J Genet Counsel (2011) 20:1–4
DOI 10.1007/s10897-010-9345-6

PRESIDENTIAL ADDRESS

Presidential Address

We Have Vision

Incoming Presidential Address at NSGC AEC 10/17/10
Karin M. Dent, MS, CGC

It is my great pleasure to be here today.

I have a secret.

I wanted to do this one day; I wanted to be president of NSGC. I first allowed myself to think about it just after grad school when I heard an incoming presidential address at the AEC in 1998. I thought, wow, I would love to be in that position some day. That must be the coolest job, representing our profession! What an honor. But then I thought that will never happen. I'm not that kind of person! I couldn't lead an organization and get up in front of everyone to give a speech!

But today after more than 10 years of dedicating myself to our profession and my patients, I think that I do have the experience. And here I am, in front of everyone giving a speech.

I am also passionate enough, and excited enough for all the rest to fall in to place. And I want you to be excited about our future with me.

Several years ago, National Public Radio featured a program called "This I Believe." It was based on a 1950s radio program hosted by Edward R. Murrow. This program encouraged Americans to share the personal philosophies and core values that guide their daily lives. I have thought about what I would write in this kind of essay for a couple of years now. I have been thinking about it a lot while deciding how I wanted to introduce myself to you today. And now that the program is over, I've finally figured out what I would say!

So what do I believe?

What are important beliefs for genetic counselors? How do these beliefs translate into leading our national organization and representing each of you? And, what are my values and professional philosophies that will benefit you, our organization, and our profession?

When I was a junior in high school I was a tutor in an 8th grade special needs class. There was a sweet girl I'll call Sarah who had Down syndrome. Several of the other students had conditions that I would probably recognize today, but of course didn't then. My friend Micah probably had Fragile X syndrome. Jenna might have had Rett syndrome.

But Sarah was my favorite. She was always happy to see me and her excitement was infectious; she brought a smile to my face just by saying hello and telling me she wondered when I would get there. We worked hard studying for her spelling tests and she almost always got 100%.

One day she was very sad and agitated. When I asked her why she was so unhappy, she explained it was because her mother said she was going to die when she was 18. I asked, why would you die? Sarah said her mom didn't know, she was just told that about her. Sarah said she didn't want to die, she liked school and living with her family.

I hardly knew anything about Down syndrome and as a result jumped to several conclusions. Did someone tell Sarah's mom that children with Down syndrome die by the time they are 18? And let's not forget the obvious, why did she share this unqualified information with a challenged 13 year old?

But most importantly, I sure hoped Sarah wouldn't die. She was a bright star in my life; I could only imagine the impact she had on her own family. And how tragic to be mis-informed and worry she was going to die too soon when there was no need.

I saw a happy little girl with challenges that her parents probably needed to know more about. And this instilled in me a desire to help families understand more about their children with special needs. Someone had to make sure the information the parents had was accurate and realistic.

I knew then, as a junior in high school, that my future was going to be about helping families understand the complexities and facts of genetic conditions. In fact, I thought *I* invented the term "genetic counseling." When people asked me what I wanted to do or be when I grew up, I said, I don't know, but something like talking to families about genetic disorders, something like genetic counseling.

I thought I was so smart. I'd created a whole profession!

Well, as it turns out, someone had coined this term long before me. Once I found out that genetic counseling was a real profession and not something I was going to have to create, I was ecstatic. This was it—this is what I was going to do! I was going to teach families about genetic conditions, what they might mean and not mean, how they happened, and possibly some of what to expect for the future.

I wanted to be sure families were educated and therefore empowered to deal with the challenges of the many aspects of a genetic condition. Sarah had intellectual disabilities because she had Down syndrome, but she could also read and write, tell a funny joke, come in from recess on time, be first in line for fire drills, and had feelings and thoughts she sometimes understood (and of course sometimes did not).

Now having provided genetic counseling in pediatrics for 12 years, I have gained much knowledge and experience. Not only in the clinical and academic realm, but in thinking about the identity, direction, and future of genetic counseling as a profession.

I believe, that being a genetic counselor is not just about providing genetic counseling.

It is also about having responsibility for our profession's growth and recognition.

This year, our Board of Directors created a new vision for our organization. Why did we do this? Because we have accomplished the major goal of our previous vision, to be "the leading voice, authority and advocate for the genetic counseling profession." How amazing, to have met and surpassed this mandate of our organization! What progress we, all of you, have made!

Our new, updated vision is entitled, "Integrating genetics and genomics to improve health for all."

How exciting is this? How inspiring? How far-reaching, broad, and possibly conceited is this?

Can we do this? I really think so. Yes, we have been recognized for our expertise. Now we need to integrate our services into mainstream healthcare from which everyone can benefit. We are professionals who can and should thoughtfully, prospectively, and responsibly help to guide the integration of genetics into healthcare.

Of course, *we* already know this. Not only are we individuals who are specially trained and thus have unique expertise and knowledge about medical genetics, but we are also experts in recognizing and helping resolve psychosocial issues and ethical dilemmas. Genetic counseling is a field in which we encounter unique ethical obstacles daily, surmount them, and have experience to lead others through them.

These skills are evermore important as ethical and social challenges surrounding the interpretation and application of genomic medicine become increasingly common.

The era of genomic medicine is HERE, not just getting close.

And WE are uniquely equipped to identify and handle the many complex and emotionally charged issues that arise. We will provide guidance to our target audience, physicians and other healthcare providers, as well as lawmakers, patients, and students in this genomics arena.

What does our new vision mean to me?

It inspires me to not only embrace our different professional roles, but also to create additional ways of practicing. I believe, that we must open our minds to the changing healthcare world and not just meet it, but lead the effort to inform and educate all its participants.

What does this mean for us? It means we have new challenges. Genetic counselors are no longer only going to be asked to provide counseling about results of testing a single gene or for a single disorder. As the use of exome and whole genome sequencing transitions from the research setting to the clinical realm, our patients and clients will have information about risk of different levels of certainty and utility from across the genome. We need to be prepared to provide guidance to them and their healthcare providers about how to interpret this information and its relevance.

One of our strategic initiatives is to position genetic counselors as genetics/genomics specialists who provide direct patient care and serve as consultants across the healthcare spectrum. We are the professionals who will translate these initiatives into actions that *improve* health.

I began a career in genetic counseling after being inspired to help families and interpret complex and heartbreaking information. As I've advanced through my career, I have developed into a person who believes that promoting access to our services is one of our most important goals. We are recognized for our expertise. Nevertheless, I believe our services must grow and evolve to meet the needs of the changing scientific and medical world around us.

This year I provided genetic counseling for several families with a rare monogenic disorder who were part of a project to resequence the whole genomes of a four person family. Not only was this the most technologically challenging genetic counseling I had ever provided, but the process of obtaining informed consent as well as interpreting, returning, and discussing the applicability of results was extremely complex. As an example, we used internet video conferencing or Skype, for both consenting and returning results.

Through this experience I obtained a small glimpse of the public's perspective of the personal utility of whole genome sequencing results.

In the project in which I was involved, the individual initially the least interested in return of results became the person most invested in interpreting his sequence data as the study progressed. In fact, he later enrolled in a community college genetics course.

The gene associated with the rare condition was identified and confirmed to be recessive. However, we also identified a second, unrelated recessive disorder in the affected individuals. This finding explained a different set of features these individuals had, but that were not previously reported within the rare condition and were puzzling to many of their care providers.

When we returned these results to the family, the mother looked at her affected kids and said, "Wow, you two really hit the jackpot!" Then she looked at me and asked, "So I could have had kids with someone else and this wouldn't have happened?" And she began to cry.

One of the most surprising things I learned was that how a person judges the usefulness of their genomic information is highly context-dependent and dynamic. In fact, the motivation to pursue this sort of testing may have little to do with the clinical utility of the information. Nevertheless, if an individual makes lifestyle changes as a result of such testing and these changes improve their health, this is important.

One of the least surprising things I learned was that as genetic counselors, our services are needed as much as before, if not more for this type of counseling.

We are going to have to be prepared for providing counseling in this unique context.

I recently discussed these issues with a geneticist friend of mine. He stated that he thinks the solution is for each person to "have their own private genetic counselor just like everyone is supposed to have a primary care provider." Some may chuckle or scoff, or be excited or scared at this statement, but there are merits to such an idea.

I believe this is one way that we will improve health for all; we will help people understand their motivations for doing genetic testing, how the information can be used, and what it might mean to them. It will be our responsibility to provide these services responsibly.

As your president, I am committed to help lead us in this direction. Our organization supports the voices of every one of you, no matter what your specialty, professional role, culture, background, or unique skill. Our members practice and educate the world about genetics and genetic counselors in multiple different roles.

We must appreciate and embrace the diversity of our talents and skill set. I believe this will help us achieve our new vision.

The author Ann Patchett stated in her May 2006 commencement address at Sarah Lawrence College that "we need to hear other people, all people..." I take that to heart and open my ears to "listen."

And maybe I can share a little saying from my father, "We need to listen with three ears: The first is used to listen to what is being said, the second to what is NOT being said, and the third—perhaps the hardest and also most important—is used to listen to what the speaker wants to say but is not able to articulate or express readily."

This is so applicable in our profession. I welcome diverse opinions and difficult conversations and recognize that constructing solutions together will create additional opportunities for growth and education. These opportunities will only exist if I open my three ears to listen. And I hope all of you will do the same.

I began my career twelve years ago as a genetic counselor in the Department of Pediatrics at the University of Utah. My roots as a genetic counselor have been established in the most traditional of genetic counseling roles; I am a clinical counselor in an academic setting.

Nevertheless, my expertise, experiences, and skills are multi-faceted and have been formulated in clinical, research, policy, and education arenas. Working primarily in this capacity has by no means limited my vision for the future of our profession.

While I currently function as a member of a clinical team comprised of geneticists, residents, nutritionists and other healthcare providers, I firmly believe genetic counselors should be recognized as independent providers and will work toward that goal for all of us. Additionally, while my work is in an academic setting, genetic counselors' roles must continue to expand in healthcare and society. And while the majority of my clinical effort is spent evaluating and counseling patients for single gene disorders, I know that we must focus on developing ways to provide counseling for a wide range of genetic disorders that will often be tested for simultaneously.

There is much on the horizon for us to embrace.

Let's build greatness and endurance for our profession together. We, as genetic counselors, the National Society of Genetic Counselors, have a vision that drives and motivates all of us, "Integrating genetics and genomics to improve health for all." When you think about these words, they are incredibly ambitious, and frankly, perhaps a little intimidating in their vastness. But it is a beautiful challenge and task that we have set for ourselves.

We are a team striving to meet our new vision. In order to achieve our vision, we must embrace, respect, and incorporate our different roles in the profession so that we can see ourselves as an evolving, growing, diversified and talented group.

In 2011 I may be the quarterback of our team, but a team we are. As your team leader I will continue to be dedicated, authentic, passionate, courageous, honest and trustworthy. It is a privilege to lead our organization and listen to you. And as our leader, I pledge to do what is right and not what is easy. Through this I hope to inspire others,

And this, I Believe.