

Introduction

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The following is the Presidential Address of Rebecca Nagy, 2013 president of the National Society of Genetic Counselors (NSGC). This address was given at the annual educational conference of the NSGC in October of 2012. As incoming president, Ms. Nagy identifies a major challenge for the profession; that is to produce more practitioners to meet the needs of our future patients and families. This is a need that will continue to grow given the tremendous amount of genetic information that will be available with emerging technologies. The future of genetic counseling is indeed, very exciting!

2013 NSGC Incoming Presidential Address: Walk with me

It is such a pleasure and truly an honor to be here today. I grew up about 45 min north of here in a town called Nashua, New Hampshire. I migrated to the Midwest after high school and have been there ever since, but spent all of my formative years in New England. My brother attended Boston College right down the street, where he played basketball. As a grade schooler, I made many trips with my parents to watch him play. So to be here in front of you today in a place that I once called home is extremely meaningful and I want to express my deepest gratitude for all of you who are here to listen. I hope you find the next 25 min inspiring, thought-provoking and worth your time. And I sincerely hope to get to know many more of you over the next year and beyond.

But the story that brings me here today really started in Minnesota. It was September of 1994. There I was in “Up-town,” a small neighborhood outside of Minneapolis, MN. My mother and I had managed to drive half way across the country. My father was behind us driving the U Haul truck. We were driving up to my apartment, which I had never actually seen in person because I was too poor to fly out and find one myself. I was hoping that my former college roommate had picked out a nice place for me. She had, although the carpet hadn’t been cleaned and there was sewer gas leaking up through the kitchen sink. But I didn’t care. It was my very first apartment, and in the next week I was starting graduate school. I was going to be a genetic counselor. I was taking that first step toward the rest of my life. I would have to learn my way around a strange city, ride public transportation for the first time, meet my new

surrogate family (aka my classmates, my program director, Bonnie, and my supervisors) and learn all about the human genome, empathy, contracting, enmeshed vs. chaotic family structures, twin studies, lysosomal storage disorders and metabolic pathways. And although I didn’t know it at the time, I would begin the journey that would land me here today, to stand in front of you as your Incoming NSGC President.

Many discoveries in the world of genetics were made while I was in graduate school. The *BRCA1* gene was cloned. DNA mismatch repair in yeast had just been linked to a human disease now known as Lynch Syndrome. The Human Genome Project completed its first phase, 1 year ahead of schedule. Some major milestones in the field, and those are just a few. It was really the beginning of the genetic medicine era.

Here are some other facts about 1996. There were ~1300 genetic counselors in practice that year. There were 21 genetic counseling graduate programs. The number of states that licensed genetic counselors? Zero. Today, in 2012, we have close to 3000 practicing genetic counselors in this country. We have 31 genetic counseling training programs in the US, 34 in North America. Eleven states are issuing licenses, and an additional 16 are somewhere in the process. We are closer than ever to introducing a bill that will make us recognized CMS providers and would allow us to bill for our services. In the clinical realm, we are now able to test for a fetus’ DNA from a sample of the mother’s blood. And we don’t just test one gene at a time. We test the entire genome!! All of that has happened in just 15 years. So what is the next 15 years going to bring? I think many of the experts in our field would say that we will no longer be treating disease based on phenotype, but based on genotype. This is already occurring in the oncology arena and others. Tumor boards won’t be based on tumor type, but on genetic pathways. But with all of these advancements comes a huge burden on our society. To apply the science in a responsible way. To make sure we do no harm to the public. To translate these test results in a sensitive, timely and meaningful way. To ensure that the patient and their family and their needs remain the focus.

Who better to do that than genetic counselors? Our vision and mission statements say it all. The Society’s Vision: “Integrating genetics and genomics to improve health for all.” 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.” Part of making sure we are the people delivering this care is to continue to adapt. We all know that genetic counselors are amazingly adaptive. But adapting, while necessary, is not going to solve one of our biggest problems. It is only a temporary fix; a band aid if you will. It’s covering up what we must fix. What we must fix is our lack of rapid growth. We must grow our profession. I don’t know about you, but I am so tired of the argument “But there aren’t enough genetic counselors.” We need to fix this. Let’s project out over the next 15 years and estimate the number of genetic counselors that will be in practice in 2027. Let’s assume that we add 10 new training programs who can take 6 students a year. We’ll assume an attrition rate from the profession of 1 %/year. We also have to assume that about 10 % of the current workforce will have retired by then. So if we have 41 programs graduating an average of 6 students a year for 15 years and we add that to the remaining workforce, by 2027 we will have doubled our workforce. About 6000 GCs will be practicing. I would suggest that this is not enough. I would say that by that point in time, we need at least 10,000–15,000 genetic counselors in practice, and that still may not be enough. That would be 200–300 per state. Or 1 counselor for every ~21,000 Americans. Currently, we have 1 for every 105,000 Americans.

So why talk about this now? One driving factor is the technology. The idea of test first, diagnose later, is going to be a game-changer. But it also has to do with where we are as a professional organization. This week our board of directors learned about the 4 pillars of organizational growth—Strategic Planning, Governance, Financial Management and Execution. We are strong in most if not all of these 4 areas. We have had a strategic plan in place for several years now. This is done every 3 years and is revised on an annual basis to make sure we are adapting to our constantly changing environment. Our governance changes have allowed us to become a more proactive rather than reactive organization, to be much more nimble. And our board has made decisions to invest in our future through education, marketing, PR, and leadership. Financially we are strong. And we are definitely executing. We are marketing ourselves and raising awareness about the importance of our role in healthcare, industry, research and public health. We are publishing data that proves our value, although we need much more. We are coming up with new service delivery models to increase access to care. We are publishing position statements and practice guidelines that show the value of our expertise. Our position statement on Non-invasive prenatal genetic testing was the first to hit the press last year, only months after the first NIPT test hit the market. We are at the table of many important organizations such as

Institute of Medicine Round table, the American College of Obstetrics and Gynecology and the National Accreditation Program of Breast Centers, where we educating the public, legislators and our colleagues about the importance of genetic counseling and the promise of genetic information, but also the dangers of genetic information if not implemented responsibly.

These are only a few of the things that we as an organization have accomplished and continue to do day in and day out. I talk about these, not to toot our own horn, but to show you that we are perfectly poised to be the leaders in the genomic medicine era. But there is one thing that we have not done. We have not had an intentional conversation about how to grow our profession. We have to do this. We have to push, not wait for our profession to grow, without sacrificing the quality of the education and the experience. We need passionate genetic counselors to take the leap and start a new program in their area. We need more funding for either new programs or an increase in class size of existing programs. Our programs need to be large enough to generate revenue. We need more clinical supervisors and clinical sites and we need to provide training to these individuals, even those who are not directly affiliated with a program. We need to make summer clinical placements easier for program directors to obtain for their students, so that we can utilize more counselors as supervisors, not only those who work near an accredited program. We need to make sure that we keep our standards for education high, without limiting the ability of our GC programs to expand in size. We need to develop readily available tools for starting a program and becoming a supervisor. We have our work cut out for us.

I realize that bringing more people into the pipeline is only part of the solution. Issues of diversity, starting salary, reimbursement, career satisfaction and retention are all critical here. Job creation is also critical, because we don’t want to create a surplus of genetic counselors if there is no demand. And there are many complexities that we simply have no control over; the healthcare system, the economy. It is not a simple, one-sided equation. And I do not have all the answers. No single person in this room does. But our first step is very, very simple. Be intentional and start the conversation. We need to take this first step. If we don’t at least do that, we are sure to fail. NSGC has already made a commitment by making growth of the profession part of our rolling strategic plan. My hope is that over the next year, the major organizations of our profession, NSGC, AGCPD, ABGC, CAGC and ACGC can come together and begin to discuss this very important issue. It will take the combined and integrated efforts of ALL of these organizations. Not just two or three. All five. As well as an engaged membership.

Of course, there are risks and discomforts with growing into a larger profession, as it usually requires change. Some

of these changes we have already faced: a change in governance structure, for example. A change in where we hold our Annual Education Conference, this being the first year we are in a convention center. Some challenges we are still figuring out. How do we effectively communicate to a much larger membership? How do we make sure what we do as a governance body remains transparent? How do you as members, trust that your leaders are making thoughtful decisions about our organization's future. These are growing pains that all successful organizations face. It is a good thing that we are facing these. Not a bad thing. But we will have to remain diligent as we go through future challenges and changes, that we don't lose who we are along the way. We have to have open two-way communication. We have to be careful to keep our identity as a profession. We have to be sure to carefully catalog our history, so we remember where it is we came from. We have to stay true to ourselves and be sure that the perspective we bring to the table remains *our* unique perspective. And in some cases, we need to get out of our own way. This will require all segments of our membership to stay involved in the process. The young, the old, the veteran, the newbie and everyone in between. It will require ALL of you to get involved or stay involved. How, you ask? Well we've already touched on what we can do at an organizational level. But as individual genetic counselors, you can encourage high school and undergraduate students to consider a career in genetic counseling. You can do things at the local level to increase awareness about genetic counseling. You can argue for a higher salary. You can offer to take a student over the summer by reaching out to programs in your area. You can serve as a mentor. You can volunteer for NSGC. You

can pick up the phone and call me with ideas. I believe we are up to the challenge.

I want to end with an exercise that we often use when developing our NSGC strategic plan. It's called Envisioning a Future State. Typically you envision a state 3–5 years ahead in time, and you allow yourself to really stretch the imagination. For the sake of today I want to push out a little further, to 2027. What will our profession look like in 2027? Everyone in this room may envision something slightly different, and I actually would encourage you to think or talk about how you envision our future. But here is how I see it:

In 2027, everyone will know what a genetic counselor is and what we do.

In 2027 we will have licensure for genetic counselors in all 50 states

In 2027 we will have been billing for our services as CMS-recognized providers for at least 10 years.

There will be 60 GC training programs, graduating an average of 10 new GCs a year.

The starting salary for a new GC? \$100,000.

All genetic counselors at academic centers will have faculty status.

Our professional satisfaction will remain high, at 95 %.

Established academic and career ladders will be something we climb, not something we wish for.

At the AEC that year there will be 10,000 attendees and we will remember the good old days when we had our meetings in hotels. And will laugh when we think about how we used to complain about overflow rooms.

All of these things are possible, if we just take that first step. I encourage you to walk with me.