

“Stepping Out to Step In”

NSGC Presidential Address

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Published online: 30 January 2010

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My first message to you, the NSGC Membership, is one of gratitude. Thank you. Serving on the NSGC Board in this era of burgeoning genomic medicine is undoubtedly the most exciting challenge I've experienced in my career thus far, and I'm so honored to represent my peers, genetic counselors whose intelligence and dedication to patients have consistently earned my respect. I've enjoyed every aspect of the role from interacting with the current and future leaders in our profession to the more mundane, like scrubbing the NSGC budget to wring out every penny possible to devote to our strategic initiatives.

In thinking about those initiatives, I'm especially excited about one in particular: NSGC's goal to position genetic counselors as the primary thought leaders for genetic counseling services. Some of you may hear “thought leader” and ask what it means. Others, if you are like me, may gloss over the phrase, assuming that you have enough work and life experience to know what a leader is. But if you stop and ask yourself the question, “What is leadership?” Could you really write down a definition on paper? Could you explain to a student what his or her career should look like as a thought leader?

I'd like to spend some time exploring this question. This fall, as part of my preparation to serve as President, I attended a leadership training. The facilitator proposed that leadership is in fact not something you are born possessing but is instead a product of your principles, environment, and companions. With that framework, I'd like to share

some of my own exploration of the question “What is leadership”?

Some of you may know that my path has been somewhat unusual in its course. Like many genetic counselors, I practiced in both perinatal offices and in the hospital setting for several years. However, anticipating the trend toward integration of genetics into more mainstream medicine, I decided to return to school to develop the pragmatic business skills that will be important for the genetic counseling profession to advocate for itself. I earned an MBA and in early 2007, for both career and family reasons, found myself in need of a job that would provide mentorship and experience in marketing while allowing me to stay in my home in the San Francisco Bay Area. I made the practical but somewhat difficult decision to temporarily leave the field of genetics to focus on developing skills in other areas. I accepted a position as an Associate Marketing Manager with LifeScan, Inc, a manufacturer of blood glucose meters and test strips and a member of the Johnson & Johnson family of companies.

I remained with Johnson & Johnson for over two years, and there were many times when I questioned or even regretted my decision to join. I sorely missed genetics and envied my friends and former colleagues as they talked about emerging genetic technologies and their challenges and rewards with patient care. However, I reminded myself often that my choice was short-term and I would eventually be able to apply these valuable new skills to genetic counseling.

A few months into my employment at Johnson & Johnson, I was assigned to manage the consumer response to the company's national television advertising. With a multi-million-dollar budget, it was the company's largest and arguably most important marketing program. However, the consumer response to the advertising had been severely

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underestimated resulting in a significant backorder and budget exposure, and the group of 15 people from various agencies and vendors who managed different aspects of the response had significant communication problems resulting in distrust and confusion.

For weeks, I went home with a migraine every night. I was unable to answer my immediate or senior manager's questions around even the simplest program performance metrics, and my communications with the agencies and vendors continued to bewilder me. We would seemingly come to agreement on a conference call, and then I would hang up only to have the phone ring from one agency calling to complain about another.

One day after such an encounter, I dropped my head to my desk out of exhaustion and frustration. I couldn't help thinking, "What bizarre series of events led me to this?" "What is a genetic counselor doing running a TV campaign?" I had no answers, but I of course knew that I had no choice but to somehow find a path to success.

I raised my head and my eyes were drawn to a knick-knack on my desk. It was a small chair from a collection of dollhouse furniture, a token my genetic counseling program director had given me on my graduation day. She did so as a reminder of how I had often translated my sales skills, which I developed as a part-time furniture sales person during my undergraduate years, to my clinical rotations as a genetic counseling student. Asking open-ended questions and establishing rapport is surprisingly similar whether you are selling furniture or contracting with a patient! I've kept the tiny chair on my desk as a reminder that when I face a difficult challenge, I should examine my strengths to apply them in a new way.

"OK," I told myself, "so what comfortable genetic counseling skills can I apply to this business situation?" At that moment, I realized that the workers on the program were scared. They were aware how much my company was spending on the program, they knew it was not functioning, and they didn't want to be blamed for it. Their behavior was quite rational. The realization that I was dealing primarily with anxious people actually gave me hope; I knew how to help anxious people cope! I've helped hundreds of terrified women with positive maternal serum tests and comforted many couples receiving an abnormal amniocentesis result. I should not find it difficult to guide colleagues worried about something as inconsequential as money!

And so began my campaign to build a team. I called each member of the group, using those critical listening skills I developed as a counselor, and asked him to tell me his story. I listened to their frustrations with the program and their proposed solutions to our predicament. As a result, I had laid the foundations of trust. Remembering the "people-first" language that is so important in patient care, I

began to speak to and about them as a team rather than a group of disparate individual contributors. I ceased use of the terms "agency" or "vendor", which in the marketing world convey different levels of importance to the client, and referred to them as my "partners". Finally, I gave a speech on a conference call to tell them, "We will either all succeed, or we all fail" to emphasize the importance of working toward solution of problems that will inevitably arise on such a complex program. Finding blame in other team members would not help us solve problems.

Thankfully, it worked. We reduced waste to save \$300,000, we reduced shipping time from six weeks to two to place 150,000 meters in valuable consumers' hands, we instituted weekly reporting to senior managers allowing timely programmatic changes, and we expanded the program to print, search, and web advertising. And we accomplished all of this in less than six months.

At one point, my Marketing Director called me to her office to congratulate me on the program. Internally, I was wondering why I would receive the credit since it was really the team that had succeeded. I told her, "I appreciate the recognition, but I didn't really do anything. The changes we made were all ideas from the team; none of them were mine. I simply helped them work together and brought their ideas to light." She looked at me with a somewhat exasperated expression and said, "Liz, that's leadership."

That's leadership. *That's* leadership? I thought leadership was having visionary ideas and convincing others to follow. I thought the leaders had to be the people with the important titles making all the big decisions. I thought leadership was flashy and obvious.

If those things aren't leadership, what is? Many have tried to answer the question, so I'd like to share some of the key lessons I've gleaned from listening and reading their answers. Leadership must involve others; great accomplishments, while wonderful, are not leadership. Leadership provides inspiration and optimism to encourage others to strive for amazing results. Leaders must set examples that require taking risks and acting on principles and integrity even in the face of their own and followers' anxiety.

I thought about genetic counselors I have known over the years and looked for examples of leadership among them. I know there are many more examples than I will list. There are simply too many, and I haven't crossed paths with everyone.

I thought of Heather Brown and Kathleen Fergus, who with the encouragement of Maureen Smith, started the Industry SIG to give a voice and support to genetic counselors forging their way through the new world of the for-profit environment. In this example, there are layers of leadership. Maureen recognized an opportunity and inspired Heather and Kathleen to take action; the SIG went

on to provide a place of encouragement for genetic counselors looking for a new career opportunity as well as for colleagues wanting to swap ideas about development of professional skills, such as networking and negotiation. Maureen, Heather, and Kathleen: That's leadership.

I thought of Samantha Baxter, who, as a new counselor, founded the New Member/Student SIG to encourage other new genetic counselors to get involved in NSGC and their profession. That's leadership.

I thought of Joy Larsen Haidle and her colleagues at a cancer center in Minnesota, who guide their center's oncologists to evaluate and integrate new pharmacogenetic tests into patient care. The trend began with Her2 testing. The oncology department sought the genetic counselors' guidance for this genetic test. Joy and her colleagues made recommendations about how to use the test but established the understanding that Her2 analysis should be ordered by the oncologist. The oncologists continue to consult with the genetic counselors as new tests emerge; this collaborative relationship does not require the genetic counselors to see every patient having a genetic test but rather integrates them into the broader healthcare team, allowing better patient outcomes and a voice for the counselors in future test utilization when face-to-face genetic counseling may be appropriate. That's leadership.

Erin Carney shared a story with me about Claire Davis and Emily Soper. These two alumni of the Mount Sinai Genetic Counseling Training Program recognized an opportunity to enhance the psychosocial content of the Mount Sinai program by developing a weekly case review of interesting or challenging psychosocial cases. Many future students of the Mount Sinai program will benefit from their efforts. That's leadership.

And what about Laura Hercher, Allie Janson, Bob Resta, Jessica Giordano, and Kelly Rogel who started the DNA Exchange Blog? Laura, Allie, Bob, Jessica, and Kelly probably thought "genetic counselors should have a blog", but instead of waiting for someone else, they did it themselves! As a result, genetic counselors have another point of visibility and a means to pose interesting, challenging questions in a forum that allows professional debate. That's leadership.

Linda Robinson, Sarah Zentack, Pia Banerji, and Sara Pirzadeh in Northern Texas chose to take action when a regional direct-to-consumer-advertising campaign began for genetic testing. Working together, they developed a marketing campaign to educate other health professionals about the value genetic counseling can bring to patients. As a result, the cancer genetics program at UT Southwestern increased by 41%, and they presented here at the AEC so others can learn from their efforts. That's leadership.

Finally, one of Monica Alvarado's employees at Kaiser Permanente in Southern California told me about Monica's leadership within the Kaiser system. Monica was a strong

voice in establishing an official Department of Genetics and has advocated tirelessly to hire more genetic counselors and to increase their compensation. One of her employees called her an inspiration. That's leadership.

These are just a few examples, but we will need many more examples of leadership as we face changes in our field. Jack Welch, the former CEO of General Electric whose own leadership is much revered in the business world, once said "If change is happening on the outside faster than on the inside, the end is in sight." Let's compare the changes external and internal to NSGC.

According to GeneTests, the number of listed diseases for which genetic testing was available grew from about 100 in 1993 to nearly 1,700 in 2008. The number of laboratories listing genetic tests on GeneTests increased from about 100 in 1993 to 600 in 2008. A recent *New York Times* article claimed that the latest and lowest price advertised to sequence an individual's genome is less than \$50,000, which is marked down from the 2003 estimated cost of \$500 million. Lastly, Duke University's DNA Patent Database reports that the first DNA-related patent was awarded in the 1970's, and today there are over 50,000 DNA-related patents issued.

Within NSGC, change has occurred, too. We now have members working in patient care, government, education, and industry. The percentage of members working in an academic center has decreased from 60% in 1980 to 37% in 2008. Our Special Interest Groups have expanded to twenty-one, including the latest, the Personalized Medicine SIG. Six states now have active licensure law and six more are writing their rules and regulations. NSGC membership has grown from around 100 members in 1979 to about 2,500 today.

Has change happened as quickly within NSGC as it has in genetics in general? The NSGC Board has identified several areas of focus to address this risk. Over the next three years, the NSGC intends to:

- 1) identify, define, and evaluate existing genetic counseling delivery models
- 2) embark on a marketing campaign to increase our visibility with physicians
- 3) continue our efforts to improve access to genetic counseling
- 4) position genetic counselors as the primary thought leaders in genetic counseling services
- 5) prepare our membership for the continuing changes in healthcare and genetics.

So let's return to the original question. What does thought leadership mean for genetic counselors in the genomic era? It clearly doesn't mean that we establish the rules and expect others to do what we say. And it can't realistically mean that we individually counsel every patient

with a genetic question. And it can't mean that we wait to see what other leaders do first and jump on the bandwagon when it appears safe.

In the interest of transparency, I don't know the answer to this question. If I did or others did, we wouldn't need leadership because there would be an established path for us to follow. But I do know that the world needs us right now. When I see something on the news about how to apply a new genetic test or questions raised about ethical dilemmas resulting from receiving genetic information, I want to shout at the television that we're here! There are professionals ready to help! Genetic counselors are trained in both the science of genetics and in translating genetic information to a family or individual's personal and medical needs.

But as a colleague of ours and incoming Vice-Chair of the Public Policy Committee, Susan Hahn, wrote recently, "opportunity is not an invitation". The timing may be right, but we need to take risks and go where we have not gone before.

I'd like to challenge each of you to step out of your comfort zone. Take a chance on a new job in an emerging area of specialty practice. Approach a non-genetics colleague to collaborate. Open your mind to opposing viewpoints and seek to understand rather than persuade. Start a new practice or a new practice model for a patient population that currently doesn't have access to genetic counseling. If you see an opportunity for NSGC, join an NSGC committee or SIG and initiate change.

When I went to work at J&J, I stepped so far outside my comfort zone, I think I lost where my comfort zone was. But I came back with a broader view of the world and the optimism that great results can be achieved despite large obstacles. So again, take the scary step outside of our safe, traditional world. And when you have something to share with the rest of us, step back in. We need you to lead.

Thank you and I look forward to the exciting challenges that await us in 2010!