

## NSGC 2014 Presidential Address: Just Own It

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I am humbled and honored to stand here today as the incoming president of NSGC. I would be remiss not to begin by thanking the many mentors, colleagues and students who have helped shape my career as a genetic counselor and I certainly recognize how very lucky I am. A special thank you to Becky Nagy, Meghan Carey, and the board of directors who have supported and guided me through this adventure so far, and it's only just begun.

We all have conversations with ourselves and others about the choices we make regarding our career. When I sit and really think about my career as a genetic counselor thus far, I recognize that there is not a day that goes by that I don't have an interaction that reminds me how much I truly love what I do. Perhaps it's one of the expected interactions, such as one with a patient, student, or other learner. Certainly, the interactions with my co-workers and other colleagues are thought provoking, inspiring and therapeutic. I even look forward to most conference calls these days, which quite frankly used to terrify me. The number and types of professional interactions genetic counselors have on a daily basis have continued to expand as we have integrated ourselves into nearly every facet of healthcare and research today. In the 2012 Professional Status Survey, genetic counselors self-identified as representing 28 different specialties, both clinical and non-clinical, and working in a minimum of 20 different settings.

However the interactions that I have found to be the most powerful and meaningful to me are the ones that are easy to overlook. For example, on the sideline of my daughter's soccer game when I'm asked "what do you do" and I proudly say "I'm a genetic counselor". More and more often there is a look of recognition on their face or a story about an experience they have had or heard about involving genetic counseling. Or when I run into a former patient while running errands, as I work and live within the same community, and she introduces me to her friend or family member as "this is my genetic

counselor"—implying that *everyone* has a genetic counselor, just like a dentist or eye doctor.

Perhaps these daily interactions I mentioned are a simply a side effect of increased interactions with counselors and awareness of genetic disease, genetic testing and advances in technology given our culture of instant news and social media. However we, as genetic counselors and as NSGC, can also take ownership in this increased recognition and awareness of who we are and what we do. If you heard the talk earlier in the week about the history of our profession, it was discussed that recognition of our profession and what we bring to healthcare has always been a priority of each individual genetic counselor as well as our organization. Certainly genetic counselors continue to position ourselves to enhance interactions with patients, healthcare professionals, consumers, and policy makers. Additionally, the technology of today has given us additional tools to help in our quest to reach the public. As many of you have already heard, in 2012 NSGC decided to make an investment and grow our public relations program. An expert media panel was created and members of NSGC received media training so that we were poised to address the newsworthy topics in genetics and genomics. Our PR firm actively pitched bylined articles, written by our members, to trade publications; and over the year NSGC has strengthened relationships with national reporters to become a "go-to-source". Given these efforts, from January to August of 2013, we have had 48 unique placements, most in high impact media outlets which resulted in nearly 600 placements after some of these stories were picked up by other sources. This is more than the number of media placements from 2007 to 2012 combined. And those numbers are just the placements tracked through our formal NSGC PR program. How many of you in the room have taken an opportunity to give an interview or write a blog or a column about genetic counseling or genetic testing this year? Considering this, we have reached more than 68 million people in this year alone. And of course, I have to

give a shout out to Angelina Jolie because that certainly helped. In addition to the media placements, NSGC and genetic counselors around the world have seized the opportunity social media gives us to connect and interact on a bigger scale. NSGC tweets and posts on Facebook regularly about high impact media placements, research publications and other key issues within our community allowing us to reach thousands at a time. Some of our counseling colleagues have even set up their own twitter accounts for their centers allowing them to inform others about their accomplishments. This is just one example of how individual genetic counselors, communities of genetic counselors and NSGC as an organization are all taking advantage of opportunities in front of us, or in some cases seeking out opportunities, to work towards the common goal of awareness and recognition. Within this context, those daily interactions that I often take for granted, seem to be more powerful and meaningful to me as I think of all of the deliberate effort behind that recognition of what a genetic counselor is and what we do.

When asked why I became involved in NSGC and started on the path that has eventually lead me this point, today, I have struggled with the answer because there are so many. First and foremost, I had fabulous mentors, the first of which were my program directors, Cathy Wicklund and Jacqui Hecht, who gave me the confidence and inspiration to take the leap. This initial nudge was followed by a long line of mentors who continued to encourage and support me in this quest, and for that I am truly grateful. Certainly I felt an obligation to give back to my profession and was given opportunities by other NSGC volunteers and leaders through simple invitations to join in on a project. After a lot of self-reflection and thought over the past year, it has become clear to me why I have stuck with this adventure and continued to seek new opportunities to remain involved. Simply, I am an optimist. I believe we have control over our own future and I have watched NSGC take that control and flourish. To be clear, I absolutely recognize that we cannot control our environment and we have definitely seen this first hand when navigating our strategic path. However, we can control how we adapt and respond to the environment and take advantage of opportunities to maximize the benefit to our profession. The meaningful interactions I described and my passion for our profession continue to reinforce my optimism and bring me here to my professional society to collaborate, take on challenges and celebrate successes with others who love the profession of genetic counseling as much as I do.

Since I entered the profession only 10 years ago, I have continued to integrate strategic thinking and forward focus into how I approach most everything I do as a genetic counselor. In 2003, as I attended my first AEC in North Carolina as an employed genetic counselor. Dawn Allain was incoming president and her speech was titled *NSGC: Living Life Forward*. In her speech Dawn emphasized the importance of

marketing ourselves to ensure our services are integrated into healthcare, education, research and public policy. She discussed the use of mass media to target the public with our messages, the need for a formal approach to join the conversations with policy-makers, and the critical importance of collaborating with other organizations. Finally, she called upon NSGC to look at our organizational governance structure to ensure we were equipped to efficiently respond to our rapidly changing environment while continuing to represent the needs of our diverse membership.

While reading Dawn's speech along with others given by our past presidents, I recognized one of the reasons NSGC has been so successful and remained the leading voice of our profession. The strategic initiatives and priorities outlined by our past leaders set the direction for where we find ourselves today. And while we have moved further down the path and continued to shape these initiatives as we grow and achieve, our direction has remained the same. This speaks to the thoughtfulness, courage and strategy possessed by our NSGC leaders. What I take away from this, along with our history lesson with Bob Resta earlier this week, is that it is important to understand what has been done in the past and respond to what's happening in the present so that we have the confidence to look to the future, to anticipate our path, and to prepare for what's to come.

NSGC is a healthy, thriving organization. Our membership has increased by 37 % over 10 years. We all recognize that diversity of various types is critical, however we are making strides—we have 18 SIGs and 58 % of our membership belongs to a SIG—of the SIG members, 43 % belong to more than one SIG. We now have formal collaborative or liaison relationships with 25 different organizations. Eleven states are issuing licenses, with many others in the process of licensure legislation, and we are closer than ever to achieving status as recognized independent providers by CMS. We continue to look toward the future with some of the very same initiatives outlined 10 years ago—Access, Value and Growth. NSGC has continued to maintain a rolling strategic plan that is focused and attainable given the talent and dedication of our volunteer members. At the same time, we have remained flexible so that we can adjust and respond to the ever-changing landscape in which we reside as genetic professionals.

This to me is the essence of what NSGC is... we are a future-focused, collaborative organization of dedicated members working diligently to move our profession forward, while being appreciative of our past and the values we were built upon. Now that I have outlined *what* NSGC is to me, I want to talk a bit more about *who* NSGC is.

At a recent leadership workshop designed for incoming volunteer leaders of various professional organizations, we spent some time discussing member value and ownership as it relates to our organizations. As with any organization or company, NSGC has both customers and owners. However,

for us, they are one in the same. The primary customers of NSGC are our members. As customers of NSGC we seek products, services and resources we need to enhance our ability to do our job. However, as owners of NSGC we seek something more external. The owners of an organization seek mission fulfillment.

**The Society's Mission:** The National Society of Genetic Counselors advances the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services.

Both customers and owners are essential for the growth and vitality of an organization. With this in mind I would say the answer to “who is NSGC” is that we, the member owners of NSGC are the ones responsible for carrying out our mission through our strategic initiatives and related charges. Each of us is a NSGC customer, paying our dues for member benefits and purchasing desired professional products, which in turn funds our mission fulfillment via our strategic plan. However, throughout our careers there are times where many, if not all of us, choose to wear our “owner hat” and step up to the challenges facing our profession. NSGC has always been incredibly fortunate to have a devoted, passionate membership that functions as owners of our society throughout their careers. Between our dedicated board of directors, standing committees and subcommittees, workgroups, taskforces and SIGs, more than 50 % of our membership volunteers their time and talents to our organizations products and mission. I am honored to be surrounded by so many wonderful leaders who work tirelessly to maintain respect and trust with our membership. This is essential for the continued success of our society and in preparation for today I came across a quote that captures this sentiment for me, it reads “An intimate and trusting link between the board and members is an association's greatest asset” (John Carver—The American Society of Association Executives).

As leaders and volunteers we should aim to ensure that the members of NSGC continue to realize a true value of being a member customer, while also recognizing the value of NSGC ownership. Market research as well as member surveys have been done throughout the years to assess the needs of our membership, determine what value our member customers seek and maintain relevance to our increasingly specialized membership. What we have learned from this research is that our members see NSGC as a connector. NSGC provides education, resources, services and products that help genetic counselors connect to their patients, other healthcare providers, colleagues and job opportunities. Enhancing this member value remains, and will always remain, a top priority for our society.

However, we likely do not know as much about the value our members seek from the perspective of being an owner of NSGC. I truly believe customer member value and owner member value are distinct from one another, so recently I sent

an informal survey to our 2013 leaders, including SIG chairs, committee chairs and board members, to ask them about the value they have realized from being a leader within NSGC. I specifically chose this group of individuals because the NSGC leaders approach their responsibilities as owners of our society and continue to enable our volunteers to accomplish a tremendous amount of work year after year. In reviewing the responses, certainly there was overlap with some of the member values we have long recognized as being very important, particularly with regard to the opportunities for networking and collaboration with colleagues. However, the general theme was much more externally focused and related to value to profession of genetic counseling as a whole, rather than value to them as an individual genetic counselor. While this was not a formal market research survey, it did drive home for me that when we deliberately think as an “owner” of NSGC rather than a “customer” we are able to see the challenges and opportunities in front of us through a different lens. One in which we recognize that while each effort, decision or charge may not directly affect our day to day activities, and in some cases may even be in conflict with what we would desire as an individual genetic counselor, it is the right decision for the profession of genetic counseling as we move toward fulfilling our mission and maintaining momentum towards reaching our strategic goals. In time, this will almost certainly result in a significant win for us all.

Growing up in Dallas, there was a radio show that I would listen to each morning while getting ready for school—The Kidd Kraddick in the Morning Show. It was a way for me to start my day with a smile—listening to silly antics like pranks in the fast food drive thru or the DJs doing an entire segment on helium. But my favorite part of the show that each day they would end the show by saying “Keep looking up, ‘cuz that's where it all is”. This simple statement at the end of a goofy morning show has stuck with me throughout the years. Our opportunities are not behind us and they are likely not right in front of our faces or falling into our laps. Sometimes we have to look harder for the right opportunity than other times as they may not look the way we expect them to. But they are there. Even if disguised a bit, even if they are a bit rough around the edges and aren't perfect, the opportunities are there and we need to take them.

When looking at lists of qualities of great leader volunteers you'll see words like “courageous”, “trusted”, “focused”, “passionate” and “self-aware”. However, what you will not see on the list is age, title, or years of experience. Each of you, as a member of NSGC, has your own unique love for you do every day and are successful in the interactions which continue to drive you towards greatness in your career and subsequently move our profession forward. I imagine that each of you can identify with one, more or many of the great leader characteristics. When the time is right for you, recognize the initiative or issue you are passionate about and put on your

NSGC owner hat to join forces with your colleagues and take hold of the opportunity. I remember my dad saying to me as a teenager and young adult, “just do it”, from the 1988 Nike campaign. I have given myself that same three word pep talk millions of times in my life. I’ve even said it to my kids (and gotten that same eye roll I’m sure I used to give my dad!). But by nature, particularly when it comes to our profession, genetic counselors are doers. So instead I say to you “just own

it”—my 2014 NSGC campaign. My hope is that when we gather together in New Orleans in September of 2014, each of you can own the successes and accomplishments we will be celebrating together.

Thank you again for your time and commitment to the field of genetic counseling and to NSGC. I’m thrilled to serve in this role and am looking forward to getting to work with, and on behalf of, you all.