

---

*Professional Issues*

---

## NSGC Foundations—Then, Now, and Tomorrow

Kelly Ormond<sup>1,2</sup>

---

This 2004 Presidential Address was presented at the annual education conference of the National Society of Genetic Counselors in Washington DC on October 9, 2004.

---

**KEY WORDS:** National Society of Genetic Counselors; genetic counselors; presidential address; genetics; future of genetics; future of genetic counseling.

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.

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

---

<sup>1</sup>Department of Medicine and Center for Genetic Medicine, Feinberg School of Medicine, Northwestern University, Chicago, Illinois.

<sup>2</sup>Correspondence should be directed to Kelly E. Ormond, MS, CGC, Graduate Program in Genetic Counseling, 676 N. St. Clair #1280, Chicago, Illinois 60611; e-mail: k-ormond@northwestern.edu.

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 it is 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

Education Committee. NSGC, represented by Lori Hamby, is also collaborating with the American Society of Human Genetics to address genetics visibility in pre-college students. Regardless of the forum, genetic counselors are terrific at speaking passionately about our profession, and many of you probably already give some talks at your local institutions. I hope that if contacted you will, in conjunction with this effort, reach out to those at your local schools, helping raise awareness of genetic counseling to both our future colleagues and clients.

With regards to leadership within our society, it is often mentioned that approximately half of our society's membership has less than 5 years of experience in the profession. As a program director, I know that many of our "newer" members enter the profession with a wide range of experiences, and great leadership potential. I've asked Nancy Callanan, our president elect, to work with the society to develop a formal mechanism to identify our future leaders, and to help provide them with the resources to become more involved in the NSGC. Many individuals have the mistaken perception that leadership in NSGC is limited to a few people, and that being a leader requires a large commitment (such as being on the NSGC board). In the past years, I have worked with leaders at many levels. Some are individuals working on a local level to host a meeting to discuss licensure in their state, or to keep other genetic counselors in the state aware of local legislation that might affect clinical practice. Some are genetic counselors who take a few extra hours to give a talk to medical students to raise awareness about genetic counseling to 20 more future physicians. Some are leaders who have helped to plan the regional meeting or the annual conference. I feel strongly that we can all be leaders in our society, and our society is built on the premise that we are as strong as our membership. I would like to challenge each of you to take on a leadership role on behalf of NSGC to further strengthen the genetic counseling profession. Whatever your interest, it does make a difference, and without it our society would not be as strong as it is today. As it was in the past, NSGC's members *are* "the society," and the success of the society remains intrinsically related to the vision, dedication and leadership of our entire membership.

In addressing our formal leadership structure, I have also asked Dawn Allain to continue the work I started this year, assessing the most optimal structure for the organization's governance. To remain well positioned for the future, we need to ensure that our organizational structure allows us to be efficient, and

able to move quickly in the new global environment. We have already assessed the various roles of each board member, and are working with the executive office to move towards a more efficient approach to many of the projects currently completed by volunteers. As our organization grows and matures, we need to regularly re-evaluate our organizational systems to determine whether they are the most effective systems to move NSGC forward into the future, and to assure that our board structure continues to provide adequate representation to our changing membership.

In an earlier plenary session at this meeting, Dr. Fernandez reinforced that the issue of health disparities are critical to the future of genomics. Many national organizations have prioritized the issue of health disparities in recent years, addressing ways that health care providers can work to provide equitable access to individuals of all racial, ethnic and socioeconomic classes. Genetic services are no different. As it relates to NSGC's mission of promoting our profession, we need to focus on two areas: First, how we can work with our research colleagues to ensure that data on racial and ethnic admixtures will be incorporated into research in an ethically and socially responsible manner. Second, along with our clinician colleagues, we need to address the provision of access to culturally competent genetic healthcare, including the relationship to minority recruitment into our profession and the provision of genetic counseling services to culturally diverse populations. We are already well aware that our profession is under-represented in ethnic minorities as compared to our national census. The dearth of diverse genetic counselors as service providers impacts our ability to provide culturally competent care. Even when we are trained to be culturally aware, patients may not feel comfortable coming for services, or may not have access to services if they are offered primarily in academic health centers. I was recently told a story by an African American physician, about how his well-educated wife, also an African American, felt uncomfortable discussing prenatal diagnosis with her Caucasian genetic counselor. He stressed that even if we feel comfortable working with clients of diverse backgrounds, our clients may not feel as comfortable, and by diversifying the ethnic faces of our profession we will serve our clients better. However, even if we begin to recruit genetic counselors from minority ethnic backgrounds, we need to provide a welcoming professional environment, and to help develop systems that will support positions in various communities so that our new colleagues have increased opportunities to give back to their

own communities. Towards this end, and building on the work of Nancy Warren and the Midwest Consortium of Program Directors addressing minority recruitment, I am establishing a multidisciplinary working group to address these issues. This working group will include representatives of NSGC and other related genetics organizations, and will have a variety of ethnically diverse members. The working groups goals over the next years will be to develop a statement of value in this area and a strategic approach, including both short- and long-term plans, for how our society can continue to move along the continuum of cultural and linguistic competency and reduce disparities in genetic services as a result.

Finally, I feel strongly that our society must both continue building our current foundations, but also be envisioning new castles that we may build in the future. To ensure that our society can do this, we need to imagine how genetic services will occur in 10, or even 20 years. This is a challenge for all of us, and requires that we think creatively. It also requires that we regularly re-assess what we are doing, both for how it is working on a day-to-day basis, and for whether it will continue to help us move our society and profession forward in both the short and long term. I am asking Susan Manley and the Professional Issues committee to take on some of the forward-thinking questions that may affect our profession, including issues such as the potential for further specialization or even a doctoral tract in genetic counseling. There are many sides to these issues, and they have the potential to broadly affect all aspects of our profession, beyond simply training and certification issues. To help evaluate this option, we will assess other professions that have made similar transitions in recent years, so that the genetic counseling profession will be prepared in the future if faced with such changes. We look forward to share our findings with our sister organizations, including ABGC, who will have the ultimate decision-making on these critical topics.

Thoreau said “We must walk consciously only part way towards our goal, and then leap in the dark

to our success.” While some of the issues that NSGC will be addressing in the upcoming years may seem unfamiliar, premature, and perhaps even a bit scary to many of you, they are issues that will become important in the next 5–10 years. By proactively assessing them our society will be stronger. While our organization grows and matures, we maintain our focus on NSGC’s mission, “to promote the genetic counseling profession as a recognized and integral part of health care delivery, education, research and public policy,” directing our energies towards the good of the entire society. NSGC’s Board of Directors, Executive office staff and contractors are a knowledgeable and dedicated group, representing all geographic regions, all areas of speciality practice, and a range of experience from less than 5 years to greater than 20 years in the profession. They truly represent the members of the society, and members can feel confident about the skills and thoughtfulness of those leading our organization through values based decision making over the years.

As a four time marathon finisher, I have learned many things. One of them is that individuals and groups can often far surpass anything that you ever thought you could achieve. But a far more important lesson is about the preparation—if you put in the training miles, the actual marathon “race” (and I use that term loosely myself), comes easily because you know what to expect, and can gauge how quickly or slowly you need to move to get to the finish line. Patience, trust in our preparation and skills, and tenacity are the key towards the finish line of our societal marathon, but we are well on our way. I assure you that, as your President in the upcoming year, I will work tirelessly to promote our society and the profession of genetic counselors, even if there isn’t a medal or discrete finish line in view. That said, in the words of Elvis, it’s time for “a little less conversation, a little more action.” I assure you the upcoming year will be action-filled for NSGC, and it will be my pleasure to serve you, and the NSGC, in the upcoming year, and I look forward to representing each of you. Thank you.