



Perspectives

Exploring insights and trends around genetic counseling

Best-Of Issue | 2022

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The National Society of Genetic Counselors (NSGC) promotes the professional interests of genetic counselors and provides a network for professional communications. Local and national continuing education opportunities and the discussion of all issues relevant to human genetics and the genetic counseling profession are an integral part of belonging to the NSGC.

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


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Editor's Message

By Shelly Cummings, MS, CGC, Camille Fisher, MS, CGC

The last couple of years could be summed up with three words: change, challenge, and compassion. We have faced enormous change in the way we see, communicate, and interact with other healthcare professionals, with patients, and with our own colleagues. This “Best of Perspectives” issue highlights many of these pivotal conversations.

Learning to modify the valuable services all Genetic Counselors (GCs) provide in the aftermath of a pandemic has pushed the field to change and create new and diverse delivery models. In ‘Gender Inclusivity in the Genetics Lab’ the authors prompt a discussion on how to make genetic lab test reports more inclusive for gender-diverse and intersex individuals by thoughtfully updating ingrained medical terminology. With recent reduction in our workforce and shifting job opportunities, we learn how our field can continue to grow through the consideration of changes to policies for faculty promotion and retention of GCs within academic institutions (‘History of Faculty Appointments for Genetic Counselors’).

In ‘Embracing Failure’ we are reminded that if you “find yourself driving down an unexpected road, do not panic. Embrace the challenge, reflect on how far you have come, and most importantly, keep going.” Great advice whether facing the board exams (‘Embracing Failure’), forming a professional society (‘Creating a Genetic Counseling Professional Society in Latin America’), or navigating the immigration process as an international GC (‘Genetic Counseling? What is That? The Impact of Professional Recognition on One Genetic Counselor’s Immigration Journey’).

Every article submitted to Perspectives exudes passion infused with compassion and allows us insights into the diverse experiences of our GC colleagues. As potential GC students forge new opportunities (‘Building Context for Genetic Counseling: A Non-Profit Perspective’) or as a practicing GC finds herself navigating genetic testing results as a patient (‘Becoming the Patient: How a Personal Diagnosis has Changed My Relationship to Genetic Information’), to when you hear about colleagues who lost their jobs (‘Laid Off. Now What?’), we all need to have more compassion and patience than ever before to face life’s constant changes and challenges.

We hope you enjoy this special edition, and we welcome your suggestions for future articles. ●

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Year-end Perspective: Language, Culture, Context, and Communication

By Heather Zierhut, PhD, MS, CGC

This was a year of great change for NSGC and the genetic counseling profession. Language, culture, context, and communication are increasingly important in times of change and the articles in this best-of series describe these elements in exquisite detail. The articles outlined are exemplary pieces that help us all learn from the journeys and corresponding stories. The power of Perspectives comes from this art of storytelling and of the reflection that brings to life NSGC members' individual experiences and hearing our colleagues' meaningful messages. These unique perspectives open and expand courageous conversations as we collectively work through the challenges faced by our profession.

Throughout the year I have posted about the many ways NSGC is doing the hard work to move this organization along our strategic and J.E.D.I. action plans. We have promoted the growth and sustainability of the genetic counseling profession through advocating for the Access to Genetic Counselors Act and accomplished progress toward advancing the Senate and the House bills with the most cosponsors ever generated for our legislation. The Access and Service Delivery Committee has taken on re-evaluation of the 96040 code and presented for the first time in many years to the AMA CPT® panel. The J.E.D.I. Action Planning Task Force developed our first ever J.E.D.I. action plan which staff, leaders, and volunteers began implementing and operationalizing with the goal of creating a sustainable organizational structure and culture that supports J.E.D.I. within NSGC.

New opportunities for professional growth were created for NSGC members and we are building on that capacity to lead both within NSGC and in expanding professional environments. This year NSGC will host the first ever hybrid Annual Conference and continue to offer outstanding educational programming in both in-person and virtual formats. The first practice guidelines were published under the new, more rigorous, evidence-based process and we have piloted a new approach for reviewing position statements as well as communicating our unique view on a number of important issues through public statements including a joint statement on the Supreme Court Decision on *Dobbs v. Jackson Women's Health Organization*.

As our field continues with its exponential growth and our organization is larger than ever before, we must also recognize the growing pains and challenges we have faced as we work to create a sustainable and efficient



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organization. Externally, NSGC continues to partner with our broader allied healthcare and patient organizations to build communities of collaboration, cohesion, and greater impact that reach across our organization and beyond. The Reproductive Access, Freedom, and Justice Task Force anticipated and guided the board of directors in addressing the ever-changing post-*Dobbs* reproductive health landscape. We are also looking at our internal communities and engaging groups of members such as our Special Interest Group (SIG) Task Force to help us re-envision these spaces for the future.

The genetic counseling field will continue to reinvent itself in the wake of great change and growth. The ways that we work, the ways we

communicate, and the ways we tell the story of genetic counselors to those inside and outside of our profession is evolving with these changes. Perspectives is one way that we continue to share information with and between our members and hear from those with differing backgrounds, cultures, identities, values, and personal and professional experiences. May this communication continue to create a space for this dialogue, supporting a more diverse and inclusive NSGC. ●

HEATHER ZIERHUT, PHD, MS, CGC is the current President of the National Society of Genetic Counselors. Outside of her work with NSGC, Heather is a professor in the Department of Genetics, Cell Biology and Development in the College of Biological Sciences at the University of Minnesota.



Gender Inclusivity in the Genetics Lab

By Vanessa Di Gioacchino, MSc, CGC (she/her); Anna Essendrup, MS, CGC (she/her); Shelly Galasinski, MS, CGC (she/her); Michelle Gilats, MS, CGC (she/her); Whitney Neufeld-Kaiser, MS, CGC (she/her).

Please note all views expressed in the article are those of the authors, not their employers.



A 2021 NSGC webinar, *Beyond the Binary: Gender Diversity in Genetic Counseling*, presented by Kimberly Zayhowski and Tala Berro inspired a group of five laboratory genetic counselors (GCs) to explore making genetics labs more inclusive for gender-diverse and intersex people. This group includes GCs from American and Canadian labs, large reference and small academic labs, and cytogenetics and molecular labs. Although labs will need to address many areas to be truly inclusive, this article focuses on gender inclusivity and describes the barriers and issues encountered or anticipated by the authors. It's meant to prompt a larger discussion, not provide finalized solutions.

The laboratory information system (LIS) may influence many of these decisions. The capability of the LIS may be limited or may be shared with clinics or non-genetics labs, where requirements may differ.

Ideally, labs should only collect clinical or demographic information through test request forms (TRFs) which is required by regulation or necessary for accurate interpretation and reporting.

- CLIA (42 CFR §493.1241[c][3]) and CAP (GEN.40750) both require TRFs to include patient sex but don't specify sex assigned at birth or sex on health insurance. Labs may need to ask for both. Ideally, labs should only collect clinical or demographic information through test request forms (TRFs) which is required by regulation or necessary for accurate interpretation and reporting.
 - In labs testing sex chromosomes or sex-linked genes, discordance between test results and sex per the TRF usually prompts an investigation into potential sample switch, unless sex assigned at birth is known and concordant with results.
 - Insurance pre-authorization might be denied for prenatal testing if "male" is checked on the TRF for a transgender man.

The laboratory information system (LIS) may influence many of these decisions. The capability of the LIS may be limited or may be shared with clinics or non-genetics labs, where requirements may differ.

- Labs directly involved in billing often require the sex listed on health insurance.
- CLIA and CAP both require TRFs to include patient name but don't specify legal name or chosen name. Labs need to know a patient's legal name as it appears in their medical record.
- Labs may want to collect gender identity, pronouns, and chosen name, depending on downstream processes like reporting of patient-directed testing results and clinical counseling services.
- Sexual orientation should not be collected on a TRF.
- Demographics included on reports serve to identify the patient to the lab and the ordering provider and must meet regulatory requirements. Most lab reports include a field labeled "sex" or "gender"; however, CAP only requires patient name and another unique identifier (GEN.41096), and sometimes date of birth (CYG.31875). Including sex and gender demographics is disrespectful to the patient when inaccurate and may lead to outing the patient if they share their report. Labs should consider limiting demographic fields on reports to those required.

Reports might also reference a patient's sex or gender in the interpretation section, and standardized terminology often inappropriately



conflates the two. Below are some of the complex issues identified by the authors.

- Cytogenetic test results typically refer to “male” and “female” karyotypes, although sex chromosomes don’t solely determine sex assigned at birth. One option is to describe the sex chromosomes identified, e.g., “normal karyotype with two X chromosomes.”
- Some reports provide cancer risk information that is dependent on an individual’s assumed organs, for which the patient’s sex/gender listed on the TRF is typically used as a proxy. We

suggest reevaluation of this practice to better represent all patients. One option is to describe risk by organ type only, e.g., “the risk of ovarian cancer.” Further research is needed to accurately inform cancer risks for people who have pursued medical gender affirmation.

- Description of inheritance often uses gendered language, e.g., “maternal” and “paternal.” However, genetic changes may be inherited from anonymous donors or people who don’t intend to parent the child, and a gender-diverse person carrying a pregnancy may not identify

Including sex and gender demographics is disrespectful to the patient when inaccurate and may lead to outing the patient if they share their report. Labs should consider limiting demographic fields on reports to those required.

with the term “mother.” “Egg/sperm donor” have existing connotations suggesting a non-parenting relationship. “Egg/sperm-derived,” “egg/sperm provider/source/contributor,” and “gamete-of-origin” are potential alternatives. This nuanced issue needs further consideration.

- Some well-established medical terminology is gendered. For example, “maternal cell contamination” implies that the person carrying the pregnancy provided the egg and identifies as the mother to the fetus. More inclusive options like “gestational carrier contamination” or “non-fetal cell contamination” could be considered.

Changing ingrained medical terminology often triggers resistance. Updates require careful



thought, multidisciplinary collaboration, and effort from both providers and patients. We strongly encourage continued conversation amongst a more diverse group of healthcare professionals and the gender-diverse and intersex communities at large. As a field, we need more research and guidelines on this topic.

Definitions related to this topic can be found at: <https://transstudent.org/about/definitions/> ●



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History of Faculty Appointments for Genetic Counselors

By Kami Wolfe Schneider, MS, CGC

Due to my passion for education, leadership, health disparities, and research, I decided to pursue a doctoral degree in 2021. I chose to enroll in a Doctor of Education (EdD) program for Leadership for Educational Equity in Higher Education. Although no formal part of this educational program is in genetics or genetic counseling, I am taking every opportunity to apply what I am learning to the profession of genetic counseling.

Therefore, when the assignment in my Policy and Governance class was to write a research paper on policy impacting higher education, I jumped at the opportunity to explore faculty appointments and tenure for genetic counselors. The process of

putting this paper together was interesting to me, and I wanted to share with others what I learned.

In learning about the history of faculty appointments, I discovered that they started more than 100 years ago, when most faculty were white, Christian, upper-class men. Faculty tenure was meant to retain the very best professors with an intention that tenure would provide them the freedom and security to pursue groundbreaking research and challenge students and administrators to excel. Because of these policies, however, tenured faculty have historically lacked diversity, research has been rewarded over teaching and poor retention of non-tenured faculty has resulted in costly and other negative outcomes (Nelson, 2012).

Academic retention of genetic counselors is especially challenged by the plethora of job opportunities outside academia (Hoskovec et al, 2018). Policies for faculty promotion and tenure are typically incomplete and left open to some interpretation resulting in inequity. Faculty promotion processes vary greatly across institutions and are influenced by best practices since the written policies are limited in scope. Methods for promotion to professor faculty tracks significantly vary, and oftentimes, policies for these promotions do not exist. However, genetic counselors at some institutions have advocated for promotion consideration, most commonly on the existing matrices of other providers.

Recognizing that many institutions utilize existing matrices for faculty promotion, I wondered why so few genetic counselors meeting the requirements for faculty appointments are on professor tracks. Is it because genetic counselors do not hold doctoral degrees? Because they are primarily female? Because there is a lack of policies or metrics for specific professional and academic activities? Because they are not eligible due to hiring practices by hospitals rather than universities? Because it depends if there is a clinical professor track available? No matter what the reason, it seems that current practice is inequitable and that taking a closer look and aiming to improve policy would be beneficial.

Many policies do not appear to have a written requirement for a doctoral degree for faculty appointment promotion. Most of the institutions with genetic counselors on professor tracks have metrics that appear to be the same for all faculty, regardless of degree. Clinical tracks are a common professor track approved for and utilized by genetic counselors. Some institutions only allow genetic counselors to be promoted if they have met certain job requirements (i.e., teaching a course), and some institutions have additional or different sub-tracks that may be more accommodating to genetic counseling skills.

Education for genetic counselors and employers about best practices is essential to increasing

consistency in metrics and avenues for academically deserving genetic counselors. Institutions with improved processes and retention would then have more opportunity for financial gain since it is the long-term, experienced genetic counselors who are likely able to develop advanced research careers and obtain grants that financially benefit the institution.

Further research should be performed to identify the practices of current institutions providing faculty appointments to genetic counselors, the similarities and differences across these institutions, and the existing barriers at institutions that do not offer faculty appointments. I look forward to continuing these discussions and invite you to reach out to me with your thoughts and experiences. I hope we can all work together toward making sure genetic counselors working in academia receive equitable faculty appointments.

I want to thank Wendy Uhlmann, MS, CGC, all individuals within the NSGC, and my institution with whom I chatted, and those who responded to my Twitter request for informal insight that helped me see where our profession stands in terms of faculty appointments, tenure, and academic promotions. ●

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Becoming the Patient: How a Personal Diagnosis Changed My Relationship to Genetic Information

By Madeline Williamson, MS, CGC

My paternal grandmother died of pancreatic cancer when I was 10 years old. She had been the primary caregiver for her husband, my Pap, who had been diagnosed with Parkinson's disease and dementia years prior. After her sudden passing, my family, and the families of my three uncles all took turns caring for my Pap in his home until his death two years later.

The experience of spending those evenings with my Pap ended up being formative for me and played a role in developing my lifelong interest in neurology. My eventual career as a neurogenetic counselor allowed me to meet with families navigating neurodegenerative diseases.

It wasn't until I was in grad school, that the other half of that story came back into play. In my hereditary cancer course, I learned that a second-degree relative with pancreatic cancer was enough criteria to qualify for genetic testing. This inspired me to do some digging and I found out that I had an extensive paternal history of cancer. My grandmother had three sisters with breast cancer, a brother with rectal cancer, and a brother with kidney cancer. I spoke with my dad about his family history, and he was open to testing, but too busy with work to make an appointment.

I wrestled with this in my mind for a few years and then this past winter I decided it was time to get tested myself. I was quite surprised when

the results came back positive for a pathogenic variant in the BRCA1 gene. This was big news, but I had known it was a possibility when I initiated the testing. Mainly, I felt satisfied to have figured out the cause of the cancer history in my family and to now have the power to help myself and my relatives consider preventative options.

You can imagine my shock when parental testing revealed I had inherited this variant from my mother. It didn't make any sense. She is in her 50s, with no personal history of cancer and no striking cancer history in close relatives. I thought my genetics background had prepared me to handle genetic testing results, but in that moment, I was blindsided.

I've experienced many highs and lows throughout this process and learned that psychological adaptation is not a one-time event. At first, I threw myself into this new identity. I signed up to volunteer with a hereditary cancer advocacy organization. I became a member of multiple online support forums. I quickly disseminated the information to my family members and helped facilitate their cascade testing. I signed up for an ancestry.com account to try to locate distant at-risk relatives.

Once the initial adrenaline wore off, I was left staring down the rest of my life with more questions than answers. How high are my cancer risks really in the context of my ambiguous family history? Am I possibly doing more harm than good by starting screening that frequently results in false positives? Should I consider PGT when I'm ready to start my family and is it irresponsible not to?

While I have only been on my hereditary cancer journey for a relatively short time, it didn't take long to notice the barriers and challenges individuals face while trying to seek appropriate care. I feel infinitely privileged to be a genetic counselor and have the background knowledge that allows me to navigate both hereditary cancer and the medical system at-large. I am also privileged in several other ways, including but not limited to being white, straight-passing,

able-bodied, insured through my employer, and located near a large medical center where I can easily access preventative screenings. Every barrier I encounter in seeking appropriate care for myself and my family is only a reminder of the challenges our patients face after receiving a positive test result.

I feel infinitely privileged to be a genetic counselor and have the background knowledge that allows me to navigate both hereditary cancer and the medical system at-large.

For us as genetic counselors, calling out a result might be the last thing to check off on a Friday to-do list. For the patient, it is only the start of the rest of their life. Although I understood this logically prior to my diagnosis, I now counsel patients with a much deeper sense of empathy. When patients respond in seemingly unreasonable or potentially frustrating ways, I find it easier to reframe the situation from their perspective, assume positive intent, and become less defensive of my own ego. As I continue to incorporate my BRCA1-positive status as a part of my identity, I've reaffirmed my belief in genetic knowledge as a powerful resource, not only for my own family, but for all patients I serve. ●



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Queer Erasure in Standards of Professionalism

By Kimberly Zayhowski, MS, CGC (she/her); Nina Sheridan, MS, (she/her)

June is Pride Month, a time to both celebrate LGBTQIA+ people and bring attention to systems of queer oppression which need to be dismantled. One way we can actively support our queer peers is by interrogating the standards of ‘professionalism’ in our field. Genetic counselor Ambreen Khan gave a thought-provoking presentation at the NSGC 40th Annual Conference on how standards of ‘professionalism’ carry oppressive ideologies. She demonstrated how ‘professionalism’ encourages obedience and detracts from authenticity and relationship-building. In this piece we aim to bring additional attention to how expectations of behavior and dress modulated by standards of ‘professionalism’ contribute to queer erasure.

Professionalism and ‘acting the part’

What does it mean to ‘act like a genetic counselor’ when the field is notoriously homogenous, comprising mostly of cisgender, heterosexual,

and white women? Genetic counselor Tala Berro has written a personal account on how in graduate training they were critiqued on their values, beliefs, and cultural upbringing rather than on their skills and expertise. This is far too common of an experience for genetic counseling students with underrepresented identities. One of the standards of ‘professionalism’ is to remain apolitical in the workplace. Existing as a queer person is a political act. What do you do when your identity is ‘unprofessional?’ As seen through LGBTQIA+ history, queerness is inherently political in America. Similarly, the lives of people of color, immigrants, and people with disabilities all have been heavily politicized. Being forced to remain silent about core aspects of your identity is just one form of oppression in the workplace that encourages conformity and prevents progress.

Toxic standards of ‘professionalism’ are baked into graduate training environments.

Often students are taught to ‘respect authority’ and receive pushback when their ideas deviate from their supervisors’. This hierarchical system fails to recognize the value of minority students’ experiences and stifles students’ abilities to develop their own identities as genetic counselors. In order to truly foster student growth and empowerment, training programs and supervisors must welcome the innovation that comes with new perspectives and encourage students to express themselves authentically. Queer representation can also create a comforting and safer environment for queer patients who commonly face discrimination in the healthcare setting.

Dress codes and ‘looking the part’

What makes an individual’s appearance ‘appropriate?’ Genetic counseling programs and clinics often put an emphasis on having a ‘professional appearance’ to limit ‘distractions’ to others. Dress codes have been weaponized against queer communities, as evidenced by sex-based dress codes that partially catalyzed the Stonewall Riots and the rise of the gay rights movement in America. To this day, celebrating freedom of self-expression and self-determination are core aspects of queer culture. Many forms of self-expression, including certain hairstyles and colors, piercings, tattoos, and general attire, are deemed ‘distracting’ and are discouraged in dress codes. Similarly, it is common to have (cis)gender-based dress codes that reinforce cissexism. For many gender diverse people, subscribing to dress codes requires conforming to a binary that is not in line with their identities.

To police the way genetic counseling students and peers present themselves is to tell them they will only be accepted and respected if they abide by standards entrenched in whiteness, fatphobia, cisheteronormativity, sexism, and class privilege. ‘Professional attire’ rarely includes non-Western dress. BIPOC individuals commonly face objections to their hair textures and styles. Fat people are held to different clothing standards than thin people are. Women’s clothing is

overpoliced because of sexist ideals of modesty, promoting a culture of victim-blaming. ‘Business attire’ can be financially unattainable for some people. This all can manifest in unfair evaluations for failing to meet standards of ‘professionalism,’ and may cause others to feel justified in rejecting a person due to their lack of conformity. To continue to enforce a dress code is to exert unnecessary control over our bodies, our gender expression, and the way in which we present ourselves to the world.

Deconstructing ‘professionalism’ to increase queer belonging

As we conflate our capabilities and expertise as genetics professionals with the white, cisheteronormative standards of ‘professionalism,’ we normalize systems of oppression, dilute individuality, and further ostracize members of our community who hold identities that have been marginalized. We all need to take a deep look at the spaces that we are in - what oppressive ideologies underscore our standards, and what can we do to change them? Are our dress codes purposeful, inclusive, or even necessary? Trusting people’s judgment and allowing them to be authentically themselves will ultimately increase a sense of belonging for people in our field. While it is essential to advocate for queer people in all months, let’s use the vigor from Pride Month to create lasting change in our profession. ●



KIMBERLY ZAYHOWSKI, MS, CGC (she/her) is a cancer genetic counselor at Boston Medical Center and an assistant professor at Boston University’s Genetic Counseling Program. A queer, multiracial genetic counselor, Kim dedicates much of her time to advocating for justice for the LGBTQIA+ community through talks, research, and blog posts.



NINA SHERIDAN, MS, (she/her) is a multidisciplinary genetic counselor at Atrium Health Wake Forest Baptist in North Carolina. She works to intertwine her passions for queer and intersex advocacy, reproductive justice, and sex education into her work as a genetic counselor.



Embracing Failure

By Alaina Heinen, MS



I'm going to cut right to the chase, I took the ABGC board exam for the first time this summer and...I failed. I realize this is every new graduate student's worst nightmare, but I am here to tell you that (1) the world did not end and (2) I have continued thriving. Since most students receive advice on how to avoid failure, I want to talk about how we deal with failure when it happens.

Failure can leave us overwhelmed and dejected especially when we experience failure during something as daunting as the board exam. These feelings may be amplified for the super ambitious, the "Type-A" perfectionists who tend to be attracted to the genetic counseling profession (*cough* me *cough*). Failure can leave us drained. We put a tremendous amount of time and energy into achieving something with the hope that our success will reenergize us and fill our tanks. However if we fail, our tanks remain empty, and we start to worry about how we will get to our next destination.

This is why I believe we need to learn not only how to prevent an empty tank, but what to do when we are already on "E." Now for my radical proposal: embrace failure. Use it as a motivator, a tool for inspiration, and for a moment of reflection. We speed through life focused on the next destination, so when we unexpectedly stop (see empty gas tank analogy above), we have no idea what to do. Failure forces us to slow down and focus on our surroundings. Recognize what it took to get this far in the first place, the support you had on your journey, and the courage it took to venture into new territory. Making it through a master's level graduate program during a pandemic is not for the faint of heart. Give yourself permission to be proud of what you have accomplished and how much you have grown as a student, as a genetic counselor, and as a person. Remember why you took this road in the first place, what



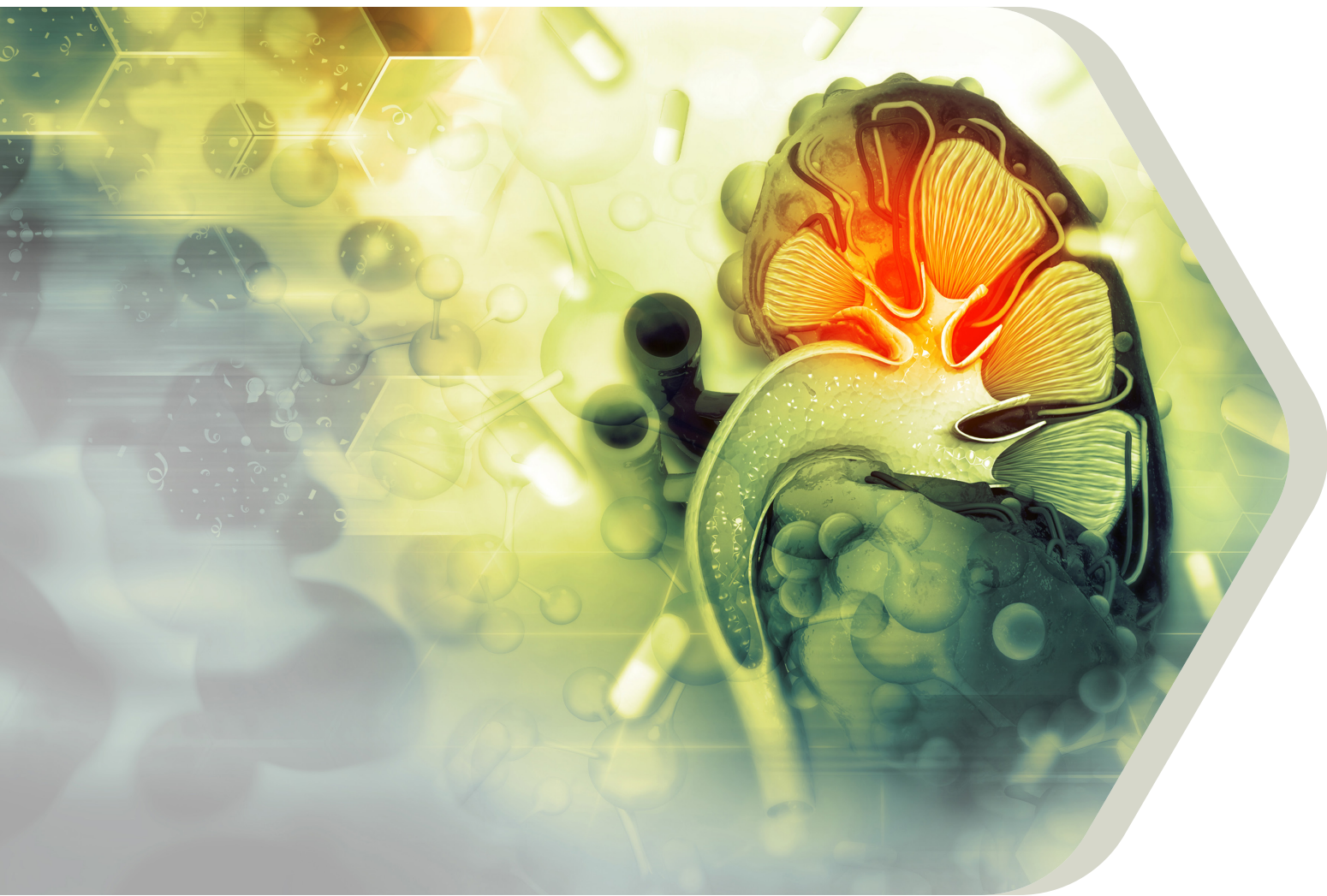
Remember why you took this road in the first place, what inspired you then, and what inspires you now. Let that reinvigorate your passion for the field and motivate you to try again. Failure provides us new perspective.

inspired you then, and what inspires you now. Let that reinvigorate your passion for the field and motivate you to try again. Failure provides us new perspective. It can ignite an even greater sense of compassion and empathy for the failures experienced by our patients, colleagues and loved ones. Simply put, failure can transform us into even better versions of ourselves, if we let it.

So if you do find yourself driving down an unexpected road, do not panic. Embrace the challenge, reflect on how far you have come, and most importantly, keep going. Maybe even turn on your favorite tune while you're at it - I would humbly recommend "Run the World" by Beyoncé. See you in February — ready to tackle the boards with renewed sense of self! ●



ALAINA HEINEN, MS graduated from the University of California-Irvine Genetic Counseling Program in 2021. She works as a primary analyst on the variant interpretation team at Rady Children's Institute for Genomic Medicine in San Diego, CA. She is a student mentor for the NSGC Student/New Member SIG.



Building Context for Genetic Counseling: A Non-Profit Perspective

By Flora Days, MS, CGC and Alaina Brock

Raising awareness for ovarian cancer and its genetic causes is my (Flora's) focus at Tell Every Amazing Lady About Ovarian Cancer – Ovarian Cancer Foundation (T.E.A.L.®). As an active board member, I partner with genetic counseling students and our program staff to develop educational pamphlets, host workshops on genetics for the public, support community events, fundraise, and vote on medical

My experience working at T.E.A.L.® is teaching me a more holistic approach and I am learning where genetics fits into the bigger picture of cancer care.

research funding. Interacting with ovarian cancer survivors, their families, and other lay community has been the most fulfilling aspect of my volunteer experience. This foundation keeps my pulse on the patient experience, which is what matters most.

At T.E.A.L.® we have happily employed individuals applying to social work, nursing, medical, public health, and now for the first time, genetic counseling programs. We are proud of our staff who have gone on to clinical or administrative positions in various medical settings, knowing they have developed awareness of the ovarian cancer patient experience. Working with T.E.A.L.® provides unique opportunities well-suited for any future healthcare provider, especially genetic counselors.

Allaina's Journey

Currently, I am applying to genetic counseling graduate programs for the second time and am also working at T.E.A.L.® as a Junior Program Associate. In the winter of 2020, I first attempted the genetic counseling graduate program application process. Surely, I thought, after completing a clinical genetics internship, acquiring crisis counseling experience, shadowing genetic counselors at Fox Chase Cancer Center, and even sprinkling in molecular biology and biostatistics research, I would have the right combination of experience to be accepted into graduate school. Only now I realize what I was missing – context! I had not learned to integrate my learnings in a real-world setting; applying the genetics concepts to people and delivering the knowledge to those who need it. All my prior experience was siloed, either genetics or counseling. Working at a cancer-focused non-profit has allowed me to combine and apply my genetics and counseling education in tandem, directly with people in need of these services.

As a Junior Program Associate, I have been leading an ovarian cancer patient membership program where I connect patients to our non-profit resources. This position has given me unique insight on the needs of patients and

survivors, who require information on a variety of topics including mental health, nutrition, and genetics. Interestingly, I am starting to understand that genetics is only a small piece of a cancer patient's journey. My experience working at T.E.A.L.® is teaching me a more holistic approach and I am learning where genetics fits into the bigger picture of cancer care.



I am grateful for this non-profit experience because it has given me the chance to enrich my psychosocial awareness and broaden my appreciation for real human needs. I think working at a non-profit like T.E.A.L.® is a beneficial experience for any genetic counseling applicant. ●



FLORA DAYS, MS, CGC is a Regional Medical Specialist in Women's Health at Myriad Genetics and has been a board member at T.E.A.L.® Ovarian Cancer Foundation for the past 8 years.



ALLAINA BROCK, is the Jr. Program Associate at T.E.A.L.® Ovarian Cancer Foundation and is a current applicant to genetic counseling programs.



A DREAMer Living Her Dreams

By Stefania Alastre, MSPH, LCGC



My journey to becoming a genetic counselor, like many others, was filled with challenges and uncertainties. However, unlike my peers, I happened to be a DACAmented student (or DREAMer), and this came with a unique set of difficulties and pain lasting almost a decade.

One month after I started working as a genetic counselor, I received a call from my immigration attorney to inform me that I had been approved for legal permanent residency (also known as a green card). My coworkers witnessed this monumental achievement and joined me in celebrating what seemed like the most unreachable dream. It was one of the first times in my adult life where I cried tears of happiness and felt free.

Although I no longer carry the weight of DACA on my shoulders, being a DACAmented student for so many years has permanently changed me. I will always feel heavily connected and protective of this community.

I am proud to be able to look at healthcare from the lens of an undocumented, uninsured immigrant and to identify health disparities as well as other areas requiring improvement within our clinic.

Currently, I am the only Spanish-speaking cancer genetic counselor providing bilingual services in Tampa and (to my knowledge) the entire central Florida region, including Orlando, Gainesville, Jacksonville, Sarasota, among others. This is not something I am proud to say. In fact, it's sad there are so few of us, especially in the state of

Florida where Spanish is the second-most spoken language.

My presence in clinic has resulted in many patients preferring to speak Spanish for their appointments, without the use of an interpreter. Only those who have struggled communicating in another language will understand the difference that receiving healthcare in your own language can make.

I have had the opportunity to engage in unique opportunities to better serve historically underserved populations, such as traveling to Puerto Rico to lecture about genetic services and appearing on a well-known Spanish TV channel to advance the public understanding of genetics. Similarly, I often attend meetings and events to increase awareness of genetic services for Hispanic/Latino patients.

It has been an incredibly rewarding ten months since my graduation. I am proud to be able to look at healthcare from the lens of an undocumented, uninsured immigrant and to identify health disparities as well as other areas requiring improvement within our clinic.

I have always been fearful of discrimination and avoided disclosing my DACAmented status to strangers. I am finally comfortable speaking about this subject. While serving Spanish-speaking patients is my main priority, I also want to inspire those students who are still protected under DACA and may want to pursue a genetic counseling career.

The genetic counseling field will benefit enormously from the continued addition of genetic counselors from diverse and underprivileged backgrounds. I encourage you to please not give up on your dreams. ●



STEFANIA ALASTRE, MSPH, LCGC is a bilingual genetic counselor working at Moffitt Cancer Center in Tampa, Florida. She graduated from the University of South Florida Genetic Counseling Program in 2021. She is now also serving as the chair of the Diversity, Equity, and Inclusion committee for the Florida Association of Genetic Counselors (FLAGC).



Genetics Down the Bayou

By Hannah Meddaugh, MGCS, LCGC

Aroux darkening on the stovetop, andouille and crawfish cooking away with the trinity of green bell pepper, onion, and celery in a pan nearby. Rich and reedy accordion music filling the heavy bayou air as a breeze passes lazily through cypress trees and Spanish moss. A dash of Tony Chachere to bring it all together. For many, the term 'Cajun' evokes romantic scenes of rural Louisiana life. In the world of genetic counseling, however, 'Cajun' represents a distinct and often overlooked American ethnic group.

'Cajun' derives from 'Acadian,' or French-Canadian and Catholic residents of Nova Scotia, which were expelled from the region in the mid-1700's. The exiled population eventually settled in communities along the Mississippi River near the Lafource, Teche, and Vermillion Bayous, where they have remained for over two centuries. Once a pejorative term used to refer to individuals with French ancestry and poor economic standing, the term 'Cajun' has been largely reclaimed as a self-identification, a place name, and an ancestral designation. At present, there are an estimated half million Acadian descendants living in Louisiana, with perhaps a hundred thousand people still speaking some Cajun-French in the home (Cleaver, 2020). For the Cajun people, laissez les bons temps rouler! Let the good times roll!

The insular and exiled nature of the original Acadian bayou communities resulted in the preservation of the cultural heritage of the Louisiana Cajuns, celebrated around the world for their language, cuisine, and music. However, the relative isolation of these populations led to other profound consequences for their modern descendants: common genetic inheritance and an increased predisposition for genetic disease.

One of the first genetic disorders identified at high rates in the Cajun population was Friedreich Ataxia, a progressive neurodegenerative disorder typically resulting from autosomal recessive inheritance of a trinucleotide repeat expansion. In the United States, an estimated 1 in 40-50,000 individuals are diagnosed with Friedreich Ataxia; studies initiated in the 1980's found that number increases to 1 in 20,000 amongst individuals with Cajun ancestry (Siguro, 1992; Guidry, 2014).

Another autosomal recessive disorder disproportionately affecting Cajuns was identified in the following decade: Usher syndrome, specifically type 1C. The so-called Usher syndrome "Acadian Allele," or USH1C c.216G>A, has been identified as a founder mutation in French-Canadian Acadians as well as Cajuns in southern Louisiana (Ebermann, 2007). Usher syndrome is so prevalent in Cajun communities that it has had an impact on American Sign

Language; the ASL dialect used in southern Louisiana borrows from tactile ASL and restricts signing to a smaller physical space (Baudoin Griffard, 2017).

Additional rare autosomal recessive disorders have been identified in Louisiana Cajuns, attributed to Acadian founder effects. Two different recurrent HEXA mutations resulting in Tay-Sachs have been identified in Cajuns; the four pair (TATC) insertion in exon 11 of the HEXA gene has been traced back to a single ancestral couple over two hundred years ago (McDowell, 1992). Carrier frequency for disease-causing HEXA mutations amongst Cajuns is similar, or greater, than rates observed amongst Ashkenazi Jewish populations. In one rural community called Iowa (pronounced Eye-oh-way), the carrier frequency is higher than 1 in 10. Tay-Sachs is so prevalent in the region that it is known colloquially as “the Cajun disease.” Written records and oral history from early Cajun settlements describe “lazy baby” disease where apparently healthy infants would decline and die in early childhood; perhaps the legacy of undiagnosed Tay-Sachs (Kennedy, 1990).

Autosomal dominant disorders have also been identified at elevated frequency in Cajun populations. Louisiana has an increased prevalence of Charcot-Marie-Tooth disease type 1A due to PMP22 duplications (Guidry, 2014) as well as oculopharyngeal muscular dystrophy due to a Cajun PABP2 founder mutation (Scacheri, 1999).

From a genetic counseling perspective, the Cajun population represents a unique cultural and ancestral community with unique needs in preconception and clinical counseling. However, the need for such services is far outpaced by the current workforce. Many studies addressing the unique genetic background of this population are outdated. Louisiana hereditary disease centers are underfunded and underutilized. Currently, there are six clinical genetic counselors in Louisiana, supporting a population of over four million residents. C’est tout. That’s all.

Ultimately, the Cajuns of Louisiana provide a reminder of the importance of understanding the unique ethnic and ancestral populations we encounter in professional practice. We are better prepared to serve the patients by taking time to engage with the history, origins, and identity of these communities.. And for all of us, ça c’est bon! That’s good! ●

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HANNAH MEDDAUGH, MGCS, LCGC earned her Master of Genetic Counselor Studies from University of Wisconsin-Madison. She is a clinical genetic counselor at Children’s Hospital New Orleans in New Orleans, Louisiana.



Laid Off. Now What?

By Marjan Champine, MS, MBA, CGC and Matthew L. Tschirgi, MS, CGC

It wasn't always this way. Genetic counseling was known to represent a small, but rapidly growing profession. According to the U.S. Bureau of Labor Statistics, a 29% growth rate was forecasted between 2014 and 2024, compared to the average rate of just 7% across all occupations. This meant that people graduating with a degree in genetic counseling often had their pick of jobs. Meanwhile, more genetic counselors were choosing laboratory or industry positions over clinical ones causing the prevalence of genetic counselors to fall short of patient demand. These market conditions left a generation of genetic counselors feeling falsely protected, maybe even immune to layoffs. Not a bad time to be a genetic counselor!

Then, the COVID-19 global pandemic turned our world upside down.

As people postponed routine healthcare visits, genetic testing appointments became even more sparse. While some genetic counselors experienced layoffs prior to the pandemic, this global health crisis exacerbated the uncertain job market. Words like austerity, pay cuts, furloughs, downsizing, layoffs, and reduction in force suddenly became a reality for many genetic counselors, regardless of employer, title, or years of experience. It became very clear that genetic counselors were not insulated from or immune to market pressures or unsustainable business models.

If you are directly impacted by a layoff, regardless of your situation, there is always a financial toll. Yet for some, the emotional side effects may feel greater. You loved what you did, you believed in the mission, and you enjoyed your colleagues whom you respected and who inspired you to

think better, do better, be better. With your team ripped apart, even if everyone finds another opportunity, it likely won't be together. Now what? Feelings of loss and less than may set in. Others may "move on" and it can be difficult to work through these new emotions especially if you feel like you were left behind.

As genetic counselors who lived through layoffs, may we offer some suggestions:

1. Allow yourself time to grieve the loss. Facing the fact that your livelihood is a vulnerable datapoint on a spreadsheet can be sobering. Remember, these decisions typically do not reflect on your performance. It's not personal, it's just business.
2. If you can, pause and reassess. Go on that trip or try that new hobby. Self-care is always important, but it is especially critical during unstable times. Is this a chance to rebrand or try something new? If you've always wanted to move into a different area of work, maybe now is the perfect opportunity.
3. When you're ready, lean on your community: NSGC, former classmates, current or former colleagues, and even your social media networks. Ask about opportunities at organizations you are connected to even if no job postings are public. Engage in conversations about your unique skill set and find ways to continue those connections even after you find your next role.
4. Take advantage of resources often made available through layoffs in the form of job coaching, resume builders, and HR to recalibrate your current market value and prepare to re-enter the job market. If you weren't offered these tools, explore publicly available resources. For example, Etsy has a multitude of resume templates at a very reasonable cost to purchase.
5. When you're ready to find a new employer, take time to explore your options. If you're applying to a publicly traded company, research financials, stock price

and executive management. During the interview process, ask about funding sources, profitability, and business outlook.

To those who make it through a round of layoffs: we see you too. You may experience feelings of survivor's guilt, tremendous uncertainty, and low team morale. You may have your head down to retain your new team, or be actively updating your resume, or a little of both. You still feel impacted, just without the outpouring of support you may have received if you had been the one let go. Neither is "easy."

Unfortunately, layoffs can happen when we feel the least prepared to handle the fallout. However, the authors have found that the key to moving forward is to lean on professional and personal networks for both emotional support and practical tools. Taking time to celebrate even the smallest win during a crisis can also be immensely empowering. While a layoff is hardly ever welcomed, when the dust settles, may you find yourself stronger, happier, and even better positioned for your next chapter. ♦

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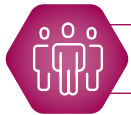


MARJAN CHAMPINE, MS, MBA, CGC is a Product Director at Quest Diagnostics with over 13 years of clinical genetic counseling, teaching, and consumer-initiated product development experience. She has personally experienced a layoff and is passionate about supporting her peers to thrive through change.



MATT TSCHIRGI, MS, CGC is Senior Manager, Genomic Services at Quest Diagnostics with over 14 years of prenatal clinical, consulting, and industry experience. He has experienced an employer acquisition and reduction in force (RIF). Matt is also affiliate faculty at Boise State University and the Founder of Genetix Consulting, LLC.





Creating a Genetic Counseling Professional Society in Latin America

By Laurie Simone, MS, CGC (she/her); Amanda de Leon, MS, CGC (she/her); Daniela Diaz Caro, MS (she/her);
Sonia Margarit, MS, CGC (she/her)



GENETIC COUNSELING IN LATIN AMERICA

The roles of genetic counselors are not yet recognized as independent professions in most of Latin America. As a result, genetic counseling services are generally provided by physicians (geneticists and oncologists) though some nurses have even reported providing genetic counseling services, despite having little to no training. Currently, there are very few formally trained genetic counselors in Latin America due, at least in part, to limited access to training programs. Two formal genetic counseling programs exist today, which include Cuba's and Brazil's master's degree programs. Although these genetic counseling programs are available, it is unclear what roles these genetic counselors are fulfilling in their areas of practice. The unmet needs in Latin America for genetic counseling need to be further investigated.

PERSPECTIVES FROM A CHILEAN GENETIC COUNSELOR

In 2004, Sonia Margarit, CGC became the only genetic counselor with formal training at the Center of Genetics and Genomics Faculty of Medicine Clinica Alemana Universidad del Desarrollo in Santiago, Chile.

In Chile, there are no practicing genetic counselors with formal training; genetic counseling is performed mainly by MD geneticists, physicians, and nurses with interest in genetics and hereditary cancer, or by PhD biologists who do research in cancer genetics. With little recognition and understanding of what role genetic counselors play in patient care, in addition to the lack of healthcare professionals in the field, Sonia realized the importance of promoting genetic counseling and the need to develop formal training programs which in turn became one of her main goals during her years of practice in Chile.

In 2013, she began a 3-year collaboration with the University of Chile in developing the diploma course in genetic counseling in hereditary

cancer. This course is still active and in its sixth version in 2022. From 2016 until 2019, with the support of the School of Nursing at the University del Desarrollo, they developed an introductory course on genetic counseling for

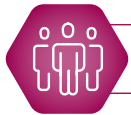
Currently, there are very few formally trained genetic counselors in Latin America due, at least in part, to limited access to training programs. The unmet needs in Latin America for genetic counseling need to be further investigated.

health professionals from all medical areas. This 3-day course included workshops and discussion of clinical cases across all stages of life. Given the interest and motivation of the students in the introductory course, an online genetic counseling diploma course was developed, which will begin in April 2022. Sonia is hopeful that more healthcare professionals from regional areas of Chile as well as from other Latin America (LA) countries can access the diploma course.

For Sonia, being the only genetic counselor has been a journey full of challenges and accomplishments but she has always remained passionate about her career and is proud to be a part of a working group (SPLAGen) focused on integrating genetic counseling into clinical practice in Latin America.

CREATING THE SOCIEDAD PROFESIONAL LATINOAMERICANA DE ASesorAMIENTO GENÉTICO (SPLAGEN)

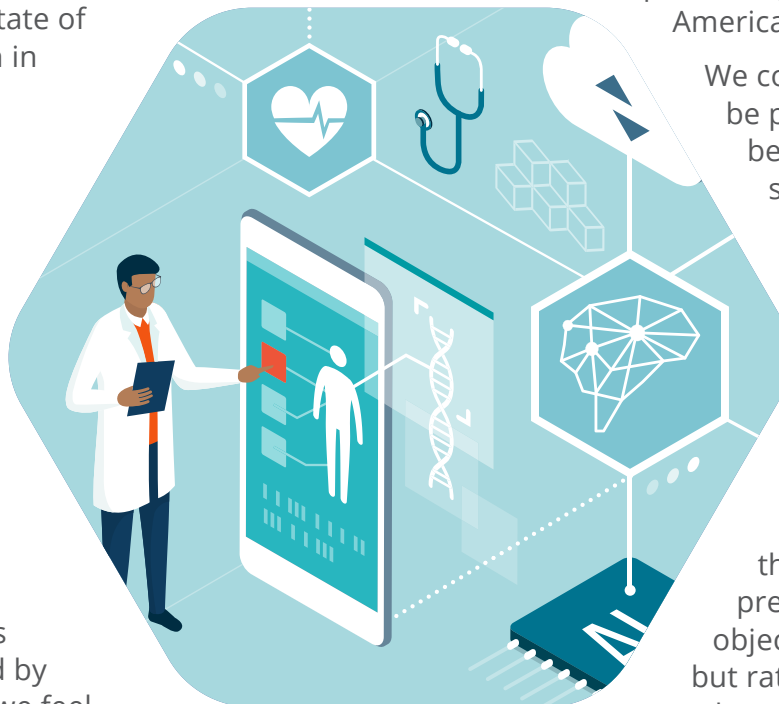
In the midst of the pandemic, Latinx members of the Minority Genetics Professional Network



Diverse Perspectives

(MGPN) gathered to find ways to increase awareness of our genetic counseling community for Hispanic Heritage Month. A project was proposed to help facilitate connections between Latin American genetics providers and local families at risk for genetic conditions. This project idea was proposed by Brenda Zuniga, CGC, and Laurie Simone, CGC. The initial result from pursuing this project was the discovery that out of 126 Latinx MGPN members, we collectively only knew of 30 providers out of all 33 countries in Latin America. This indicated a shortcoming in our community regarding our understanding of the state of the genetics profession in Latin America.

Through this project, several individuals began to think of ways to (1) connect with genetics professionals, (2) understand how genetic counseling is practiced, and (3) contribute to the field in Latin America. Discussion of these topics amongst Latinx members of MGPN was undoubtedly motivated by the strong connection we feel to the countries, communities, and cultures of our heritage. Laurie Simone spoke with Sonia Margarit, CGC about genetic counseling services in Chile. Around this time, Daniela Diaz Caro had a conversation with Mercy Laurino, CGC, PhD who shared her experience establishing the Professional Society of Genetic Counselors in Asia (www.psgca.org). These conversations provided a direction and the necessary impetus to propel Laurie Simone, Daniela Diaz Caro, and Amanda de Leon, CGC forward, to begin formulating how to best support the field of genetic counseling in Latin America.



Our first step to achieve this goal was to establish a name: The Latin American Professional Society of Genetic Counseling (abbreviated in Spanish as SPLAGen). We then set our goals which are to promote awareness of and access to genetics services and counseling in Latin America. We plan to accomplish these goals by fostering genetic counseling education, advocacy, research, networking, and public policy. It was imperative that we established an organizational structure that ensures appropriate decision-making inline with SPLAGen’s goals while also prioritizing the interests of Latin American genetics providers.

We consider this structure to be particularly important because we want to safeguard against our biases as genetics professionals trained in the United States. We aspire to create a collaborative organization that utilizes the development of genetic counseling in the United States not to prescribe practices and objectives for Latin America, but rather to inspire, support, and contribute to the vision

Latin American professionals have for the field in their communities. To this end, we have written our bylaws and hope to soon establish the leadership positions necessary to carry out much of this work. Looking ahead, we hope to apply for 501(c)(3) status and find ways to fund projects, like those described below, that align with our goals.

OUR FIRST STEP TO INCREASING ACCESS TO GENETIC COUNSELING IN LATIN AMERICA

We recognize that this is an ambitious mission but we know that we would need to set a strong

foundation in order to support the success of SPLAGen. Our three initial goals to establish this Society are: create awareness, grow our community, and define our leadership structure.

To create awareness, we created a website, as well as built a social media presence on platforms such as Instagram, Twitter, Facebook, and LinkedIn. Two social media interns, Kevin Bowles and Isabela Bucco, are prospective genetic counseling students who have been instrumental in creating posts in Spanish and Portuguese. Jimena Prado, CGC is a Canadian genetic counselor that currently serves as SPLAGen's Marketing and Communications Director. In order to grow our community, we

Our most demanding project right now is to build a directory of both Spanish-and Portuguese-speaking genetic providers in the U.S. and Latin America on our website. We hope to continue to expand this as more providers become aware of the directory.

first need to understand who would be interested in joining. Our most demanding project right now is to build a directory of both Spanish- and Portuguese-speaking genetic providers in the U.S. and Latin America on our website. We hope to continue to expand this as more providers become aware of the directory. This directory will provide us a diverse membership to collaborate with and will be beneficial for connecting patients for appropriate cascade testing in various Latin American communities. Finally, we are hoping to start recruiting individuals who are interested in

leading this society as we transition into the next steps.

We appreciate this opportunity to showcase the first steps of our journey and are excited for what our future holds. If anyone is interested in becoming involved, please reach out to us! There are many different ways that both genetic professionals and students can contribute towards our goals and we would love your support. ◆



LAURIE SIMONE, MS, CGC (she/her) is a general genetics genetic counselor and graduate of Rutgers University Genetic Counseling Program. She currently practices as a genetic counselor at Hackensack University Medical Center. Laurie's professional interests include expanding access to genetic services in Latin American communities.



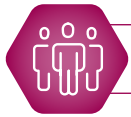
AMANDA DE LEON, MS, CGC (she/her) is a cancer genetic counselor at the University of Texas Southwestern Medical Center and a graduate of the University of Minnesota Genetic Counseling Program. Amanda's professional interests include supporting underserved patient populations such as those she sees at the county hospitals that she works at. She also has a strong interest in barriers and motivations to cascade testing for this patient population and their families.



DANIELA DIAZ CARO, MS (she/her) is a research genetic counselor at Columbia University Irving Medical Center and graduate of Stanford University Genetic Counseling Program. Daniela's professional interests include translational research focused on improving genetic counseling services and outcomes for Latin American communities.



SONIA MARGARIT, MS, CGC (she/her) is a general genetics genetic counselor and graduate of Sarah Lawrence College Genetic Counseling Program. She currently practices as a genetic counselor at Universidad del Desarrollo in Chile. Sonia's professional interests include developing genetic counseling training programs and genetic counseling in Latin America.



Diversity Dialogue: Confronting Ableism in Medical Professions

By Sarah Hunt, MS, CGC



“Wow, lucky you,” she said sarcastically. I was at an appointment and had just explained the inheritance and genetic mechanism of my rare skeletal dysplasia to the new orthopedic resident.

As a genetic counselor with a genetic condition, I’m used to knowing more about my diagnosis than anyone else in the room. I’m also used to the assumptions and limitations placed on me by medical providers.

“Yes, I’m very lucky,” I replied, without skipping a beat. “I have an amazing partner, wonderful family, a career I’m passionate about. I love my life.”

The assumption that disabled people have a poor quality of life is widespread, including among medical professionals. A recent study found that over 80% of doctors rated the quality of life for their patients with disabilities as low. (Iezzoni, et al., 2021)

The conversation with the orthopedic resident was far from my first experience encountering this attitude. Once when seeing a new doctor for hip and shoulder pain, I was told, “Well you’re already in a wheelchair, how much worse could you get?”

There is also the more insidious but prevalent reactions of shock when a new provider discovers that I work at their institution; that I am planning my wedding; that I sing in a community choir; that I’m an avid swimmer and exercise regularly; that my life isn’t 100% about my disability.

In a global pandemic, where there are emergency triage protocols, these attitudes are not just annoying, they are dangerous. Doctors who view people with disabilities as having a lower quality of life may be less likely to fully investigate symptoms or offer all treatment options (Shapiro, 2020).

Over the past several years, our profession has begun to look inward to confront racism, homophobia, transphobia, xenophobia and ableism. I would like to call on genetic counselors to take this one step further. Next time you hear

an assumption about someone with a disability, gently challenge it. For example:

- In response to “this patient uses a wheelchair, they must not exercise,” you could mention the adaptive sports clinic you saw advertised at your local gym.
- “This patient with chronic illness/pain must stay in bed all day” could be met with wondering aloud what creative outlets they have discovered or if they engage in online advocacy.
- “This patient has intellectual disability so I shouldn’t ask about sexual activity” could be an opportunity to share about the young couple with Down syndrome on the news who announced their engagement.

Genetic counselors work with patients often dealing with difficult diagnoses, debilitating symptoms and loss. Confronting ableism doesn’t need to ignore these realities. It simply challenges us to remove our own assumptions about the impact of a condition or diagnosis. It allows us to celebrate the full diversity of humanity and human resilience. It is an appreciation of the fact that wellness and happiness can be worked towards regardless of ability or disability, if the right support, medical care and accessibility exist. ●

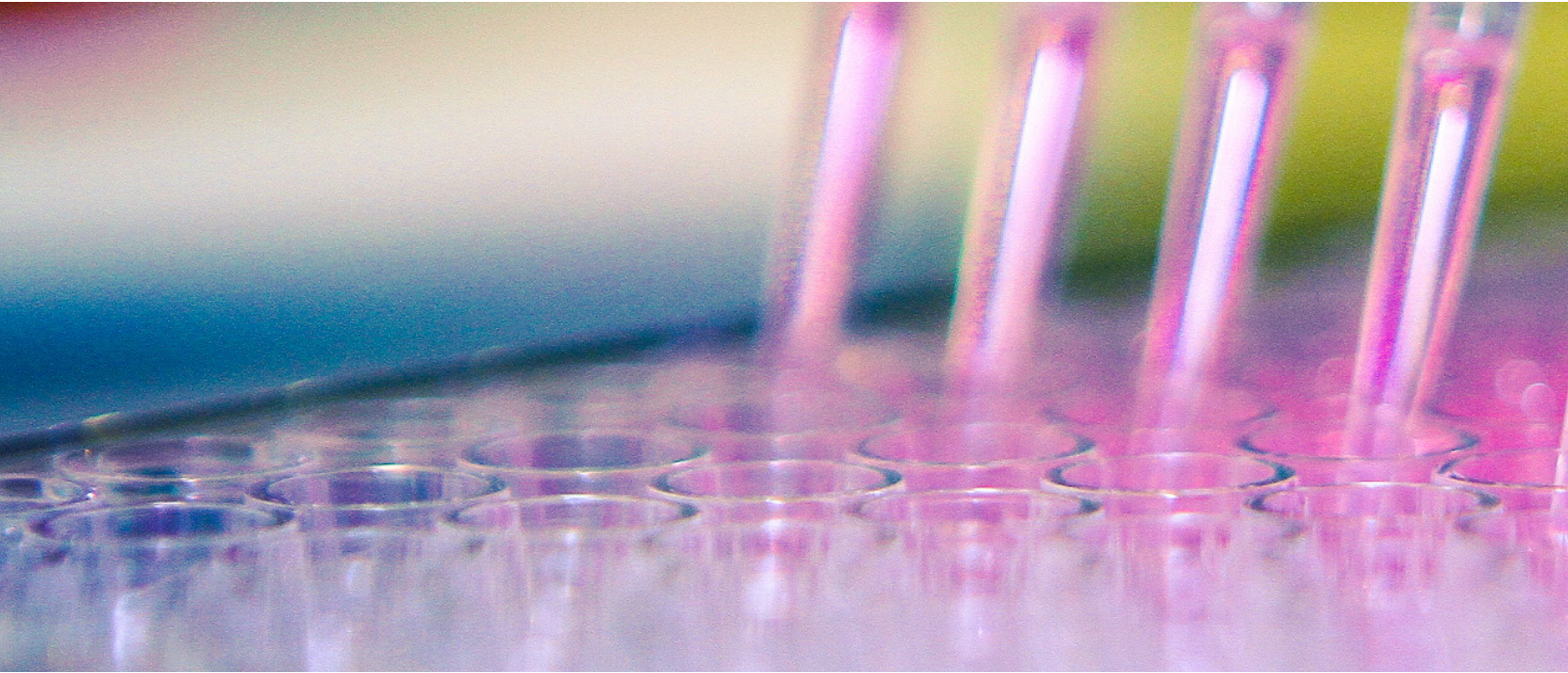
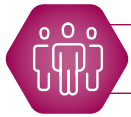
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“Genetic Counseling? What is That?” The Impact of Professional Recognition on One Genetic Counselor’s Immigration Journey

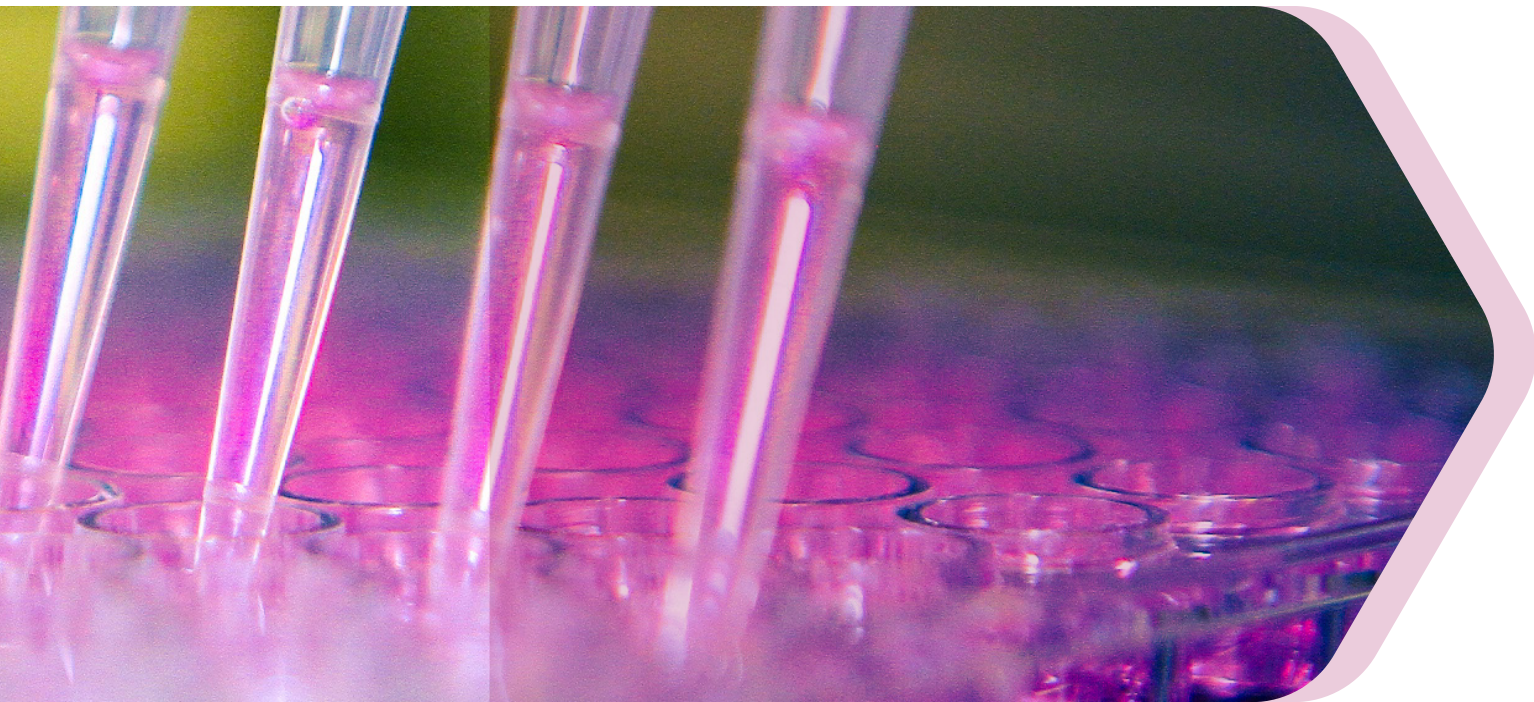
By Arpita Neog, MS, CGC

In April 2022, for the first time in ten years since calling this country my home, I could breathe a sigh of relief. I no longer had to worry about needing to leave my husband, my cat, our home, or my job, due to visa issues.

Most genetic counselors on a visa in the U.S. navigate complex immigration policies. While I never expected the journey to be easy, I was ill-prepared for the extent to which limited professional recognition would impact my personal immigration journey. My employer declined to process my paperwork because they had never done it for a genetic counselor before, and their attorneys didn’t think genetic

counselors qualified for sponsorship. I advocated hard for myself and our profession, but by the time they agreed, it was too late; the paperwork would easily take 2 years and I had less than a year left to stay in the country.

I searched for attorneys to help with “self-petition,” a process that doesn’t take as long but is exponentially more difficult to accomplish. There was a plethora of information on how engineers, scientists, physicians, nurses, artists, athletes, models, actors, and musicians could pursue self-petition, but nothing for genetic counselors. The biggest immigration firms in the country declined my case because they didn’t



know what genetic counseling was, despite all the background I provided. All they saw was the lack of an MD or PhD after my name.

I finally found an attorney willing to take the leap with me, and it turns out that was the easy part. The next step was to find leaders in the GC field who didn't know me personally but would be willing to write a letter of support. My stomach was in knots, and I felt physically sick when I reached out to potential recommenders. These letters had to explain the significance of the genetic counseling profession to a U.S. immigration officer, highlight my role, and convince the government that I was deserving of the most exclusive visa category.

My immigration story would have ended very differently without the support of friends and colleagues I met while volunteering. Half of my letters came from people I met through the International SIG, and I'm incredibly grateful for their graciousness. To help demystify the process, some of us have put together immigration resources tailored for GCs on a visa. However, there are still many things our community can do to help international

GCs. Something simple which would result in substantial impact is an official document describing the scope, significance, and value of genetic counseling, to which NSGC leadership has been receptive. My hope is that other international GCs won't have to start from scratch while navigating such a complex and confusing process; and, these resources are important first steps in that direction.

If you are an international GC, or employer/colleague/ally of international GCs and would like to learn more, please reach out to me at arpi.neogi@gmail.com. ♦



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