

2008 National Society of Genetic Counselors Presidential Address: The NSGC Should Do Something About That... and We Are

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Received: 10 December 2008 / Accepted: 15 December 2008 / Published online: 20 February 2009
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We are approaching our 30th year anniversary in 2009 and now is the perfect time to start thinking of where genetic counseling is going and where we want the NSGC to move over the next 30 years. Before we get to tomorrow I think we can learn a little from looking back at our history. In Audrey Heimler's Oral History of the NSGC (*Journal of Genetic Counseling*, Vol. 6, No. 3, 1997), she talks about the formation of the society about 30 years ago. During early discussions some counselors maintained "we are gaining ground as professionals, let's not be too aggressive right now". In April of 1978 a committee was formed to write the by laws of this new society. This task took 14 months. Why so long? Luba Djurdjinovic was quoted as saying "How we do this will determine how we will be perceived. We are charged with the responsibility of defining the profession of genetic counseling and the professional who is a genetic counselor. The by-laws of the proposed society will set the tone for the profession". And so they did.

The first NSGC business meeting was held this month in 1979. The Board had been alerted about physicians who were contemplating action against the Society. Possible outcomes included confrontation at the pending NSGC Business Meeting, legal action, and, worst-case scenario, demise of the fledgling society. It was decided that Board members would present brief reports and avoid discussion. The Board believed that genetic counselors would have a mandate to guide their own future if the plans for the

proposed society were intact at the conclusion of the meeting.

About 100 members and other interested genetic counselors were seated facing the Board. Unobserved by most of the audience, but visible to the Board, were about 20 grim-faced physicians standing in the rear of the room. The meeting proceeded as planned. This unusual meeting lasted 1 hour after which the physicians exited without comment. The cost of survival was high. At the first public business meeting, the *ad hoc* Board had been compelled to project the impression that it did not value communication among members.

Following this meeting, Audrey received a thoughtful letter from Gillian Ingall stating she was disturbed that there had been no forum for discussion at the recent business meeting. She suggested that the Board consider a more open format for future business meetings. In *Perspectives* Vol. 2, No. 3, the announcement of the Annual Business Meeting the following year includes an implied apology and acknowledgment: "The theme of this year's business meeting is 'Discussion'. From that time to the present, communication has been an NSGC priority".

Looking back over the last 10 years, Wendy Uhlmann spoke about the importance of billing and reimbursement as an issue for our membership. In 2000, Vivian Weinblatt spoke of how genetic counselors right here in California will soon have the ability to apply for licensure. However she cautioned that this success needed to be tempered by the tasks we have yet to accomplish, namely obtaining reimbursement for services.

Kathy Schneider spoke about the journey genetic counselors had taken during the first 20 years of our society and focused on our need to strengthen our presence in Washington. Robin Bennett spoke of how the one voice of the NSGC is comprised of the individual voices of our

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members and mentioned how the field of genetic counseling is in need of outcomes studies to show the value of genetic counseling. In 2003, Dawn Allain reiterated how we cannot speak of reimbursement without addressing licensure. Kelly Ormond spoke about the formation of a genetic counseling foundation to support research and education and continued the process of looking at our governance structure.

Nancy Callanan spoke of how as an organization we took the lead on the billing and reimbursement issue and did not depend on others to do the work for us. Cathy Wicklund spoke about change going forward and focused on a journey as well but not where we have been but where should we go. Last year, Angela Trepanier discussed the processes of changing our organizational structure and governance to better enable us to accomplish our current and future strategic plans.

So over the last 10 years it became apparent that in order to continue growing we needed to change the way we do business as a society. The governance changes that were implemented last year have enabled the NSGC to be more nimble in reacting to media requests, legislative issues and other important issues that impact the workforce. In addition we are set up to better serve our members and meet their demands even as the membership becomes more specialized.

I review our history to stress the founding themes of our society as well as taking the opportunity to pay tribute to those individuals who gave of themselves for the greater good. It is in that spirit that I take on the challenge of helping guide the NSGC to the greater good. However, this is not something that any one person can do independently. It is the collective effort of our entire organization that is needed to accomplish our mission. Our members have spoken and repeatedly stated that billing and reimbursement for genetic counselors is a top priority. This has been incorporated into our strategic plan and continues to be a focus for the board of directors.

I know that as an organization we seem to always be looking back as a guide to help us determine the direction we should be taking when moving forward. So after looking back at how we got here, I believe this is the perfect time for us as a society to focus on the future and where we want to go, where we can go and where we should go. Unlike our founders who had to tread lightly until they could gain a foothold in the medical community and prove their worth. We as a profession have already done that and cannot wait for others to lead us where they want us to go.

I think we are at a crossroads in healthcare. Things are changing all around us. Technology is advancing faster than most clinicians are able to keep up, costs are increasing and people can afford less. The way healthcare is delivered is

also changing and it is not always changing in the best interest of the NSGC and genetic counselors. However, is that really a true statement? What may seem like an obstacle may really be an opportunity. If a company decides to market the importance of a genetic test how do we handle that as an opportunity? If a primary care physician in our referral area wants to start ordering genetic testing on his patients without sending them for counseling, how do we handle that as an opportunity? Adaptability and flexibility are important traits for all of us now. We need to be able to look at these situations as opportunities for growth in our business, in our careers and in our profession.

We should do something about this. And we have, this year the NSGC was instrumental in helping the Cancer SIG develop proactive messaging, a media release and a provider's portion of our website to take advantage of Myriad's marketing campaign.

I want to take a moment to talk about marketing. Marketing our society, marketing our profession, and marketing yourself. How is this done and who is it done to? This is done on two levels, in the grand scheme this can involve communications directly to consumers, physicians, targeted marketing pieces that appear in local regional and national media. On a more local or small scale this can involve letting area physicians and clinics know about the services that are available. When you meet someone at a party and they say "what do you do?" you get the opportunity to market yourself and the profession all while drinking alcohol and eating spanikopita. These are the opportunities that where we need to take full advantage. There are currently about 2,400 genetic counselors in the NSGC. There are companies that have sales forces larger than this. You are our national sales force. To borrow a line from the former chairman and CEO of General Motors Charlie Wilson, who in 1955 stated "What is good for General Motors is good for America". I would like to remind everyone that what is good for one counselor is good for all counselors. We can all help by just getting involved. As renowned anthropologist Margaret Mead said; "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."

We should do something about this. And we are, as we enter into the final year of our 3 year strategic plan. The board of directors will be undertaking the task of developing our next strategic plan during a board meeting in late February. We will need significant input from the membership to help accomplish a plan that is inline with the goals of our membership. This means that when you receive a survey or email asking for your input, you actually need to complete the survey or respond to the email. Those of you that are here are the ones who are likely to follow up on these requests. It

is your responsibility to get your friends and colleagues to do the same.

What do we really need to help complete our strategic plan? Well, many of the items we want to accomplish cannot happen without money and in most cases time from the volunteers, that would be you. As an organization we are very ambitious. However, we are only able to include projects in our strategic plan that we can reasonably expect to afford. We have tried many new ideas over the last year and some were not as successful as we would have hoped. As our organization grows and becomes more specialized it becomes increasingly more difficult to be all things to all people. We want to provide all the services that all the members want but we need to focus on the greatest good for greatest number. We need to find out more ways to increase our revenue to pay for all of the services we want to offer.

We should do something about this. And we have, our executive staff is always looking at ways to increase our non dues revenue and there have been several implemented this year. However, there is also something that everyone in this room can do. Help increase membership. Each one of us has a friend or colleague who is not a member. If everyone here just signed up one person, it would go a long way to fulfilling our mission.

One way in which we are trying to fulfill our mission is to secure reimbursement for genetic counselors from third party payers for their services. You heard about our federal legislation that will allow Centers for Medicare/Medicaid Services (CMS) to recognize genetic counselors as providers who would be eligible for reimbursement through Medicare. Most other payers will follow the guidelines set forth by CMS. In addition, we are helping states pursue licensure. The more states that have licensure the easier it will be to have support for our bill in congress. We are embarking on a marketing and PR campaign to help position genetic counselors as the recognized experts in the delivery of genetic medicine.

Genetic counselors have long been trying to get to the table where decisions are made. For many years now we have been asked to the table; yet we somehow have always been relegated to the kids table. Cathy Wicklund has been serving as a member of the IOM roundtable on genomic medicine, so now we get to sit at the grown up table. Not only is the food better at this table but you get to plan the menu. Since Cathy is such a great cook she participated in the planning of a workshop specific to the provision of genetic services which will be summarized in a written report published by the IOM. As a result of the workshop in July, Cathy is now co chairing a Genetic Services and Education Sub-committee. In addition, we have been invited to a lot of tables this year including HRSA, NHGRI (a couple of times), Family Practice Physicians, CDC

(twice!) and ACMG. We are not being asked to just observe, we are now being asked to sit and help plan the menu because our opinion matters.

You have also heard about many of the great things that are taking place under current president Angela Trepanier. This includes an increased media presence, the research task force, the core skills task force, the organizational cultural competency task force, our new mission statement and the accomplishments of the Genetic Counseling Foundation. Under Angies's lead we are working toward commissioning research to demonstrate our value, identifying core skills of genetic counselors in clinical and expanded roles to meet the needs of our members, and working towards becoming a welcoming place for all members. We now have a board culture statement for not just board members but all volunteer positions in our society. Numerous relationships have either been started or enhanced this year which will help us achieve our overall goals.

Education is still one of the primary needs and expected benefits for our membership. As you heard earlier, much has already been accomplished by the education committee under the leadership of Ellen Schlenker and Jen Hoskovec. In addition, there will be more new educational opportunities to meet the varied needs of our members in 2009. As we finish these tasks and move into 2009, we need to look at more than just 2009, we need to look at where we want to be in 2039. Then we can figure out how we get there. That is reason for the focus groups that have been held with thought leaders in the genetics community as well as the sessions that were conducted here at these meetings.

I believe that we are in one of the greatest professions possible. I believe we can do anything and I urge all of you to believe in that as well. As Michael Strahan told his N. Y. Giants teammates just before they took the field for the final 2 1/2 minutes of the super bowl this year, "The final score will be 17-14, believe it and it will happen". The only limitations we have are the ones we set ourselves. Let's not limit what we can do. Together let's see just how far we can all advance the field of genetic medicine. I believe it will happen and it will be through the hard work of many of the people in this room as well as some of those who could not attend these meetings. There are also some students that are sitting out here now who will become the future leaders of our society and finally, right now somewhere, there is some boy who is currently sitting in an 8th grade classroom who will probably be the next male president of the NSGC.

We should do something about this.

We are all the NSGC.

With all of us together, the NSGC can and will do something about all of this.

Acknowledgements I want to thank the entire membership for giving me the privilege of leading the society over the next year. I want to thank our staff Kathleen Tindall, Laura Quinze and especially Emily DiTommaso and Meghan Carey who make it possible for all of us to accomplish the things we do. I want to thank all of the current, past and future board members who are not only my colleagues but many who have become my best friends. I also have to thank Luba Djurdjinovic, my colleague, my mentor, and

my friend who showed me 25 years ago what being a genetic counselor can be. I also want to thank my colleagues at Ambry Genetics, Brissa Martin, Alisara Ateerat, Lori Ross and Charles Dunlop for enabling me to accept this responsibility by supporting me in my daily job responsibilities. I also need to take this opportunity to thank my wife Pam for holding down the home front during my travels away from home; I could not have done any of this without you.