

Presidential Address 2003: NSGC Living Life Forward

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Soren Kierkegaard, a Danish philosopher, once wrote: "It is quite true what Philosophy says: that Life must be understood backwards. But that makes one forget the other saying: that it must be lived forwards." (Andrews et al., 1996)

Each time I begin a new challenge, I reread Kierkegaard's quote. It helps me reflect on the path I took to get where I am in the present and then begin thinking about where I am going in the future. Today I am here in North Carolina as the President of the National Society of Genetic Counselors (NSGC) because you, my colleagues, believe and trust that I will represent your interests and the interests of our organization. It is a privilege and honor to have been elected to this position. I look forward to representing NSGC over the next year.

But let us apply Kierkegaard's quote to the NSGC. Robin Bennett, Past President I, and Bea Leopold, our Executive Director, have just highlighted what NSGC has accomplished over the past year. I will discuss how NSGC can live life forward. Clearly, since the inception of NSGC the practice of genetic counseling has changed. Our special-interest groups (SIGs) alone illustrate the diverse roles we have created for ourselves. Even how we provide services is evolving, with counselors using telegenetics and web-based modalities. We are all well aware that the promise of new information and technology arising from the completion of the human genome sequencing portends more change for us in the future. To paraphrase Dr. Francis Collins' address to us at our 2001 annual education conference, "Now is the time for genetic counselors, and the NSGC, to embrace these changes and step into our rightful leadership role and lead others into this new and exciting future" (Collins, 2001).

There was a time when NSGC's primary focus was to establish itself as a professional organization. This is no longer the case. NSGC is recognized by many

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as the leading voice, authority and advocate for the genetic counseling profession. However, our profession is not as well-recognized as needed. We must continue to market ourselves to make sure that genetic counseling services are integrated into health care delivery models, education, research and public policy.

With the expertise of our public relations firm, STAR/Rosen PR, a division of the STAR Group, NSGC has been successful in targeting the general public through mass media exposure. Through the work of our social issues committee, led by Cheryl Scacheri, and presidential testimony, we have also succeeded at being heard on important policy matters such as genetic non-discrimination, oversight of genetic testing, funding for clinical genetic research, and access to genetic services. Publication of our practice guidelines has also increased recognition of our professional expertise. However, increased professional recognition requires more than media exposure, practice guideline publications, and government testimony. As president, I will make every effort to ensure that the NSGC implements a broader approach in marketing our organization. We need an approach that both raises our voice in policy decision-making and increases awareness of our profession among those from other agencies, including third-party payors, health care service providers, other professional organizations, consumer advocacy groups, law, ethics, and policy institutions and the business community.

Why is increasing our visibility to organizations outside of the genetics community important? Allow me to highlight a few examples. First, the Reproductive Health Technologies Project (RHTP) is an organization whose mission is to advance the ability of every woman to achieve full reproductive freedom with access to the safest, most effective, and preferred methods for controlling her fertility and protecting her health (Reproductive Health Technologies Project, 2003). According to one of our colleagues, RHTP is currently educating their membership about genetics and genetic technology because RHTP believes they need to be informed about these technologies and the issues involved in order to have a voice in future policy discussions. As our colleague pointed out, NSGC is the logical choice for them to turn to for assistance—if they were aware we existed. Imagine the influence in policy discussion we could have if RHTP were willing to collaborate with NSGC on issues of reproductive options and equal access to genetic technological advances. As a second example, I recently had the pleasure of attending the Genetic Alliance conference this past August. While there, I spoke to families about reimbursement for genetic services. Consumers are just as frustrated as we are that they cannot obtain adequate coverage for clinical genetic care. Imagine the force we could be if we formed a coalition group with consumers to fight for reimbursement of medical genetics services. Finally, NSGC needs to reach out to biotechnology and pharmaceutical companies and inform them about the knowledge, experiences, and skills of genetic counselors. Imagine the impact we could have if industry looked to genetic counselors for assistance in executing and implementing profitable, yet responsible, product launches.

I submit to you that the opportunities for collaboration, which in turn will increase recognition of NSGC and its members, are endless. They are also critical to the future of our profession because policy-makers, third-party payors and industry are influencing the use of genetics in medicine. If genetic counselors want to be an integral part of future delivery models, NSGC must increase our leadership role with these entities. As your president, I will strive to find ways to make these various communities aware of the unique skills genetic counselors have, our professional expertise, and how working together can be mutually beneficial. It is only through persistent global marketing of our profession to a wide variety of organizations, including the general public, that we can truly make genetic counseling and the NSGC well recognized by all.

To this end, I am appointing a Visibility Task Force, whose mandate is to develop a plan to increase NSGC's recognition among governmental agencies, third-party payors, professional and consumer-based organizations, health care providers, and the business community. Using data from the environmental scan, this task force will work with a consultant and perform a feasibility study to assess the workforce demand, logistical processes, and financial aspects necessary to achieve our goal of increased recognition and a seat at decision-making tables. But what will this ultimately mean, you may ask? Does this mean that we will hire a lobbyist or a genetic counselor to officially represent us? Does this mean we need to focus on educating human resource professionals that they should include genetic counseling services as a health care option along with other sought-after health care benefits? Does this mean we need to focus on educating other health care providers about the value of genetic services? This is what we need to decide. It is a complicated decision, which requires objective information and involves weighing the benefits and limitations of each option while taking into account the financial implications for our organization.

In addition to the task force, I have asked Susan Manley, chair of the Professional Issues Committee, to continue the work of our previous chair, Kristen Shannon Mahoney, and explore the possibility of NSGC joining organizations, such as the Health Professions Network [HPN] (2003). HPN represents diverse aspects of allied health, including provider organizations like NSGC. The mission of HPN is to work together in a cooperative and interactive manner on issues relevant to health care (<http://www.healthpronet.org>). For their fall meeting, HPN is holding workshops on working toward allied health reinvestment legislation, licensure, Medicare and Medicaid services, lobbying, and increasing training of allied health providers. Clearly these topics are all relevant to NSGC. To acknowledge that we are part of a large group of allied health care providers, in October you will be receiving an Allied Health Provider pin from our executive office with your membership mailing. I encourage you to wear this pin during Allied Health Professions Week, which takes place during the first full week of November. If genetic counselors achieve greater recognition as allied health providers and

collaborate with organizations such as HPN, we may be able to achieve our objectives regarding educational funding, reimbursement and other professional goals more quickly.

At our board meeting, your board of directors will be addressing other methods NSGC can use to increase our professional recognition and leadership role in the world of medical genetics. For example, we will be considering a proposal from the Industry SIG to update our fact sheet and develop a business-focused brochure about NSGC and our diverse membership. This brochure will be used to solicit support and funding from industry, as well as to market the NSGC to other organizations, consumers, and potential students. Your board of directors will also be discussing the methods NSGC uses to reach out to other professional organizations. There are a number of questions at hand. For example, which external meetings should a board representative attend? When and why should NSGC appoint liaisons to other professional organizations? At which conferences does NSGC want to have an exhibitor booth? Also, in today's electronics-savvy era NSGC must continue to insure that our electronic face to the world—our website—provides state-of-the-art information about our organization and high quality resources for members and non-members. At our board meeting, we will be deciding what financial commitment is necessary to continue enhancement of our website.

Another area I hope to address in the coming year is the organizational structure of NSGC. The manner in which our Society is governed is directly linked to its mission and focus, as well as our ability to successfully meet the goals delineated by strategic planning (Reid, 2003). NSGC currently has a 20-member board consisting of elected officers, appointed committee chairs and regional representatives. We need to insure that our board is nimble enough to respond to a changing environment quickly, efficiently, and cost-effectively, while taking into account the diverse voices within our organization. Does our current board structure meet this demand or does it need to change? To address this question, I have appointed our President Elect, Kelly Ormond, to chair a task force that will assess how well the board of directors currently functions to represent and lead the organization. This committee will present their findings at our interim Board of Directors meeting in the spring of 2004; depending on the committee's report, we may consider ways to restructure the board to increase NSGC's effectiveness.

NSGC also needs to insure that dissemination of important information to our membership occurs rapidly. I am pleased to announce that we have budgeted for mass e-blast communication. This will allow us to inform you of important issues or request your input on matters, with an e-mail directed at each of you individually. I hope this will prevent important issues from being lost amongst the active communication on our member listserv and will allow us to maintain fast and secure communication with those members who choose not to utilize the listserv. These e-blasts will also be the medium for sending out your electronic copies of Perspectives and the Journal of Genetic Counseling.

When we live forward, we cannot overlook the projects that we have already committed ourselves to such as billing and reimbursement, licensure, and mentoring. Although increasing our visibility and leadership role is an important goal for our organization, if we cannot bill and obtain reimbursement for our services it may affect our profession's survival. NSGC must continue to pursue a multi-pronged approach to obtaining third-party payor reimbursement of genetic counseling services. We must continue to have representation in committees like the American Medical Association's health care professional advisory committee, to which Debra Lochner Doyle was appointed this past summer. NSGC must also continue to encourage and promote research aimed at obtaining current information on the scope of billing practices. In addition, as your president, I will use our testimony before the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) and other government organizations to illustrate why it is critical that the federal government support and influence appropriate federal and third-party payor reimbursement of genetic counseling services. I also commit to initiating NSGC's efforts to educate employers and insurance providers about the benefits of comprehensive coverage for clinical and diagnostic genetic care.

One cannot talk about reimbursement without addressing licensure. The NSGC has been promoting the pursuit of genetic counseling licensure for the past 10 years (Bernhardt and Doyle, 1994/95). Yet many members are quick to point out that only California and Utah have approved licensure legislation and only 14 other states are discussing or actively pursuing licensure. Do not be discouraged, after all NSGC is only 24 years old. According to Willaim Northey, the Professional Development Research Specialist from the American Association of Marriage and Family Therapy, it has taken AAMT 30 years to obtain licensure in 42 states (W. Northey, personal communication, April 13, 2003). Elizabeth Clark, the executive director of the National Association of Social Workers, informed me that it took over 20 years to obtain social work licensure in 48 states (E. Clark, personal communication, June 17, 2003). Both organizations stressed that the keys to acquiring licensure are hard work, money, patience, and then more patience.

While genetic counselors have patience and commitment to hard work, we lack the financial means necessary to achieve licensure. To address this issue, Katherine Schneider, Past President II, and I are recommending the creation of a Licensure Finance Subcommittee. This subcommittee's role will be to develop a mechanism to disburse a percentage of your membership dues back to your individual states for assistance in procuring licensure. This money will be available to hire lawyers, licensure consultants or a state lobbyist to assist with your licensure efforts. Obtaining reimbursement for our services and licensure will not happen immediately. Under my leadership, the BOD will strive to be persistent and continue to find ways to advance these causes.

I see mentoring as another key issue that NSGC needs to continue to address. Our organization depends on the engagement, involvement, and commitment of

all of us. Membership in NSGC means ownership. Ownership means investment of time and responsibility. Currently, 46% of our members have 5 or less years of experience. Consider this—almost 50% of us have been practicing for fewer than 5 years. We may think this is a limited amount of experience, yet it is you, those members with less than 5 years of experience, who will soon take on the leadership roles in our organization. I encourage new members to join a committee, participate in an SIG, or talk to a board member; your active participation is needed. Those of us who have been practicing for 5, 10, 20 or more years must encourage and welcome new members. They are our future. Each and everyone one of us must reach out to our newer members and educate them about the history of NSGC and about the benefits of being involved in NSGC, both professionally and personally. We must also listen to them, seek out their talents, and utilize their ideas and energy to advance the mission of our organization. I assure you, I would not be standing here today as your president, if I had not been so warmly welcomed into NSGC, listened to, and mentored. Mentoring must be a concerted effort by the entire organization. This year the Board of Directors will continue the Leading Voices campaign, which Robin Bennett created, to recognize members who contribute to NSGC. I have asked Stephanie Kieffer, chair of the membership committee, to expand our mentoring program to include mentoring of leaders. I have also requested that every board member commit to mentoring our future leaders and have set aside time during our board meeting to address how we will achieve this goal. Today, I challenge those of you in this room to do the same. Look around you. Find someone you do not know and before you leave our open mike session introduce yourself. Welcome them into NSGC and into the exciting profession of genetic counseling. Perhaps the person you meet today will be a member of our Board of Directors in the future.

In pondering Kierkegaard's quote we must remember that although looking back at the past is important, it does not mean we must be wedded to the past. NSGC has many challenges to incorporate into our fourth strategic plan. I remind you that strategic planning is not something done in isolation by the leadership for the members—it must be done by all of us together. I, like others before me today, urge you to complete the internal scan survey as soon as you get back to your offices. It is imperative that you voice your thoughts about the critical issues facing the NSGC and our profession. Many of you have already contacted me to voice concerns, pleasures, or ideas regarding our organization. I encourage you to continue to pick up the phone, write, fax or email me, your region representative or other board members your thoughts over the next year. Your input is critical to the success of NSGC living forward. This is an exciting, yet challenging, time for the NSGC, as we work toward broadening our visibility and voice among a diverse group of communities. As your president, I look forward to working with each of you to tackle the issues before us. Thank you for this opportunity to represent you.

REFERENCES

- Andrews, R., Biggs, M., & Seidel, M. (Eds.). (1996). *The Columbia world of quotations*. New York: Columbia University Press.
- Bernhardt, B., & Doyle, D. (1994/95). Gathering reimbursement and licensure strategies. *Perspectives in Genetic Counseling*, 16(4), 11.
- Collins, F. (2001). Mainstreaming genetic medicine: A golden opportunity for genetic counselors. Paper presented at the *National Society of Genetic Counselors 20th Annual Education Conference: Current Advances—Anticipating Change*, Washington, DC.
- Health Professionals Network (2003). Retrieved September 3, 2003, from www.healthpronet.org/newsletter/spring03.pdf.
- Reid, K. (2003). The right size for strategy. *Association Management*, 55(1), 54–61.
- Reproductive Health Technologies Project (2003). Retrieved September 5, 2003, from www.rhtp.org/about/about.htm.