

2015 NSGC Presidential Address: Gifts of Genetic Counselors: Life's Leadership Lessons

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Good morning everyone. It is a pleasure to be here with all of you and an honor to be the incoming President of NSGC. The theme of my speech is leadership so it is really special for me to have Jay Flanagan introduce me. There is nothing better for a mentor than to share the podium with a former student who is about to assume his own leadership role in the AEC subcommittee! Congratulations Jay!

There are times that I still need to pinch myself to believe that it is true. I am in awe at the amazing skills, energy, resources, and talks shared with us over the course of the conference. Thank you to the presenters for sharing their experiences and making the conference a huge success and thank you to the AEC subcommittee for the countless hours of hard work over the course of the year to provide us with this fantastic opportunity.

NSGC was built on a strong foundation, which is a true credit to the vision and perseverance of our founding members. For the past 20 years, I have watched NSGC mature and grow into an influential organization that has a seat at important tables. Genetic counselors are an important part of medical care. What is nice about this statement? Others agree! We have made some incredible strides and should be proud of our efforts.

I would like to share a little bit about myself and share some highlights from the path I followed. Then I'd like to share with you my vision for the coming year. I graduated in 1995 from Sarah Lawrence with a talented group of classmates; many of whom have gone on to hold their own leadership roles in the profession. During the first year of my career, I like many of you, was busy learning the responsibilities of a new job,

planning a wedding and studying for the boards. However, at the AEC in 1996, I listened to the presentations with a different ear, because all of the items from the previous year were under my belt and I could start to envision what my career might look like long term. It hit me that I worked really hard to complete my training, pass the board exam, and enter a profession that I had really grown to enjoy in such a short time. I had a lot of years ahead of me to practice as a genetic counselor and I wanted to get involved so that I could contribute to the growth of the profession. In turn, this would ensure that the profession continued to fuel the spark that had intrigued me so much in the first place and took a direction that would fuel my passion over the course of my career.

As luck would have it, BRCA1 and BRCA2 were found while I had been in my second year of graduate school. The handful of us practicing in cancer genetics at the time met under the leadership of Rob Pilarski, Cate Walsh-Vockley, June Peters, and Mary Ahrens to discuss the issues we faced. Through the vision, need for support in a new sub-specialty, and the need to develop a protocol for counseling families with a potential inherited cancer predisposition, the Cancer SIG was born and became a model for other SIGs to follow. That pivotal development happened because a group of people who were struggling to find the best way to care for our patients in this new era put an idea into motion. I was also working in Iowa at the time, which did not have many genetic counselors. It was extremely important for me to network at the AEC so I could bring ideas back to the state and attempt to stay abreast of the new trends. I volunteered early on with the education committee and practice issues committee. I volunteered to chair a subcommittee inside of the Cancer SIG, which became the start of my leadership tract.

As the needs of our profession grew, my interests became more diverse. I volunteered to work on the projects that interested me and were in some way pertinent to my job (frankly all of the tasks were relevant). The volunteer time

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was invaluable for expanding my skill set, the network of colleagues, and with it the available opportunities. During the 2008 budget crisis, the genetics program at my hospital was threatened to be cut from the service offerings. It was then that I became interested in billing and reimbursement to find a way to save the cancer genetic program and began working on mechanisms to demonstrate the value of the genetic counselor in patient care. It would have been a huge mistake to lose a well established and much needed program in the height of the DTC era. This process involved working with the regional payers to be an expert resource on cancer risk assessment, genetic testing technology, and develop a mechanism to be credentialed and reimbursed for our work. In Minnesota, we are very fortunate to have medical directors who are supportive of genetic counselors and appreciate the value that we add to their policy holders' care. Our services are reimbursable even though we do not yet have licensure in our state. It was this experience that led to my involvement in the Payer subcommittee the past 3 years. I served on the BOD initially from 2008 to 2010 as a Director at Large. This was a rewarding experience and helped me envision the big picture of medical care and the various places where genetic counselors could have an impact.

I shared past president, Liz Kearney's, vision to create a strong leadership pipeline within NSGC to ensure that our organization would always have well-prepared and confident leaders to strategically take us towards the horizon. Following my initial time on the BOD, I chaired a leadership development taskforce to evaluate the needs of our members at different points in the career continuum and determine how to keep members engaged in the NSGC activities. We are very fortunate that Liz has taken her passion for leadership training and has been hard at work developing a process to prepare our volunteer leaders for their new role and enhance their skills.

The skill sets held by genetic counselors are a unique combination of intense science, critical thinking, and empathic counseling. It is unique to understand complicated scientific concepts and be able to explain them in a meaningful and supportive way. Almost 5 years ago, I had to learn a "new normal" to support my son and the first people I turned to were genetic counselors. I am intentionally using humor to share this story with all of you knowing full well humor was very hard to find at the time. My son was 10 years old and so proud of how quickly he was growing and becoming a "big kid." Every morning he would keep me company while I was getting ready for work and stand on the scale in hopes he had gotten bigger for football. Without really thinking about it, I had been making mental note of his growth curve thanks to my beginning roots in pediatric genetics. Like half of the school that winter, Alex came down with a nasty virus leading into holiday break. During the few days of this event, I subconsciously noted that on his morning visits to keep me company, he was losing weight pretty steadily even though he

was eating really well. I was starting to get quite anxious...he had lost 10 lb in 7 days.

We went to the pediatrician and I flipped into "medical history mode" while filling out the paperwork and found myself writing "unexplained weight loss" on the papers. In this mode, the wheels in my head started turning quickly while the pediatrician ran some basic tests. As I was hearing the conversations and activities happening in the hallway, I had the sense that they were talking about my son. While as genetic counselors we are taught that our words matter, I came to appreciate that concept as the next words the doctor said and his compassion by having an immediate plan for us will not be forgotten. He said... "Mrs. Haidle, it appears that your son is presenting with type 1 diabetes. His blood sugar is over 500. I have called ahead to Children's Hospital and you will be a direct admission. Here are the driving directions. You may not go home first. His sugar is critically high. You must go directly to the hospital." I was completely shell shocked and started to tear up. Out came the infamous box of Kleenex that we always struggle with how quickly to hand to the patient so as not to thwart their emotional response. I saw my son intensely watching my face to determine if he should be worried. Time to be strong. Time to hold it together. Time to drive to a place that I had never been nor thought I would ever need to go because I was healthy. You see, my son had not met his maternal grandfather, because he had died from complications related to type 1 diabetes while I was in my second year of graduate school. Parental guilt and survival guilt are very real.

We were immediately enmeshed in learning everything possible about diabetes, carb counting, insulin doses, finger pokes and shots. The crash course started when we got to the hospital room with no time to really process what had happened in the last few hours. As we were getting settled for the night, he looked very intently at me and asked me if he was going to be ok. Every cell in my body was screaming internally as it hit me, I did not have time to process it for myself let alone for Alex so how do I possibly answer this important question. Yes...the true genetic counselor in me said...I haven't gotten to role-play the answer to this question yet! And I also knew that the way I answered this question would impact how he adjusted to his new diagnosis and accepted it. I learned this lesson from the families of children with chronic conditions I had the privilege of meeting through the years. Leadership was going to be important to help him take control back from a process that didn't feel like we had any control over. I heard myself answering his question and said "I would do everything in my power to make sure the answer to that question was always yes. This is our new normal. You will do all the things you wanted to do. It will take us a bit of planning and organization to make sure you feel good while you do it, but we will do it together." Two days later at discharge, we walked to the door and he said "Are you ready momma?" and took my hand as we started our new journey.

My daughter taught me a lesson that afternoon too. She was seven at the time and we had spent so much time at the hospital and trying to figure out how to make the first family meal that we really didn't have a chance to explain everything to her. I had hoped to talk with her when it was quiet and we had our alone time. We stopped by the store to get a treat for her brother and I watched her reading the package labels and trying to sound out some of the big words. She brought me something and said confidently that her brother would be able to eat this for free without needing a shot and it would be a treat he would enjoy. I looked and she was completely correct, but I had no idea how she knew already. She said "Momma, my ears hear everything. Even what they weren't supposed to."

We worked hard to educate everyone who was a part of Alex's life from family to friends to other parents and the school. It was time to help balance his desire for privacy versus the need for people to know so he could be safe and advocate for his needs. And, it was time to find every possible research option to help fight the disease or prevent it from getting worse. I was so grateful to be a genetic counselor at that point because I already knew how to find research options, read protocols, and could speak the "language." But I also learned pretty quickly that as a mother, I struggled to objectively weigh the risks versus benefits of each protocol because in my mind, each of them HAD to work and I only had 90 days to find something. So, I called on my friend and classmate, Heather Hampel, to help me critically review the protocols. Who better to help me than another genetic counselor! I was so surprised as to how alone families are to navigate this process. As genetic counselors, we advocate for our patients and help them find these resources. From personal experience, it is an amazing gift that you provide to your patients.

I also called on my classmate, Daragh Marnane Conrad. She understood the journey we had started and it was such a relief to connect with someone who understood our experience. As genetic counselors, we connect our patients with support groups or other families when possible and it really does make a difference. Her compassion and counseling skills were invaluable to me during the crisis. This is another part of the skills that help separate genetic counselors from other providers. Just before day 90, we learned that Alex did not qualify for the research trials. That was a hard blow because, I had to come to terms with the fact that the disease had won this battle, but it was not going to win the war; because on day 91, I remembered that I had banked his cord blood as a newborn and his cure was in the freezer whenever science could catch up. My training as a genetic counselor helped me to realize the potential utility of the technology and envision future uses beyond what was available at the time. Alex has shown his own growth and leadership in adjusting to the diagnosis and has made it a normal part of his life. I am really proud of him.

Five years later, he is doing great and we are on to our next adventure...Driving.

Leadership comes in many ways. It may be activities performed to enhance services and provide high quality patient care in our individual work setting. It may be related to the activities genetic counselors are involved with at the community, state or national levels. As genetic counselors, we are all in the trenches and our individual efforts make a difference.

I attended a leadership training conference this summer with leaders from many other types of organizations. As I listened to the presentations about the ingredients for strong member associations and resources that we could be tapping into to ensure best practices, I was making mental notes that NSGC is already utilizing everything on the list. In fact, we were highlighted during their presentations. NSGC was selected this year by the Trade Show News Network as one of the top 25 tradeshow in net square foot growth from 2011 to 2013! That is an amazing accomplishment. The others at the table began to seek our opinion on issues they were facing and how we might address them. Clearly if we have been successful, we must be doing something right! While we have been fortunate to have very strong volunteer leaders, I would be remiss without highlighting our partnership with Smith Bucklin. Meghan Carey, NSGC's Executive Director, has been a seamless partner with NSGC for the past 9 years. She has been a consistent presence and really understands genetic counselors...to the point that I have to remind myself that she is not a formally trained GC. Her drive and passion for NSGC and desire for our success is part of the reason that we are already utilizing all of the best practices outlined at the leadership conference. She is amazing at identifying resources to help us complete our strategic initiatives. For these reasons, the BOD chose to honor Meghan with an award to recognize her leadership and dedication to NSGC. We also have the strategic efforts and dedication of John Richardson to guide us in the Federal efforts, state licensure, and payer efforts. I would be remiss for not acknowledging the rest of the executive office staff for their tireless efforts on a year round basis, but also the efforts needed to launch and coordinate the logistics for a successful conference in collaboration with our Education Committee. The seamless partnership with PCI has been extremely valuable in helping us extend our reach and elevate the awareness of the profession. I would also like to recognize Jen Hoskovec for her efforts on behalf of NSGC. She has represented our profession with such grace, poise, and leadership that is inspiring. As members of NSGC, we are fortunate to have the combination of skills from our leader volunteers, members, and the executive office staff.

Looking forward, as an organization and a profession, we must build upon our successes. My volunteer activities with NSGC have given me the opportunity to work with some amazingly talented people through the years and develop

friendships all across the country. There once was a time that I knew almost everyone in the room at the AEC. But we have grown dramatically since 2006! There has been a 75 % increase in the number of board certified genetic counselors in just 8 short years.

We are at an exciting crossroads and more work must be done. Currently, we do not have a shortage of genetic counselors, but as other providers, industry, and policy makers realize the value that genetic counselors add to the patient care continuum, the demand for our high quality services will expand rapidly. We must proactively look at ways to increase the number of genetic counselors trained per year to meet the growing demand. Sometimes this means increasing the number of students accepted to each program, starting new programs, and/or evaluating alternate education strategies that maintain the high standards, academic rigor, and counseling skills that have formulated the successful profession. For these efforts, we are extremely fortunate to have collaborative conversations with ABGC, ACGC, and AGCPD in addition to a workgroup led by Becky Nagy and Cathy Wicklund. They are thoroughly vetting barriers, strategies, and goals for expanding the workforce. Each of the genetics organizations plays an important part of this process and the conversation. Working together, we will have greater impact, cohesiveness, and success in these efforts. To those of you involved in the workgroup, thank you for your dedication and vision. I look forward to your recommendations.

As I have spent time at the podium the past few years, I am always thrilled to see familiar faces. But I am realizing there are many members that I have not yet gotten a chance to meet and I would like to. We all have unique experiences and skill sets. Something about the genetic counseling profession was a draw for all of us. It is up to us individually to keep that passion alive and up to us collectively to ensure the profession continues to grow in a direction that fuels that initial spark.

A common question is “How do I get involved?” At the local level, identify the needs of the patients and providers in your work setting. Develop the strategy and business plan to make it relatable to those in administration. Build the case for additional FTE or for support staff so that your skills can be used in patient care. The NSGC course entitled “Business Foundations for Genetic Counselors” has wonderful information to help your institution bill and be reimbursed for your services in addition to business skills. I encourage you to utilize this resource! Consider supervising a genetic counseling graduate student for the training programs. Additional supervisors are needed to help train additional counselors. Take advantage of the opportunities to offer education about genetic counselors to other providers and the public.

Over the course of the year, there will be calls for member feedback on topics. I encourage you to participate and provide feedback. Your opinion is important and I would appreciate hearing your thoughts.

There are many needs for volunteers inside of NSGC too. There are SIGs, Committee, subcommittees and task forces... all of which are very active in moving us towards completion of projects based on our strategic plan. There are a variety of options to fit the time you are able to contribute. Each of the groups have their own process to get involved. Some of the committees are actively recruiting new members through an application process. I encourage you to reach out to the chairs of the group where your interests lie and determine the process. Another easy option, is to check the box indicating that you are willing to volunteer when you update your member profile. The Membership committee created a volunteer opportunities discussion forum. Please subscribe to the forum as it is a great way for committees to communicate about actual projects where members could participate. The forum provides the opportunity for you to select projects that interest you and includes the contact information for those leading the project. Of course, you may reach out to me and let me know your interests. I would be happy to guide you to the correct person if needed. I encourage you to get involved. We could use your help and it is such a rewarding experience.

As I say this, I still have a lot of years ahead of me to devote to the genetic counseling profession. However, the leadership baton will need to be passed to the next generation of genetic counselors for fresh ideas and fresh energy. It is important for the next generation of genetic counselors to be aware of the roots and values of NSGC, be aware of the environment within which we function, and ensure that their skills are strong so that they are prepared to take their turn. The founding members should be quite proud of NSGC's position today. I am looking to all of you to make me proud over the next 20 years!

As an organization, we must be nimble and be able to respond to issues in a quick yet thoughtful way. Just a few days ago, we did just that when Dr. Mary-Claire King recommended that all women in the United States who are 30 years of age and older pursue DNA testing of the BRCA1/2 genes regardless of their personal or family history of cancer. NSGC responded very quickly with a thoughtful and respectful response. This is an important concept for us to consider. What might this process look like? How can we educate the providers and the public to use this information well? Can the healthcare system afford it? Is it the best option for patients or is there another option that might reach a similar goal? What are the risks, the benefits, and the limitations of the potential solutions? Most importantly, what is the role of the genetic counselor in this process and what is the role of NSGC? As a profession, genetic counselors will play an important role in these conversations as we understand the needs of our patients. We have experienced genetics done well and when it was not. Our voice matters in this conversation and it should be heard, but we must also be ready to listen. I have an

enormous amount of respect for Dr. King and her work. As a clinician who has spent close to 20 years caring for patients with cancer, I would love to prevent another woman getting diagnosed with breast cancer. The lack of systematic collection of useful family history and the educational gaps, which limit the identification of appropriate testing candidates, makes the notion of general population screening tempting. But before it could become a reality, there is much work to be done in order for the full benefit of the technology to be realized. We have the skills, experience, and the vision to lead the effort, but collaboration with other groups will help ensure that the appropriate infrastructure and resources are available to support everyone involved in the process, especially our

patients. This is an exciting challenge as we move into 2015. In the words of my son, are you ready?

Remember, the work you do on an everyday basis is important whether it be in a clinical role, industry, policy, research, or novel role. I appreciate all of your efforts and our patients have benefited from your dedication.

NSGC is strong because of our members and their involvement. The efforts, passion, and vision have helped us shape our current direction but have also given the foresight to lead us to a bright future. I am grateful for the opportunity to represent NSGC and the genetic counseling profession in 2015. I welcome your input over the coming year and encourage your participation in these important conversations.