

EDITORIAL

2019 National Society of Genetic Counselors Presidential Address

Empowering Ourselves, and Each Other, to Own our Power and Pioneer our Future as Genetic Counselors

I grew up in rural Ohio, in an Appalachian county. My dad was a blue-collar man with a great sense of humor, love of barbershop singing, the banjo and piano, and he was a small business owner who kept our family farm as a hobby. My mom was a stay-at-home mom with a bachelor's degree in sociology from The Ohio State University who later went back to school to obtain her teacher's certificate, and later, her Master's, to be a teacher in our local school district. I'm the first born, with a younger sister and brother. My only neighbors for much of my upbringing were my Nana, Grandpa, and Gramma. I was extraordinarily shy, and the only people I encountered frequently until I went to elementary school were family and close family friends. In fact, when I started Kindergarten, my teacher informed my mom that I might need to be in a "special" type of class, since I never really spoke.

Then, this little girl found piano. I fell in love with it, with music and how it made me feel. Playing piano was also a special bonding time for me and my dad, as every evening he sat on a chair right next to this piano while I practiced. I worked hard. Every single day. And I became good. Really, really good. I felt like a different person when I was at the piano—confident, powerful, the best at something, at least in my small town. I continued taking lessons until I graduated from high school, competing in contests and playing on stages with our high school's band, orchestra, and choir. Looking back, I think these were the first experiences that allowed me to build confidence, feel ambition, and along the way, become a bit empowered. These words from the poem *Adolescence* by Amber Tamblyn embody these thoughts—*"Never forget the first moment you realized your power. Let me say it again: never forget the first time you realized your power, potent as the salt that moves an ocean, strong as a dress made out of golden yeses."*

Today, I'll be focusing on two major themes. The first, that of empowerment—of ourselves, and of each other. What has empowered me over the course of my life, my career? What have I done to empower myself? What have I done to empower others? And, how has, and will, NSGC empower us all? The second theme, pioneering as a genetic counselor, even when you are *not* (yet) an expert! I'll share how big, and little, things have empowered me, equipping me with both the confidence and mindset to pioneer in genetic counseling.

So, where to begin? One of the first things that empowered me, as a genetic counseling graduate student, was my "Sister Chromatids."

The first sister chromatids I had were my fellow classmates at the University of Michigan. We always had each other's backs, even though we were from diverse backgrounds with divergent interests. We endured September 11th, 2001 together. These types of bonds allow us, as genetic counselors, to support each other and cheer each other on, through close-knit, collegial relationships, and often deep friendships, via our shared experiences and challenges. Sister chromatids—you've empowered me.

After graduation, I took my first position as a pediatric genetic counselor at Children's Hospital in Columbus, Ohio. Through networking, and approaching every single conversation with intent, 18 months later, I was recruited to Ohio State University Medical Center to create a cardiovascular genetics program. Now, back in the day, we're talking 2003, there was no cardiovascular genetics curriculum in graduate school, and only a handful of clinics really in the world. But, my passion for preventive genetics was born before I even went to graduate school and I was excited by the opportunity to build something new, so, I said yes. I said yes emphatically...Even though I legitimately had *no* knowledge-base in this area and had never developed a program before. I remember reaching out to the few genetic counselors across the country who were also pioneering in this area. They were all willing to give of themselves and their time to help me. This was truly the first time I felt and benefited from the NSGC community. I had no clue how to spell arrhythmia, or what the heck a beta-blocker was, yet I co-founded the NSGC Cardiovascular Genetics SIG with another genetic counselor, Deb McDermott. And, this is how I first learned, you do not need to be an expert to be a pioneer. But, pioneering when you're not yet an expert, and becoming one over time, empowers. Other genetic counselors empowered me, and I empowered myself.

While I was building my expertise and establishing my program, I learned that little things can also empower. I did, and continue to do, a lot of public speaking. This was a big part of growing my program locally and growing my reputation nationally. A lot of presentations in front of a lot of audiences I wanted to influence and impress was stressful and intimidating. So, before each presentation, I would give myself a little pep talk with an inner mantra before taking the stage. *"Confidence Ignite!"* I would repeat to myself. Yes, this is horribly dorky, but it worked! It still works! Don't think I didn't say it

before I walked out here today. I've shared this story with friends and colleagues over the years, not only to give them a good laugh at my expense, but especially as I became more established, and more comfortable in my own skin, to let others know that even tiny methods such as this inner pep talk and mantra can be utilized to build confidence and allow you to own that stage. Practice confidence enough, and one day you just will be.

Pretty early in my career, the members of our Division went through a 360-review process, where you are reviewed by your peers, your director, and individuals who report to you. You then receive an anonymous report of what they all said about you. I'll never forget one of the things a peer said—"Amy has good ideas. But, she doesn't speak up enough. She needs to speak up more and share these ideas." Wow. Deep down, I knew this person was right. I had been holding back. I didn't speak up enough. I was surrounded by genetic counseling giants and wasn't sure how my voice could mean as much as theirs. But, this single statement gave me confidence. Confidence to speak up in a room already filled with loud, strong voices. So, to the genetic counselor who wrote that on my 360-review many moons ago, and I think I know who you are and I'm buying you a drink tonight, thank you—you empowered me and probably didn't even realize it. These few sentences had a huge impact in altering my view of myself and gave me the confidence to speak up—you saw my potential, before I saw it myself. And I benefited greatly from knowing you felt that way. So, in turn, I challenge all of you, what can, and will, you do to empower others?

Over time I learned that big things—and surviving them—can also empower. This is me, I'm the proband here. The day after I gave birth to my first child, Jackson Augustus Sturm, I said goodbye to my father, Paul Augustus Curry. The cancer had gotten him. He was gone. And, I was a new mom. And, I learned, through my grief, grief that was with me while I nursed my newborn child at night, grief that is still with me at times...I learned what is truly important in my life. After living through this juxtaposition of the saddest, and happiest, times of my life overlain with each other, this "Dance of Grief and Joy," I had higher expectations for myself, and the strength I then knew I had. I learned that love, and loss, and grief, and surviving it all, empowers. I view these experiences as the epigenetic effects on my life. Environmental influences, laid on my DNA, that transformed me and mutated me into a super hero version of myself. An evolved version. I know I am not the only one who has been transformed into this super hero version. Most all of us have experienced, and survived, tragic events or painful times. So, I know this—all of you are, or can be, super hero versions of yourself. I know this because I never really felt like a super hero, but now I know that I, and you, can fly. Music provided comfort to me during that time, and I listened to a lot of it, especially while I paced my house, night after night, trying to get my newborn son back to sleep. These lyrics from my favorite song by Nada Surf stood out to me then and gave, and still give, me strength.

"Maybe this weight was a gift

Like I had to see what I could lift."

Our NSGC community experienced our own weight of loss and pain and grief earlier this year, and we collectively saw what we could lift, when our NSGC Operations Manager, Kathryn Whitmer, was tragically lost from this world. During this time, that just wasn't comprehensible, our fearless leader, President Erica Ramos, pulled us together via her actions and her words. Erica wrote, "*We can take our community of caring further than we ever have before. We can be advocates for each other in ways we didn't think of before. Champions, fighters, and crusaders for each other. Promoters, supporters, and boosters of each other.*" Erica, thank you, for your leadership, for uniting us, for working so hard to build community, even, no—especially—during this time. You empowered us all.

There came a point in my career when I knew it was time to move on and fly. I had built and grown a successful program. One that was strong and could move forward successfully without me. I had outgrown my role. I felt stagnant and needed something new to tackle. I was itching for an opportunity to once again, pioneer. During this same time, I had the gradual realization that I had developed the expertise, confidence, and leadership skills to rise up—I had ideas I wanted to actualize. It was time for *me* to be the *boss*. I didn't want to answer to someone else's directives. I wanted to answer to my *own*.

So, what did I do? I talked to a Sister Chromatid, Heather McLeod, right here at an NSGC Annual Conference, the perfect opportunity to connect, reenergize, and reimagine. Heather gave me the advice I needed to hear. Her exact words most likely aren't quite proper for a presidential address, but it goes something like this: "*Get your cojones out of your purse, Amy!*" Yes, this sweet, angelic face said that to me. Cojones—officially defined by Merriam-Webster as "boldness or courage needed to do something." A month or so later, I received a package delivery to my office. It was a cute little purse with silver bells, or balls if you might, with a note inside from Heather—you can guess what it said. Her supportive gift of confidence-boosting words was just the kick in the butt I needed to make the decision to take steps to alter my own destiny. It was at that moment that I knew, in my gut, I was going to pave a new path.

I felt empowered—to do multiple things that scared me. I had always networked, but then I *really* networked, promoting myself and my unique value and voice, advocating for *myself* as I had done for thousands of patients and families before. Yes, I hustled. I sought negotiating advice from one of the best in our field, Past President Steve Keiles. I negotiated role and salary and title face-to-face with my prospective new boss. I asked for the money I felt I deserved. I asked for the leadership opportunity I wanted. And, I showed I was ready to be a pioneer again. Genetic counselors are *phenomenal* at advocating for our patients. But, we need to become *phenomenal* at advocating for ourselves. The very promising news is that, for those genetic counselors who used the Professional Status Survey to negotiate starting salaries and increases, reasonable caseloads, additional genetic counselors, education reimbursement, and additional support staff, well over half were very or somewhat successful! However, only 25% or less of us, according to respondents, are actually negotiating any one of these important professional matters. We need to *ask!* We need to advocate for ourselves! And negotiate more

for ourselves! There are colleagues, including me, who are out there and willing to give you guidance on how to best approach these conversations, as well as books, websites, blogs, and guess what, there's even a chat bot for that.

After my negotiations, I got the offer I wanted. I'll never forget that moment, looking down at my wrist, at that red "Do Something That Scares You" bracelet from Past President Mary Freivogel, when I officially made my decision to accept a new, challenging position. Sometimes, to keep growing, professionally and personally, you must move on and fly. In the words of Dolly Parton, *"If you don't like the road you're walking, start paving another one."*

About 3 months or so into my new position, I was given the opportunity to take on the leadership of a large Genomic Screening and Counseling program along with another genetic counselor. Oh boy—this is what I wanted, right? This type of leadership opportunity? It was finally *real*, and it was time for me, for us, to step up and be the bosses. Now what?! For those of you who might be intimidated or unsure of your leadership capabilities, there are so many resources out there! To start, check out the work of NSGC's Leadership and Management SIG. In addition to other activities, this SIG holds regular book clubs, with the next in December on 'Dare to Lead' by Brene Brown. I'm sixteen chapters into the audio book, narrated by Brown herself. Genetic counselor Kate Wilson is hosting the SIG's book club, and guess what, the first eight to register receive the book for free! I asked Kate why she's decided to lead this book club to empower herself and other genetic counselors. Kate shared, *"I just love that vulnerability and being okay with not being perfect has given me the foundation to reach out and encourage others. I always thought that the genetic counselors who were involved in NSGC had it all together and what could I offer? It turns out that all of us has something to offer, but first we have to find our own strength and put it out there."* Sounds to me like she's daring you all to lead. Resources like this and others exist within NSGC and beyond to support you all as you dare to lead in your individual positions.

So, I challenge you, empower yourself to lead! Lead locally! Lead nationally! Be a boss if you can! Who else will advocate for genetic counselors as much as other genetic counselors in positions of power? I recall when my former genetic counseling coworker, Heather Hampel, advocated for me to get a 10% salary increase. She went to bat for me—with Human Resources, with our boss—and she accomplished this for me, from her position of power. I learned from this example, and have now, from my own position of power, advocated for other genetic counselors to receive salary increases and adjustments. While we work to diversify our workforce in many ways, the fact of the matter is that, today, our profession is approximately 95% female. And in a profession where 95% of us are women, you better believe that we need more women bosses, we need more women leaders, we need more women asking for more, and we need more genetic counselors overall, *all of us*, advocating for ourselves, and each other, so that *all* genetic counselors will be elevated in healthcare. Rise up. Advance. Be a Boss. And, when you do, bring others with you! I am convinced of the importance of this for the future of our profession. According to the 2018 PSS, 82% of

respondents graduated after 2000 and a little over half from 2010 until now. Rise to your potential, so we can raise you up, too!

For those of you in the position to influence the futures of other genetic counselors, I challenge you—Be a Sponsor. Sponsors are advocates in positions of authority and power who use their influence intentionally to help others advance. I have benefited from several sponsors—individuals who intentionally gave me props, publicly, in front of C-suite leaders and influential decision-makers. These selfless acts of sponsorship have the power to open doors to new opportunities and advance the careers of others, significantly.

J.D. Vance, in his New York Times bestseller, *Hillbilly Elegy*, wrote about a separate, yet closely related, notion—that of 'social capital'. In other words, surrounding yourself with people who can help you learn, network, and advance. Mr. Vance grew up in rural Ohio, like I did, and became a successful Yale-educated lawyer. He counts the "social capital" he proactively sought as a major facilitator in his success. In talking with genetic counselor and now CEO Jill Davies, her experience resonates as an example of earned "social capital" and this was one of the things that empowered her to start her own telegenetic counseling company as a first time CEO. Jill said, *"I was more excited about the possibility of finding success than I was afraid of failing. I had a great business plan and an idea I believed in and was willing to ask for help along the way. I had built a network I could turn to when things got tough."* Jill had sought and nurtured her "social capital," thereby gaining sponsors who knew she was worth enabling and supporting.

Just as so very many individual genetic counselors, like Jill, have paved their own paths and come such long ways, so has NSGC. NSGC is turning Forty and Fabulous next year! For those of you, like me, who have celebrated your big 4-0, you know that it is empowering! Some people might even say we're in our prime! For those of you who haven't yet, you have so much to look forward to! But you know what I say? Our *best* is yet to come—for *all* of us. Thanks to countless genetic counselors working hand in hand with NSGC staff we have H.R. 7083! Our journal, *Journal of Genetic Counseling*, had its first issue published in March of 1992. We now have 4 to 5 new submissions each week, and a new publisher as of the first of January 2019, which will allow for the continued reach of genetic counseling research worldwide. We have continued to establish ourselves as leaders of the integration of genetics and genomics into healthcare, as Jehannine Austin inspired us to do during her incoming presidential address, 2020 Vision. Recall her words and use them to empower yourself as I remember doing in the audience that day, and every day since—we, genetic counselors, will *not* be the handmaidens to the integration of genetics and genomics into healthcare—we will be the *leaders*. Just as we tell our patients that DNA does not have to determine their destinies, others do *not* determine our personal destinies, or our destiny as a profession. Others do not define us. We do that.

Years ago, I was a member of the NSGC Logo Development Team. We were charged with developing a logo to represent the mission, vision, and future of NSGC. It was a group composed of genetic counselors from diverse backgrounds and settings, Liz Kearney, Elissa Levin, Steve Keiles, Lori Correia, and myself, working

with SmithBucklin marketing lead Jennifer Kasowicz. There were two things we all agreed on—the first was incorporating the DNA double helix and that it needed to be open, symbolizing outreach to and collaboration with the communities we serve, bridges to our patients and our healthcare partners. The second was our unanimous decision to display the words “GENETIC COUNSELORS” large and emphasized. As a profession, we have accomplished what this logo represents in so many ways, and the future we imagined for NSGC at that time. This visual continues to inspire me, and I hope it does you, to embrace novel models of collaborative care, while inserting the unique voice and promoting the unique value of genetic counselors in these models. We should *not* feel threatened by these approaches, because we have the power to insert *our* voices to ensure we *lead* the way these collaborations and innovative models move forward. We can work with others in new ways without taking anything away from ourselves. This includes both real, and artificial, forms of intelligence that can assist and support genetic counselors, allowing us to work at the very top of our scope of practice. These models will enable us to focus our energies on shaping the future of genetic and genomic counseling while moving us into *elevated* roles.

Look at last month's publication in the *New England Journal of Medicine* presenting results from the NIH-funded Undiagnosed Diseases Network. This work truly has integrated genomics for the care and empowerment of patients and families. I was so excited when I saw this major publication hit the presses and social media and hurriedly Googled to find the full text, utterly thrilled to see the name of a genetic counselor as the first author and overjoyed to learn how the results facilitated precision genetic counseling for a substantial number of participants. I reached out to first author Kimberly LeBlanc, who shared, “*The UDN provides a unique opportunity for clinicians and basic scientists to come together. My hope is that the results will inspire others to implement some of the network's approaches, ideally leading to more diagnoses for patients with rare conditions. That opportunity, along with the privilege of working with these patients, their families, and the UDN investigators, motivated me to take on this project.*” What an inspiring example of collaboration for the integration of genomics into healthcare with the voice of the genetic counselor leading the way!

Genetic counselors will need to continue to pioneer to maintain our roles as leaders of this integration! From the birth of our profession, genetic counselors have been pioneering. Our profession continues to be abundant with pioneers, and there is always room for more! Continued pioneering in polygenic counseling, artificial intelligence, novel clinical specialty areas, gene editing, gene therapy, cutting-edge genetic counseling research, technology-facilitated genetic counseling—these are all areas where we can, and need to, pioneer while elevating our roles at the same time! Even our genetic counseling graduate students are pioneering! Remember, you do *not* need to be an expert to pioneer! All you need is curiosity, optimism, and perseverance! So, I challenge you, Be a Pioneer!

I recently came across this quote from Rumi, a 13th-century Persian poet, scholar, and theologian. He wrote, “*Live life as is everything is rigged in your favor.*” What does this mean? Perhaps something

a bit different to each of us. To me, it means that we can control our own destiny *and* that we need to be willing to view what might appear to be challenges, or fearful conditions, instead as opportunities. The surge in direct-to-consumer (DTC) genetic testing has provided opportunity for genetic counselors to pioneer! I reached out to Brianne Kirkpatrick to ask about her experience as a pioneering genetic counselor who is the founder and president of her own company providing services for individuals with DTC results. Brianne shared, “*Being a pioneer is dogged persistence without immediate reward, saying no to comfort, being able to handle disappointments and keep going, correcting the path after inevitable mistakes, and imagining what's over the next mountain before you are able to see it. Sounds crazy, right? It is, but the rewards of being able to help others in a new and unique way are worth it.*” Brianne approached life as if it were rigged in her favor!

As we continue to pioneer in new space, genetic counselors must be willing to persevere, not giving up when we see roles we want, things we want to accomplish. Genetic counselor Adam Buchanan shared with me how he was tired of being told genetic counselors can't accomplish certain research initiatives, including obtaining NIH funding, without a PhD. Adam had a research question he wanted to study—the return of genomic risk results for adult-onset conditions to children. He submitted a grant proposal and received an un-fundable score. So, what did he do? Did he give up? Heck no! He persevered. Well, guess what? Upon resubmission, after months and months of hard work and perseverance, Adam received his official Notice of Award from NIH. He is now an NIH-funded Principal Investigator with an MS and MPH as his highest degrees. Adam fought for this funding and didn't give up. NHGRI leadership will be here Saturday morning! They want the voice of the genetic counselor inserted into their 2020 strategic plan! They want to incorporate our ideas into the way federally funded genomics research will be shaped. Insert yourself in this conversation! Accept that party invitation!

Wow—genetic counselors, and the work being done by this profession, is insanely inspiring!

Which all brings me to this—Why did I want to be your NSGC president? It was simple for me. It's because I believe in my own value as an empowered genetic counselor and because I believe in the unique value, voice, and expertise of every single one of you in this room. And because of that, I want to do everything I possibly can to make sure you all value yourselves and that you have the tools you need to empower yourselves and advocate for yourselves to advance, elevating us all together. I *know* our collective, united, empowered voice has the capacity to make certain that all stakeholders value genetic counselors—our patients, other healthcare providers, the public, the research community, the payers, and yes, Washington D.C. I feel deeply honored with the privilege to serve as your NSGC President and to work to carry out the initiatives of our new 2019-2021 Strategic Plan, all of which were developed with the ultimate mission of empowering and advancing genetic counselors. This is also my mission. So, when Jehannine Austin calls you to inform you that you have been slated as the 2018 NSGC President-Elect, you jump up and down in the parking lot where you took her

call, and you say yes, you say yes emphatically, and then you thank your husband and your children in advance for supporting you on this mission. Thank you, Jeff, Jack, and Stella. You are my super heroes.

At a SmithBucklin Leader's Forum this past summer, one of the activities I participated in, called Visual Explorer, involved selecting a photo, from hundreds around the room, that represents the leader you want to be. I walked around the room's perimeter, gazing at photos of people skydiving and white-water rafting, fierce lions, images of beautiful, strong statues, and multitudes of other visual representations of "leadership." I landed on two photos, but there was one I just couldn't quite bring myself to walk away from. Yes, albeit dated, with no Zoom videoconferencing or multiple monitor set up, but I see myself in this photo. I'm a full-time working parent, with a crazy life, who balances a bajillion things, but I attempt to approach my work and my life with optimism and positivity, like so many of you in this room. This is my actual version. A photo of the notes both of my kids left taped to my home office door one summer's morning, while they were home with me during their summer vacation, and while I was on yet another conference call. Yes, I am a genetic counselor...and a parent, and a boss, and the breadwinner, and it's messy, but it works, via an uber support system, and I'm proud of it. Thank you, mama! Just as all of you should be proud of what you accomplish every, single day. The other photo I was attracted to that day? Well, it's one that represents pioneering to me. And, you know what, the beauty is that these two things can coexist. This is what being empowered looks like, and means, to me. What does it look like for you? It's different for every one of us. Define empowered for yourself and strive to achieve it!

My career and the course it's taken makes a lot more sense when I view it in the rearview mirror. Sometimes it was a winding road, with ups and downs, stops and starts, sharp turns and curves. Experiences I didn't realize were shaping me at the time, good and bad, made me stronger and led me to where I am today. I truly feel that I created my own destiny—and you can, too. As I drive through beautiful Ohio and Pennsylvania toward my work where I get to integrate genetics and genomics for individuals in rural areas, individuals like me and the family I hail from, and offer them preventive, potentially life-saving genomic information, pursuing my passions, I am fulfilled. What will fulfill you? What path will you pave? There are countless opportunities out there. You have the power to own your future. You are the only one who has your unique experiences

and voice. In the words of the whimsical, yet inspirational, one and only Dr. Seuss, "*Today you are you, that is truer than true. There is no one alive who is youer than you.*" What do you have to say that you haven't yet said? What do you want to do that you haven't yet done? Look for opportunities to pioneer—and seize them! Reach out directly to those in influential, leadership, decision-making positions, and via connection and passion, your voice will be heard. Display your knowledge and your value and your expertise, and I assure you that opportunities, and sponsors, will present themselves. Figure out what you want and go after it. You, as genetic counselors, as powerful individuals, need to insert the genetic counselor voice any time you can. Do not allow yourself to be small. Do not doubt your abilities. Now, when I look back at this little girl, I don't see a shy child, who may be unsure of herself. I see a determined, strong, ambitious girl who will never give up, and who will fight for what she wants. We all have opportunity to define who we want to be as genetic counselors, and who we want NSGC, the Leading Voice for Genetic Counselors, to be. We should not be afraid of the future and what it may hold. As our Annual Conference theme says—ADAPT, EVOLVE, THRIVE. We need to immerse ourselves in the evolving landscape so that we too may change and adapt to it, in turn evolving ourselves, envisioning and re-imagining our roles, which will lead to the continued thriving of each of us as individuals, and our field as a whole!

So, what does a genetic counselor do? Anything they put their damn mind to! As one of my first powerhouse sponsors, Dr. Charis Eng, used to say, and as I now say to the genetic counseling teams I work with—Onward and Upward! You are powerful. You are limitless. You are genetic counselors! You chose to be a genetic counselor because it rocks. And we are rock stars. And super heroes. So, own it! Shine bright and own your inner rock star! In the words of the goddess Rihanna, "*Shine bright like a diamond. Find light in the beautiful sea, I choose to be happy. You and I, you and I, we're like diamonds in the sky.*" Be Positive, Passionate, and Proud! In these ways, we can, and will, all be empowered to lead the integration of genetics and genomics for all together, owning our power and pioneering our futures as genetic counselors. Thank you.

Amy Curry Sturm

Geisinger, Genomic Medicine Institute, Danville, Pennsylvania

Email: asturm@geisinger.edu