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Exploring insights and trends around genetic counseling

Best-Of Issue | 2023

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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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Growth, Change and Future-Facing Reflections

By Deepti Babu, MS, CGC

As I write this, it's early October and the buzz and energy of fall is undeniable. The NSGC Annual Conference is right around the corner. Somehow, 2023 is whizzing by and it feels too soon to be writing a President's message for the end-of-year *Perspectives* issue. Of course, there was no such end-of-year issue when I first joined NSGC. Our organization's member newsletter has evolved and changed a great deal over the years.

I mentioned this in my incoming presidential address at last year's Annual Conference, but getting my first paper copy of *Perspectives* was a Big Deal (those capital letters are intentional!). When I became a student NSGC member in 1997, getting that paper copy was the first time I received mail from my professional organization. It made me feel very official. I couldn't fully understand all the articles yet, but it helped me get a sense of the field and what my future colleagues were doing. It sparked my curiosity and helped me feel connected to the career I'd just entered.

In the fall of 2008, after years of not volunteering with NSGC, I decided to apply for the open Editor position at *Perspectives*. And, I got the gig! Kirsty McWalter was my partner in crime as Associate Editor, and our small-but-mighty team of volunteers and staff ultimately transformed the newsletter into a digital magazine in 2013. I had no idea what I was doing at times, but I loved the experience and learned many skills – and I layered those skills right back into my day job, where I continue to build upon them today.

Perspectives is now exclusively online, a content hub available to anyone – no more member paywall – making its reach greater than before. I can tell you with certainty, the readership goes beyond our genetic counseling community. Just last week, an external organization reached out to me because of a *Perspectives* article they read, in which Kimberly Zayhowski and colleagues discussed the urgency of care for transgender, gender diverse and intersex (TGDI) communities (psst... their article is in this very issue, dear readers, so you can enjoy it right away!). The article sparked curiosity and the organization now wants to hold a webinar to delve into the topic, which I immediately redirected to Kimberly and the group.

The online format for the publication can also streamline the publication process, make searching for articles/topics easier and create new pathways to reach different voices, insights, and... you guessed it... *perspectives* than ever before. That's a wonderful thing, because NSGC and our field are growing at an incredibly fast rate. We need to ensure we're including and uplifting



diverse voices that accurately reflect *all* of who we are as we expand.

So carve out some time, make a cup of chai, and settle in for a *Perspectives* issue that features many of our colleagues and the valuable insights they have to share. The themes I see are growth, change and future-facing reflections about our field. As this *Perspectives* issue offers, that means the impact of U.S. legislation on our profession (like advancing our Federal bill or working in a post-Roe America), innovating and stretching (like shifting to remote work or product management, pursuing a dual degree career path or practicing in a new country), exploring new solutions (like using artificial intelligence-powered tools or ways to identify fellowship training opportunities) and

speaking truths (like being a genetic counselor with an “invisible illness,” or promoting the care needs of TGD individuals and communities).

Speaking of future-facing – a few changes are coming to *Perspectives* in 2024, such as a new Executive Editor and volunteer team members. Thank you kindly to Shelly Cummings, Camille Fisher, Hannah Durnas and the entire group of volunteers and staff that makes *Perspectives* happen. It’s a team effort, and I know that firsthand. ●

DEEPTI BABU, MS, CGC (SHE/HER) is 2023 NSGC President and Founder of Integrity Content Consulting. Deepti’s engagement with NSGC spans 25 years, since joining as a student member and catching the volunteerism bug. She enjoys making meaning of complex scientific topics for varied audiences through her medical writing.



Editor's Message

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



Beth Fine, my genetic counseling training program director at Northwestern, instilled in me the importance of being actively involved in NSGC and being vigilant in furthering my professional development through volunteerism. Since that time, I have been a member of *Perspectives* in some fashion — What's on the Web, Book Review column lead, Associate Editor, and Executive Editor — all roles where I relied on many wonderful colleagues to share their expertise on a variety of topics that would benefit NSGC members. It is with great honor and mixed feelings that after nearly 30 years, I'm stepping down from my work with *Perspectives*. As you can see when I start something I love doing, it can be somewhat hard for me to give it up. Stick-to-itiveness is one way to describe me. However, the time has come for a new set of leaders to rise to the top and move *Perspectives* beyond what it is currently. Speaking of resilience, this 'Best of' edition truly highlights the dedication and focus our members have in advancing our profession and providing equitable patient care. I'm so proud to call myself a genetic counselor and cherish all the friends and my learnings through my work with *Perspectives*.

SHELLY CUMMINGS, MS, CGC is the Vice President of Oncology Medical Affairs at Myraid Genetics. She is the Executive Editor of *Perspectives* and has volunteered her time to NSGC and specifically to *Perspectives* for 29 years.



One thing I cherish about being a part of the genetic counseling community is the draw this profession has for considerate, ambitious, and compassionate people. Building connections with other genetic counselors has always and will always be an opportunity for me to learn and consider how this profession continues to adapt in the face of technological advancement, a changing social and political landscape, and evolving patient needs. My work with *Perspectives* over the past seven years has allowed me to hear from many genetic counselors, adding to the diverse insights I've gained from my more immediate colleagues. With my term as Associate Editor ending, I have decided to explore new ways to keep growing alongside and building connections. Our community is one built from a strong foundation of volunteerism, and I am grateful *Perspectives* provided a space for me to contribute to our society and even more grateful to the genetic counselors who shared their words and wisdom during my tenure. This 'Best of' edition showcases the breadth of experience and depth of dedication of the NSGC membership which daily inspires me. ◆

CAMILLE FISHER, MS, CGC is a board-certified genetic counselor and current medical science liaison with GRAIL. She graduated from the University of Wisconsin Genetic Counseling Training Program before returning to her native Texas. She is the Associate Editor of *Perspectives* and has volunteered with the publication for 7 years.



For the Unicorns: Facilitating Manifold GC Career Paths during GC Training

Caroline Aragón, MS, CGC
RESEARCH & EDUCATION |
6.21.2023



Embracing AI in Genomics: Our Role as Genetic Counselors

KT Curry MS, CGC (She/Her); Jeffrey
Bissonnette, MSc, CGC (He/Him);
Anna McGill, MS, CGC (She/Her);
Elizabeth Wiley, MS, CGC (She/Her)
PERSONAL PERSPECTIVES |
9.27.2023



Does Empowerment Always Improve the Patient Experience?

Sophia Bradley, BA
RESEARCH & EDUCATION |
5.25.2023



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NSGC NEWS | 9.13.2023



Your Questions Answered: Frequently Asked Questions about State Licensure

Brittney Murray MS, CGC
NSGC NEWS | 7.13.2023

None of this would happen without you.

So, please continue to reach out to NSGC Senior Content Manager, **Hannah Durnas**, with your creative ideas for articles, opportunities to highlight yourself or a colleague's great work, or suggestions on ways we can continue to make our content valuable to all NSGC members.



Dedication

This message is dedicated to **Lauren Ryan**, a passionate NSGC volunteer. May we all share in her passion to further the profession



by increasing access to the field of genetic counseling for underrepresented students.

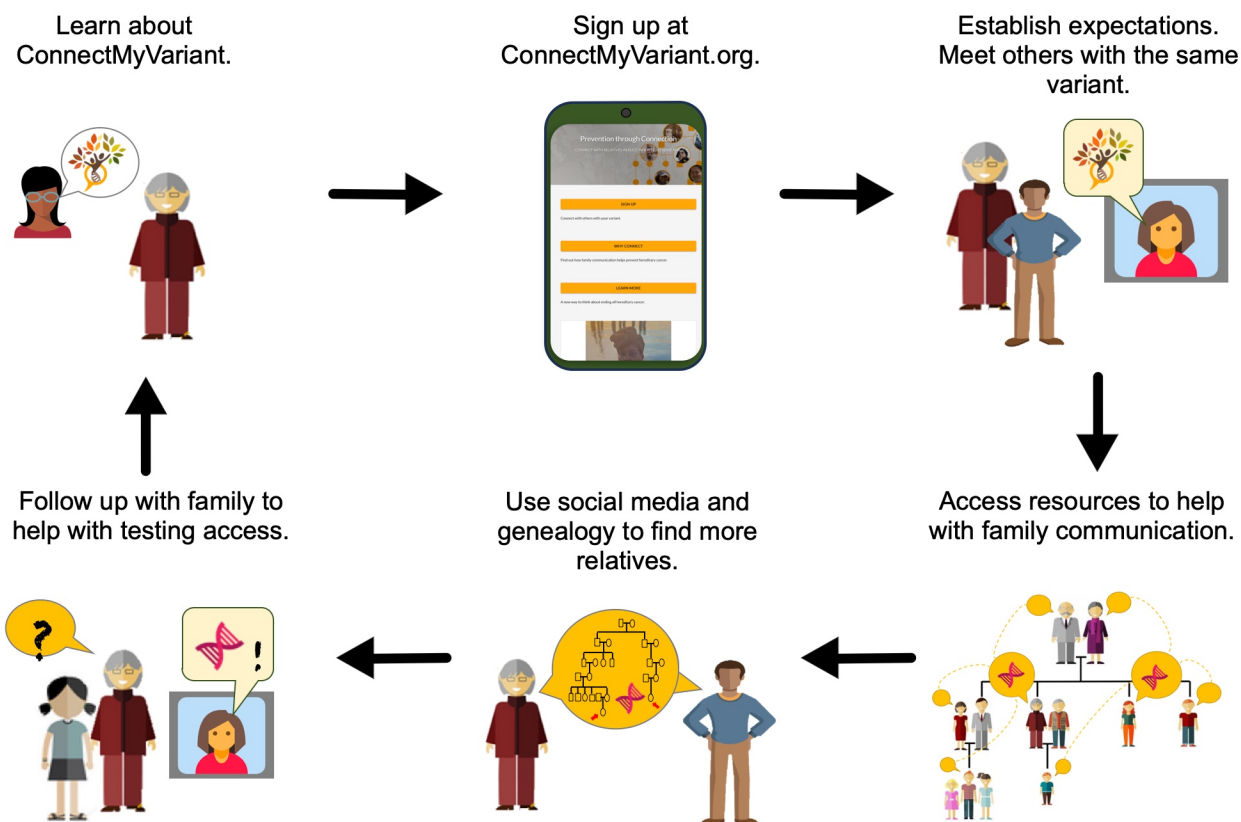
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Fighting for Recognition of the Genetic Counseling Profession

By Valerie H. LaCroix, MSc, LGC

Many of us have spent time in our jobs educating administrative, clinical, billing, and human resource personnel within our institutions on the function and scope of practice of a genetic counselor. In some systems, we are hindered and unable to practice fully because we do not fit into any of our institutions' existing staff categories.

The genetic counseling profession has long fought for recognition of our profession. The

creation of the American Board of Genetic Counseling (ABGC) was an initial step toward distinguishing our role and ensuring that any certified genetic counselor has met a certain level of knowledge, skill, and ability to practice as a genetic counselor. This is one way for the public to know they are seeing a qualified provider. In addition, NSGC has and continues to advocate for the creation of state licensure for genetic counselors. State licensure increases protection for the public by establishing a scope of practice

and standards for practitioners governed by a state medical or licensing board. It defines who can use the title “Genetic Counselor” and provides an infrastructure to ensure that those providing care in the state meet a minimum set of educational and practice standards.

In some medical centers, genetic counselors have privileges. Privileges may be granted by a committee that reviews the qualifications of a health care provider who has applied to participate in a system. Privileges also define scope of practice within the specific medical center and may indicate if the genetic counselor can place orders for genetic testing. To attain privileges, some medical centers require at least board certification and others may also require state licensure. Some genetic counselors have been credentialed by institutions or health systems, or by payers. Under credentialing, a committee reviews the qualifications of a health care provider who has applied to participate in a health system. Similar to privileges, to become credentialed, some medical centers require at least ABGC certification and others may require state licensure. Licensure, privileging, and credentialing are all ways genetic counselors can become more visible in the medical community and acknowledged as highly specialized providers. Many medical professionals have all three of these requirements in addition to being Medicare providers. This seems to be a standard for recognition in the medical field.

In the health system where I was employed, genetic counselors are mostly considered administrative staff, which greatly limited our ability to fully function within our scope of practice. The closest staff category, in this health system, that could fit our scope of practice is that of a midlevel provider, also known as an advanced practice provider (APP). However, genetic counselors do not have all the defined qualifications needed to be an APP. Both genetic counselors and APPs have certification, state licensure, and health system credentialing but APPs are recognized providers under the Center for Medicare and Medicaid Services

(CMS) and are thereby able to be reimbursed for services provided to Medicare patients. Genetic counselors need the last qualifier to be considered an APP. This may not be true in all healthcare systems, but it is for my center. Becoming a Medicare provider would increase our medical recognition and would be a big step towards becoming categorized as an APP.

NSGC is advocating for federal recognition of genetic counselors by the CMS through the [Access to Genetic Counselor Services Act \(H.R. 2144 / S. 1450\)](#). Federal recognition is a very important step for our profession, which will help to define us as independent providers. In many cases this will allow us to be designated as mid-level providers or APPs within our healthcare systems, enable us to be credentialed and allow our institutions to bill for our services. These factors will increase our real and perceived value within our health systems and amongst our healthcare provider colleagues.

NSGC is leading the way to help us grow our footprint in health systems and other communities by working towards recognition of our profession on the local, state, and federal levels. I encourage you to learn about and support these efforts if they are new to you and get involved. Not only will this benefit the profession, but it may also benefit you in a real and tangible way. This is a very important step for our profession, which will help to define us as independent providers.

The author wishes to thank Colleen Campbell, PhD, MS, LGC & Kristen Shannon, MS, CGC for their encouragement and editing expertise. ●



VALERIE H. LACROIX, MSc, LGC practiced primarily as a reproductive genetic counselor for over 30+ years before she recently retired from her position at Dartmouth Health (aka Dartmouth Hitchcock Medical Center). She is an American who graduated from McGill University genetic counseling program. After graduation, she worked briefly in Montreal Canada, Burlington VT, and Charlottesville, VA before she spent the rest of her long career at Dartmouth Health.



For the Unicorns: Facilitating Manifold GC Career Paths During GC Training

By Caroline Aragón, MS, CGC



During my graduate training, I attended a meeting with a bioinformatician who exclaimed, “Ah! You’re the PhD student who’s also in the genetic counseling program.” I affirmed that I was indeed the dual degree student. She shared, “I’m glad to work with you. You’re a unicorn.”

It was the perfect word to describe me - a unicorn. Unlike my fellow classmates, when I stepped into that first medical genetics class, I was already a year into graduate school. I’d taken courses in research techniques and settled into a *C. elegans* research laboratory. Even from the first day of school, as I rushed to care for my worm stocks between classes, my perspectives and goals looked different from my peers.

The further I journeyed down my training path, the more I realized that my experience was not unique. With one foot in the clinic and the other in the lab, I often felt like I didn’t fit the mold of a “good” genetic counseling student. Genetic counseling students were supposed to be pursuing clinical careers. But what about students who envision and apply their knowledge and skills differently?

Recent events have increased all of our attention to issues of access in the admissions process, and rightly so. Yet after admission, throughout coursework and fieldwork, and as students approach graduation and search for jobs, the next steps may look intimidating for those interested in alternative opportunities. While the roles new grads are landing rapidly expand, the training and certification requirements remain stuck in a one-size-fits-all approach. Rather than embrace the application of our GC skills into novel realms, a prevalent “this is the way it’s always been done” mindset and its accompanying expectations may discourage students from embarking down those new roads.

A strength in the evolution of our profession is the universal application of our intertwining medical, research, and counseling skills. As such, the coursework, rotations, research, and opportunities facilitated by training programs

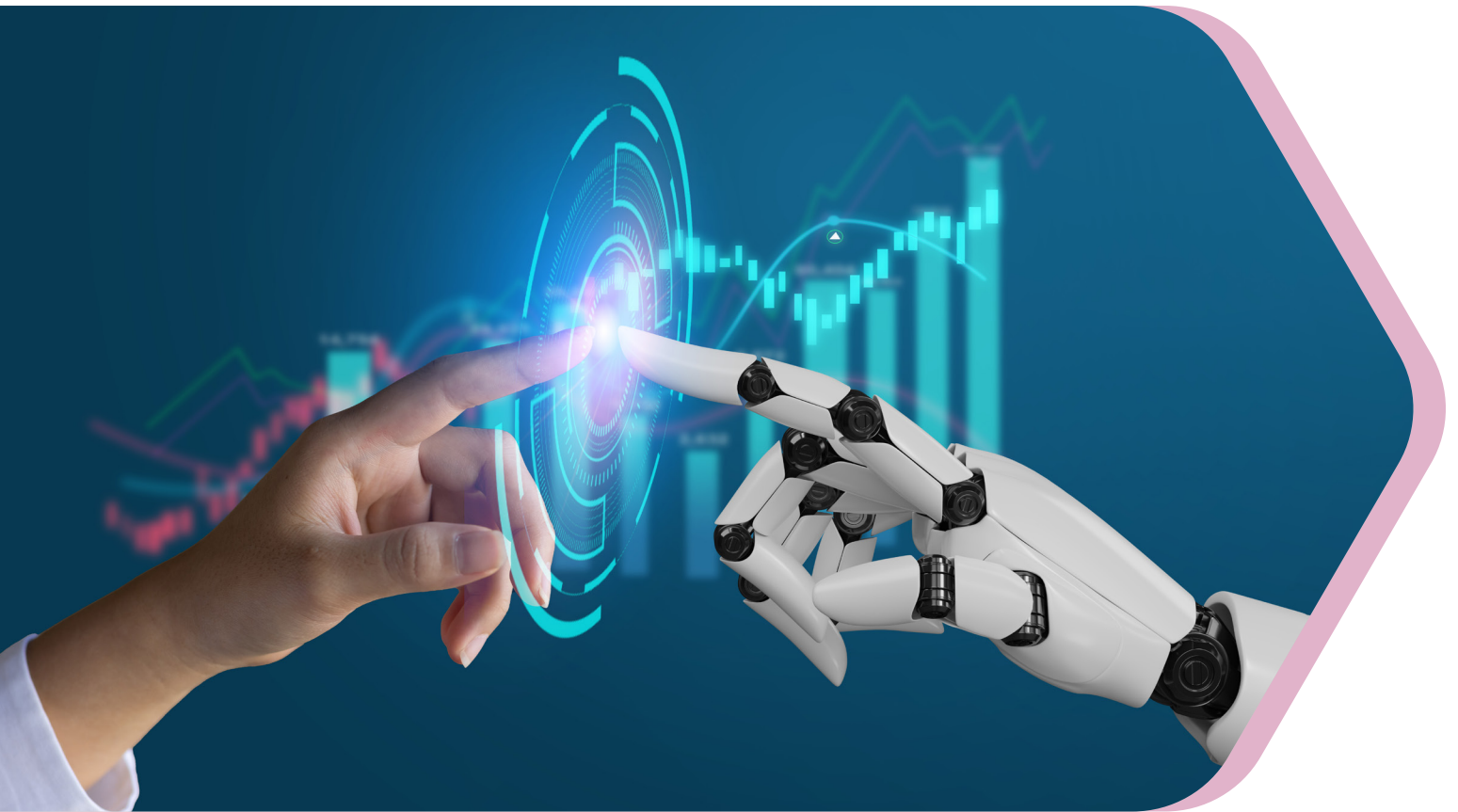
A strength in the evolution of our profession is the universal application of our intertwining medical, research, and counseling skills.

ought to reflect this heterogeneity. They should seek to prepare students for a wide range of career trajectories and even encourage them to explore uncharted settings. Adhering to traditional expectations of the training course and career progression instead perpetuates a culture of limiting these goals. In my professional life now, I could not be more grateful for those late nights spent designing experiments and observing worm phenotypes. My wet bench work prepared me to understand the research process and its application in genetic counseling, equipping me to bring unique technical and analytical skills to the table.

Many days throughout my training, I felt like there really was a sparkly horn on my head. But I’m so grateful for the ways my program and my classmates adapted to my unexpected path. Their willingness illustrates the innovative mindset within our professional community. Looking to the future, I urge graduate programs to embrace diversity not only at the beginning of training (admissions) but also at its conclusion (graduation and beyond), as their students push the boundaries of the field and explore new frontiers. ●



CAROLINE ARAGÓN, MS, CGC graduated from the University of Minnesota genetic counseling program in 2022 and is passionate about the role of genetic counselors in research. She currently serves as a Research Associate at the National Tay-Sachs and Allied Diseases Association (NTSAD).



How Artificial Intelligence will help Genetic Counselors

By Kenny Wong, MS, CGC (he/him)

Since OpenAI's launch of ChatGPT in November 2022, there has been an influx of news and speculation on how artificial intelligence (AI) will impact various industries. AI can enable more people to access genetic counseling, a field that is growing rapidly due to the advancements in precision medicine with currently more than 160,000 genetic tests and 30 new tests each day.

Artificial intelligence has the potential to help scale genetic counseling by providing a more efficient and cost-effective way to deliver care. AI can be used to automate many of the tasks involved in genetic counseling, such as providing education and support to patients, interpreting genetic test

results, and developing treatment plans. This can free up genetic counselors to focus on the more complex and psychosocial aspects of genetic counseling. While AI-powered tools are still in their early stages of development, they have the potential to revolutionize genetic counseling in a number of ways.

How are AI-powered tools already helping genetic counselors?

A few ways genetic counselors are utilizing AI-powered tools include, but are not limited to, the following:

- Genetic counselors have more time to screen more patients for risk assessment: AI can

be used to analyze a patient's personal history, family history, and lifestyle factors to identify those who are at increased risk for genetic diseases, so that they can be offered preventative care. This helps genetic counselors focus their time and attention on the patients who need it most.

- AI can help interpret genetic test results: AI can be used to interpret the results of genetic tests and provide patients with clear, understandable, and up-to-date information about their genetic health. This alleviates the need for genetic counselors to deliver routine negative results and enables them to focus their time with patients that have complex results or have additional questions.

What's the future of AI-tools in genetic counseling?

- These tools could reduce costs: AI could automate administrative tasks that are currently performed by genetic counselors, such as writing consultation summaries, or interacting with payers to ensure their patients' tests are covered. This can make genetic counseling more affordable for patients.
- AI could provide personalized educational and psychosocial support: AI could be used to provide patients with educational and psychosocial support, that are tailored to individuals based on their needs. This includes help with coping with a genetic diagnosis or making lifestyle changes to reduce their risk for disease. This could help patients deal with the emotional and practical challenges of living with a genetic condition after genetic counseling sessions. Those in need could also be automatically triaged for a follow-up appointment with a genetic counselor.
- Virtual reality could be utilized to enhance medical education: AI could be used to create virtual reality simulations that allow patients to have a more immersive experience when learning about genetic conditions. This could help patients better understand and make more informed decisions about their health care.

What are the challenges with using AI in genetic counseling?

AI is still a developing technology, and there is a risk that it could make errors. Additionally, AI may not be able to provide the same level of personalized care as a human genetic counselor.

Despite these challenges, the potential benefits of using AI in genetic counseling are significant. AI has the potential to increase access and reduce the cost of care. Over 50% of genetic counselors in a recent survey revealed that the wait time for an appointment for new patients is more than two weeks (NSGC Professional Status Survey 2023). In the same survey, genetic counselors reported on average spending ~50 minutes on preparation and follow up for new patient appointments.

What's the takeaway?

As AI continues to be adopted and further advancements are made, its transformative impact on genetic counseling is poised to revolutionize the field. AI could help drastically reduce the wait times for genetic counseling appointments and time spent on its preparations and follow ups, ensuring that everyone who needs genetic counseling has access to the care they need in a timely manner, ideally within a week. In many cases, genetic counselors have taken the lead in developing these tools and the research evidence to support how they're impacting care.

Editorial Note: The author utilized Google Bard, an AI software, to create an initial draft of this post - drastically reducing the time needed to write this content. 🌟



KENNY WONG, MS, CGC (HE/HIM) is the National Society of Genetic Counselors' Genetic Technology Expert and can discuss the intersection of genetics and technology, and how advancements such as artificial intelligence and precision medicine contribute to positive patient and provider outcomes. He previously was the host of NSGC's Genetic Counselors and You podcast. Wong serves as Chief Product Officer at xCures, where he helps develop innovative products for cancer treatment.



In a Post-Roe America, Genetic Counseling's Path Forward Must Embrace Reproductive Justice and Abandon Ableist Narrative

By Philip Connors, MS, MPH, CGC

Like many genetic counselors, I wear many hats and carry intersectional personal and professional identities. Take, for instance, this article – which I write as a practicing prenatal genetic counselor who is also an incoming member of NSGC's Board of Directors (and note the importance that my comments below reflect my own views, and not that of the Board or of my employer). Wearing another hat, I have interviewed hundreds of prospective GCs applying to our university's training program and have followed a familiar line of questioning and discussion. I'd ask:

"As reproductive GCs, we find ourselves at the intersection of advocating for patient's rights to end a pregnancy due to the diagnosis of a congenital or genetic condition – and advocating for the highest level of support, resources, and access to services for the next patient in this scenario to care for a child who will be born with that same condition. Have you thought about this juxtaposition before?"

There are many avenues to explore. Yet, in 2022, a new Supreme Court majority pulled the rug out from under all of us who support pregnant patients, who might become pregnant patients,

or who believe in the right to privacy in medical care by reversing *Roe v. Wade* in its ruling in *Dobbs v. Jackson Women's Health*. What do we do now? How can we support our patients and providers targeted by heinous state laws criminalizing those providing and seeking well-established, safe, and routine abortions as healthcare?

In reflecting on this over the past few months, I found the answer to this crisis was also the answer I've been looking for when conferring with applicants. The end of *Roe* marks a turning point in our country and our profession – and I see no space left for inconsistency in action or values. Genetic counseling must exist as a profession which is UNABASHEDLY pro-choice and anti-forced birth, without perpetuating an ableist narrative of what makes a good or bad abortion. This starts with recognizing all abortion as healthcare that is life-affirming and validating for a patient's control over their own body and future. We must recognize reproductive justice as a core value and fundamental right. And we must recognize the damage we have caused to both patients seeking reproductive autonomy, and patients with disabilities.

We might begin to handle this apparent juxtaposition of values and communities by ending the narrative that some abortions are justified, and some are less so. Indeed, many of our patients seek abortion after a planned and desired pregnancy is found to have a severely life-limiting diagnosis. We sit with these patients in the most challenging times of their lives, and we carry these experiences with us across our careers. Still - we must STOP placing these stories above any other patient seeking abortion. In a post-*Roe* world, all patients are at risk of being forced to continue a pregnancy they otherwise do not wish to continue. Recall that according to the Guttmacher Institute, 90% of abortion care in the United States in the past decade occurred before serum screening, cfDNA, or CVS results would have ever been available, and only 5% of abortions are provided after 16-weeks' gestation ("Induced Abortion in the United States" Fact Sheet, September 2019).

We might also address any similar juxtaposition felt within ourselves by recalling that when our own values or beliefs are affecting the healthcare we offer, we are doing it wrong. Genetic counselors who may personally be uncomfortable or opposed to abortion may well struggle to weather this internal conflict, and those colleagues deserve our support in processing those feelings. As a profession, however, the space for nuance has closed.

Pregnancy is in and of itself a risk to a patient's health, and all patients deserve access to information about that pregnancy to inform their own decision-making around accepting risk. Genetic testing and ultrasound assessment represent some of that information, and our profession is familiar with how this data can completely shift a patient's perception of risk. As genetic counselors, we must confront the fact that the intent of our words is often not the same as their impact. When members of our community publicly or privately relay the stories of these diagnoses – often infused with dramatic and emotive rhetoric – we are conflating a conversation about reproductive autonomy with offensive and ableist perspective.

The medical community's words and attitudes in navigating these diagnoses with patients during pregnancy are fully informed by our own community's history of eugenics. We must constantly inquire how we can do this better and accept this as a life-long journey for our area of practice. But we must do so on the platform that all patients deserve access to safe and legal abortions in our country, where the only reason they need cite is "I do not wish to continue this pregnancy." ◆



PHILIP CONNORS, MS, MPH, CGC is the Lead Genetic Counselor for Boston University Medical Group/Boston Medical Center and Assistant Professor in the Department of Obstetrics and Gynecology at Boston University Chobanian & Avedisian School of Medicine. He provides reproductive genetic counseling services and is engaged in research and policy work surrounding the intersection of genetics and public health – including access issues and health outcomes disparities in genetic counseling, genetic testing, and care promoting reproductive justice.



A Tradition of Being Non-Traditional

By Mike Peracchio, MS



It was not an easy decision for me to pursue a degree in genetic counseling. I previously taught high school biology and when I left teaching to go back to graduate school, I intended to pursue a PhD in genetics. However, I realized that my passion was not in the research lab, so I instead earned a master's degree. I then joined a clinical genetics lab, where I felt I would have a more direct impact on patient lives.

Yet, I still felt something was missing. I like connecting with people and I love teaching about genetics, so I thought genetic counseling could be a great fit for me. I was hesitant to enter yet another round of graduate school but, fortunately, my family could see how sure I was that this was what I wanted to pursue. I took the plunge and already know that it was the right decision.

I did not expect that my first job would be working from home as part of a laboratory genetic counseling team. I worried that I should start out in a more "traditional" role to get "proper" experience, and then I could consider a lab position later in my career. However, I got an opportunity to transfer to the genetic counseling team at the lab where I had been working throughout GC school. It seemed like an opportunity I should not pass up.

As a telegenetic counselor, I provide post-test counseling for expanded carrier screening. I get to have the direct interaction with patients that I was seeking.

I really enjoy my remote laboratory role. I am part of a strong team of genetic counselors with a wide range of experience in a variety of settings. I learn so much from my team and I appreciate the supportive environment. As a telegenetic counselor, I provide post-test counseling for expanded carrier screening. I get to have the direct interaction with patients that I was seeking. However, in the lab setting, there are also many other types of roles for a GC, such as in variant curation or as a medical science liaison.

Working remotely offers certain lifestyle benefits as well. I have traded a 2-hour daily commute for a walk downstairs. I can help get my kids on and off the bus and to their various activities. I have more time to spend with family and friends or getting back into an exercise routine. I worried about the isolation of working alone at home everyday, but my team makes many efforts to connect regularly.

I'm thankful that I decided it wasn't too late to make another career change, and I'm glad I was willing to explore a "non-traditional" genetic counseling position. I think the laboratory setting and its variety of roles can be a good fit for both new and experienced GCs. I'm grateful to have finally found the right career in genetic counseling, and I hope others know that it's never too late to pursue your dreams, and those dreams may not be what you once thought. Now I just have to pass that board exam! ♦



MIKE PERACCHIO, MS graduated from the Bay Path University Master of Science in Genetic Counseling Program in 2022. He works as a genetic counselor with the Women's Health Remote Genetic Counseling team at Sema4, where he provides post-test counseling for expanded carrier screening.



A New Need Arises as Fellowship Training Opportunities Emerge

By Molly Marra, PhD, MS, CGC

In the short few years since I entered the field of genetic counseling, I've watched several post-graduate training opportunities (termed "fellowships") grace my Inbox and Twitter feed. As a student, I was intrigued by the possibility of continuing my education by participating in a fellowship year of subspecialty practice. When I ultimately landed as a newly minted genetic counselor immersed in an ophthalmology practice immediately after graduation, I often considered how I could have benefitted from the mentored fellowship year. And now, as a genetic counselor preparing to host a new fellowship program, I continue to reflect on how these

emerging post-graduate training opportunities may impact our profession.

In the development and promotion of a fellowship program, one noticeable limitation is the lack of a centralized repository for information regarding available fellowships. Some opportunities are advertised as standard job postings, promoted on NSGC Job Connection and LinkedIn. Others are shared more widely on social media or advertised to students through correspondence with program directors. This is further complicated by the intermittent nature of some of these programs, which sometimes support a fellow one year and not the next,



due to factors including grant funding or mentorship availability.

Currently, it is difficult to track the number and availability of current fellowship opportunities for genetic counselors. Unlike genetic counseling training programs, fellowships are not currently standardized or accredited. Existing opportunities are diverse in their offerings and purposes. However, if the pattern of more mature healthcare professions is predictive for genetic counselors, the number and availability of these programs may increase.

As a result, there is a need to increase the visibility of emerging fellowship programs. Perhaps NSGC or ACGC could consider hosting a website with information on fellowships and advanced training opportunities. The development of a resource that houses information regarding fellowship opportunities is timely, and could streamline advertisement of the programs, alleviating pressure from

individual fellowship programs and training program directors. The resource could also provide more transparent and equitable information regarding deadlines, stipends, and selection criteria.

Other healthcare professions have walked this road before us, and now have well-established fellowship programs and publicly available guides for these opportunities. As genetic counselors have always done, we will adapt to the changing demands of our field and the emergence of fellowships within our field. I look forward to being part of these conversations in our ever-changing profession. ◆



MOLLY MARRA, PhD, MS, CGC is a genetic counselor in Inherited Retinal Disease and Retinoblastoma at Oregon Health and Science University's Casey Eye Institute. She recently launched the first genetic counseling fellowship in inherited retinal disease. The grant funded program will welcome the first fellow in June 2023.



From Genetic Counseling to Product Management: Five Transferable Skills

By Carrie Haverty, MS, CGC and Nivi Ahlawat, MS, CGC

Genetic counseling is an evolving profession, and with the development of new genetic products from cell-free RNA analysis and machine learning-based screening that predicts pregnancy complications, to AI-assisted chatbots that can collect family histories and draw pedigrees, genetic counselors are making their mark as product managers. Product management involves discovering, designing, implementing, delivering, sustaining, and improving tests, tools, or services that meet the needs of users. Genetic counselors are uniquely qualified to excel in product management, building products to serve the needs of patients, healthcare providers, and researchers.

As genetic counselors, we leverage five key transferable skills in our work in product management: tailored communication, stakeholder management, active listening and motivational interviewing, logical and structured

thinking, and empathy. These skills allow genetic counselors in product management to center users and their needs.

- **Tailored communication** is crucial in product management to convey complex information in a way that is both motivating and easily understood by customers, stakeholders, and collaborators, similar to how genetic counselors communicate information to patients. Shivani Nazareth, Vice President of Digital Products at Myriad Genetics, explains, "Good product managers are storytellers at heart. They understand the end user and can craft a compelling story about what to build and why it matters. I would argue that most genetic counselors know how to use stories to motivate behavioral change."
- **Stakeholder management** is another critical skill for product managers, who may work with stakeholders from engineering, UX, marketing, sales, business development, legal, regulatory,

clinical, product end users, and more. Similarly, genetic counselors must be able to work with a variety of stakeholders such as patients, healthcare providers, payors, and internal teams. Kaylene Ready, Vice President of Product Management at Strata Oncology explains, “Balancing the needs and concerns of multiple stakeholders is critical to success. You must be able to earn the trust of many people in the organization and reflect and represent their needs and concerns to others in order to build consensus and achieve the company’s goals.

- **Active listening and motivational interviewing** are important skills for identifying the root causes of problems and finding meaningful solutions. Carrie Guy, previous Product Manager at Quest Diagnostics, emphasizes, “Knowing how to set a mutually agreed upon agenda, active listening, and informed decision making are critical to success in product development and test launch.”
- **Logical and structured thinking** is vital in product management, and genetic counselors already analyze complex data and information, identify patterns and trends, and make informed decisions. Sarah Witherington, Senior Product Director at Bioreference states, “The ability to critically evaluate and translate scientific literature and data are skills I use on a regular basis.”
- **Empathy** is perhaps the most important and fundamental aspect of product management and genetic counseling. Kenny Wong, Chief Product Officer at xCures, notes, “Being empathic to customers to truly understand their needs is necessary to build great products” and is a key transferable skill for genetic counselors in product management. We, as product managers, design and deliver products that meet these needs while considering technical specifications, regulatory requirements, cost, and other factors.

The number of genetic counselors reporting they work in product management (PM) has consistently risen in the NSGC Professional Status

Survey since the role first became an option in 2015. Genetic counselors are also increasingly interested in learning about product management, as evidenced by the high attendance at events like the oversubscribed “GC Fingerprints on the Business Side” workshop at the 2019 NSGC Annual Conference in Salt Lake City and the [“GCs in Business” webinar](#). In addition, we receive multiple requests for informational interviews, mentoring, and lectures on PM from aspiring product managers, GC training programs, and those simply curious to learn more about these roles. We love to see the growing interest and while admittedly biased, we know that genetic counselors make great product managers.

With our clinical and research expertise, genetic counselors bring a unique perspective to product development and help ensure that products meet the needs of customers – patients, clinicians, healthcare systems, payors, advocacy organizations, employers, and any other stakeholder in the healthcare ecosystem.

We hope that genetic counselors will continue to be curious about product management and become more knowledgeable and prepared to either work with those leading product development in their own workplaces or incorporate aspects of product work into their own career trajectory.

Ultimately, patient care is improved when genetic counselors are actively building the future of research and healthcare. ♦



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Invisible Illness: The Whole Story from a Genetic Counselor-Turned-Patient

By Jessica Isaacs, MS, LCGC

For my entire life, I have been great at dropping things, horrible at sleeping, and debatably the clumsiest being to walk the Earth. For the longest time, I attributed all of this to my own *weirdness*, but when I went for my genetic counseling master's degree, I started to wonder if there was more to the story.

I'll never forget one rotation that was held at a busy hospital. In almost every shadowing session, there were more students than chairs in the room, so I ended up standing all day. Most days,

I'd come home with an aching back and feet that felt like they were going to fall off. At the time, I was only 23 years old.

Eventually, all these *weird*, little things accumulated until they felt like they were towering over me. It all culminated when my boyfriend and I went to a water park. I stood up after exiting a waterslide, and suddenly, my foot started throbbing. I limped over to my boyfriend—embarrassed and unable to explain why my foot felt like it'd been impaled with a

sword from the simple action of standing up. These feelings persisted at the hospital, where I was asked what kind of “trauma” I’d endured to cause me so much pain. The doctors eventually concluded that I’d injured a tendon in my foot, and they gave me crutches—which did *not* end well. The muscles in my upper body were far too weak to use the crutches for more than 5 minutes, and I was far too uncoordinated to use the crutches safely.

We decided that a cane was the best option for my safety, but it was not the best option for my mental health. When most people saw *me*—a perfectly “normal-looking,” young girl—with a cane, they looked at me like I had three heads. Others treated me like I was a child playing sick. Some people even pitied me, and that was the worst reaction of all.

In that moment, I developed a profound understanding of what it meant to have an “invisible illness.” This perspective helped me connect with patients on a deeper level than I ever thought possible. It also made me realize that we, as genetic counselors, may need to reconsider how we think about psychosocial aspects of genetic disease. Our knowledge about genetic disease is often drawn from the facts that we learned in medical textbooks, conference lectures, and board exams—but what if I told you that there was more to the story? The things that *actually* keep patients awake at night might surprise you.

Take me, for example. This year, I was diagnosed with hypermobile Ehlers Danlos syndrome. My biggest fear growing up wasn’t any of the things that you’d assume—like getting covered in bruises, having my joints pop out, or getting teased about my stretchy skin. It was sleepovers. I’ve had awful, chronic neck pain since I was 12 years old. Every single night, for as long as I can remember, I’ve had to lay on an ice pack before bed, or I cannot fall asleep. The idea of showing this vulnerability to others was terrifying, and it is still difficult today.

In that moment, I developed a profound understanding of what it meant to have an “invisible illness.”

My biggest issues even as an adult are things that the medical textbooks don’t talk about—like tendonitis, chronic muscle pain, hot-cold intolerance, and a crappy immune system. Balancing a full-time job, constant doctors’ appointments, and life can often feel like a Star Wars saga. Those underlying fears of being “different” and “not enough” still make their way into my head when I’m at the pharmacy for the third time in a week, and the pharmacist looks at me like I’m a drug addict—or when I’m at the gym lifting my five-pound weights, and I see a woman double-my-age lifting 80 pounds.

The moral of this story is that you can never tell what a person is going through by glancing at a medical diagnosis in a chart. The things that patients struggle with the most are often things that you’d never guess, or things that the average person may take for granted. I hope that genetic counselors will attempt to study the psychosocial aspects associated with specific genetic diseases in the future. There is currently a lack of published research on this topic and investigating this may help us better understand and serve our patients.

National Institute of Health’s Cancer Genetic Physician Data Query (PDQ) content: [PDQ® - Cancer Genetics Summaries - NCI](#) ◆



JESSICA ISAACS, MS, LCGC graduated from the Arcadia University Genetic Counseling program in 2018. She is a writer/editor for the National Institute of Health’s Cancer Genetic Physician Data Query (PDQ) content, linked in the article above.





An Urgent Call for Genetics Organizations to Support Transgender and Intersex Communities

By Kimberly Zayhowski, MS, CGC (she/her); Diane R. Koeller, MS, MPH, CGC (she/her); Lauren Giannetti Sferrazza, MS, CGC (she/her); Andy Cantor, MS, LCGC (she/they/he); Leah Zaretsky, MS, CGC (she/her); Victoria Groner, MS, CGC (she/her); Michelle Moore, MS, CGC (she/her)

In recent years, there have been strong grassroots efforts in the genetics community to draw attention to the care needs of the LGBTQIA+ community. However, due to the lack of practice resources pertaining to the

care of the transgender, gender diverse, and intersex (TGDI) communities, we are missing clinically important information needed for genetic risk assessment and contributing to patient harm. At least **5% of young adults**



in the US identify as transgender or non-binary, and approximately **1.7% of the world population is intersex**, each representing massive communities of people that genetic counselors are not sufficiently prepared to serve. With the history of eugenics practices targeting the LGBTQIA+ community, as well as genetics being commonly cited in anti-TGDI legislation, trust with the LGBTQIA+ community continues to be broken. It is time for genetics organizations to push back against the marginalization, discrimination, and political targeting of the LGBTQIA+ community to create systemic change.

Increasing Discrimination in Legislation

Over the past several years there have been an unprecedented number of bills introduced

that attack LGBTQIA+ rights; per the ACLU, **over 491 bills (as of 6/1/2023) have been proposed across 46 states**. While not all of these bills become law, they each pose substantial harm to the LGBTQIA+ community. Common targets for these bills include preventing access to gender affirming healthcare, criminalizing gender affirming treatment for transgender youth, weakening, or eliminating anti-discrimination laws, preventing transgender people access to sports and public restrooms, and banning educators from teaching on LGBTQIA+ topics. It is common for these bills to falsely conflate sex chromosomes with sex and gender, weaponizing genetics against TGDI communities. In short, these pieces of legislation are being used for eugenics practices against the TGDI communities.



It is common for these bills to falsely conflate sex chromosomes with sex and gender

Genetics organizations have remained silent at the misuse of genetics in this way, despite [public calls that urge organizational action](#). It is high time that genetic counselors take steps to stand against this harmful legislation.

Insufficient Practice Resources and Guidelines

It is well known that TGD/ people experience medical discrimination and abuse. Several professional societies have endorsed position statements, practice guidelines, and education on LGBTQ+ health including: [The American College of Obstetricians and Gynecologists \(ACOG\)](#), [The American College of Radiology \(ACR\)](#), [The American Society of Clinical Oncology](#)

[\(ASCO\)](#) and [The Society of Gynecologic Oncology \(SGO\)](#). The National Society of Genetic Counselors (NSGC) published a recent [revision to its standardized pedigree nomenclature](#) practice resource, with the goal of respecting individual differences and identities and maintaining clinically meaningful information. However, beyond these long-awaited updates, little other guidance on care for TGD/ individuals exists in the genetic counseling realm. Currently, the only other resources that acknowledge and address LGBTQIA+ patient care in genetic counseling has been through grassroots efforts from community members and their allies, such as through NSGC conference presentations and recent publications.

Genetic counselors [have reported feeling underprepared to counsel TGD/ patients](#) in clinical practice, such as with risk assessment in cancer and cardiac clinics. / Moreover, genetic counselors have noted [erasure of TGD/ communities with fetal sex prediction](#) via noninvasive prenatal screening. In addition, genetic counselors employed by commercial laboratories have acknowledged [the need for increased standardization for gender inclusivity in patient-facing materials](#) such as requisition forms, genetic testing reports, and marketing materials. Genetic counselors need guidance, such as practice resources, to correct the suboptimal access and care that our LGBTQIA+ patients currently experience.

A Call to Action

Bureaucracy has prevented *necessary* and *timely* statements and resources to give support and provide comprehensive care to TGD/ people. We call for:



1. Position statements that clearly support the TGDI communities, describe how sex chromosomes are not the sole determinant of sex nor gender and highlight how genetics should not be used in legislation to bolster false bio-essentialist views of sex and gender determination.
2. Practice resources on gender-and-sex inclusive and -affirming genetics practices.

As a genetics community, we cannot claim to accept and celebrate all people when we lack fundamental knowledge to care for TGDI people and remain silent about modern day eugenics practices against these communities. *Silence is complicity.* Organizations have more power to create systemic change than individuals do, and we call for genetics' organizations such as The American College of Medical Genetics (ACMG), The American Society of Human Genetics (ASHG) and NSGC to act *now*. ♦



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From West to East: Understanding the Cultural Implications of Genetic Counseling in the Middle East

By Dianne Alameddine MS, LCGC



A little over six months ago, my husband and I left our home in Michigan and relocated to Dubai in the United Arab Emirates (UAE). It was a move we had been contemplating for several years, hoping to eventually settle down somewhere closer to our home country, Lebanon. I had been practicing in a cancer genetics clinic for over four years, and up until deciding to leave the country, had not really thought about switching specialties, or changing jobs. However, the field of genetic counseling in the Middle East and Arab world is still in its infancy with a primary need for genetic testing and counseling in the preconception/prenatal and pediatric spaces. I knew a move to that part of the world would likely entail a major transition. When I was offered a genetic counseling position at an IVF/PGT laboratory in Dubai, despite being anxious about the move, I took a leap of faith and accepted the position.

I was excited to be practicing in the Middle East and serving the Arab community, but I was acutely aware of the challenges that lay ahead. The concept of prenatal genetic testing was something vaguely familiar to me, but I was certainly not well-versed in its intricacies. Additionally, while I speak Arabic, providing genetic counseling in Arabic was not something I was particularly comfortable doing or had great confidence in offering. And last, but certainly not least, even though I am Arab and identify as part of the Arab community, serving a primarily Western community throughout my professional career made me realize that I did not really understand the cultural implications of genetic disease in the Arab world and the differing goals of genetic counseling among Arab patients.

Therefore, the transition, at least in my own view, was not particularly smooth. Providing even basic education in Arabic was a trying and painstaking task. So, I decided to master one skill at a time. I focused first on becoming familiar with medical and genetic terminology in Arabic, testing options, their benefits and limitations, and the general structure of the healthcare

I did not really understand the cultural implications of genetic disease in the Arab world

system in the UAE. As I began gaining more confidence in my counseling and knowledge, I was able to slowly start shifting the focus back to the patient. The Arab/Middle Eastern world is made up of more than 15 different countries, each with their own unique cultural backgrounds and unique needs in education and counseling. I began to understand patients' expectations and understanding of genetic testing and could use this new understanding to better connect with and counsel my patients.

It's only been a few months, and there is certainly a long path ahead, but I've learned a few important lessons, about the practice of genetic counseling, but more so, about myself. Below is a list of some of the most important lessons I have learned:

- Genetic counseling skills are 100% transferable and it is vital that we recognize and capitalize on the versatility and strength of our training and leverage our unique skill set.
- Cultural competency is key to the provision of equitable genetic services to all populations we serve.
- Confidence in your capabilities is critical. Typically, things are much more overwhelming in our heads than in reality.
- Challenge yourself and take on new roles – it's the best way to grow.
- Be patient and kind to yourself – the path to success is often not a linear one. ●



DIANNE ALAMEDDINE, MS, LCGC is a certified genetic counselor currently practicing in the field of reproductive genetics. She graduated from the University of Oklahoma and is currently based in Dubai, UAE.

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