategic initiatives endorsed by the Board of Directors last year. We need to continue to raise visibility and awareness about genetic counselors—our varied roles, our flexibility in roles, and our availability to serve in less traditional non-clinical roles. We must take every opportunity to educate health professionals about our knowledge and expertise, but is it just as important that we do so in a way that does not define our practice in an exclusionary or exceptional manner. As we define our scope of practice, we must, at the same time, act confidently on both the national and local level to demonstrate how we can fit into current health systems, focusing on the strengths that we bring to the health-care team, and initiating outcomes-based studies to document, in an evidence-based manner, the value of our services. Because there is increased power when our voices speak together, we must also work together with our geneticist colleagues and with other allied health professions. Key to increasing our visibility in the medical system is teamwork—in each of our workplaces, we face different issues, and bring different strengths to the medical teams around us. We must listen with respect to the specialists around us, project confidence in our own skills and expertise, and work together with our medical colleagues, both in and outside of genetics, to develop creative solutions to provide high caliber services to all our patients. Beginning tonight, when we host our open discussion of progress on the strategic plan, we will regularly invite feedback on the scope of practice and genetic service delivery models as data emerges. In the upcoming year, we will also continue to host discussions, both at our conferences and in our publications, about the role of “non-directiveness” in genetic counseling, and who the users of our services are. I invite you to share your thoughts at these forums.

Under the leadership of Robin Bennett and Dawn Allain, a task force will establish an NSGC Foundation in the upcoming year. The mission of the foundation will be to support genetic counseling research and education, and enable the profession to develop innovative programs and to reach out to new fields and organizations around our mission. Establishing this new, related organization will require hard work and dedication of our members as we establish a new founding board and initiate a capital drive to support the foundation in achieving its mission over the next several years. While the process of beginning a foundation is not a short-term project, nor is it one to be taken lightly, we expect that ultimately an NSGC Foundation will provide new financial resources towards achieving key goals in our strategic plan, as well as visibility resources for genetic counseling. I hope that many of you will support our foundation in the future, both through charitable donations as well as in assisting to identify individuals who may be interested in making private or organizational contributions.

To maintain our forward progress of the society, we must ensure that we have strong new professionals entering our field with key strengths that will help us continue to grow. Long-term professional stability requires that we raise awareness of our profession, continue our ability to successfully recruit facile new professionals, nurture leadership within our society and maintain an effective organizational structure to achieve our society’s goals. As such, many of our initiatives in the upcoming year will be directed internally, at our own organizational foundations.

To support our society’s mission, our incoming colleagues are critical, and it remains important that our society dedicate resources towards raising the visibility of our profession, and identifying and recruiting top candidates to join our profession. I have asked Jolie Matheson and the Membership committee to develop a rigorous plan to raise awareness about genetic counseling in colleges and universities across the nation, and in the long term we must also address visibility at younger ages, in the K-12 school programs. In conjunction with the Association of Genetic Counseling Program Directors, the NSGC will work to identify contacts at specific colleges, and to identify genetic counselors who are willing to work together to offer resources to advisors and students nearby. Our society will also unveil an online speakers’ bureau in the next several months, spearheaded by Terri Creeden and Kristi Morrell in the