Perspectives

Exploring insights and trends around genetic counseling

JAN. 2024 - OCT. 2025

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1. Towne MC, Huang J, Saliganan S, et al. Impact of laboratory-driven proactive reanalysis: reclassification to positive in 5% of initially negative or uncertain exome sequencing cases. Genet Med. 2025;101464. doi:10.1016/j.gim.2025.101464

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Perspectives

Exploring insights and trends around genetic counseling

JAN. 2024 - OCT. 2025

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The National Society of Genetic Counselors is the leading voice of genetic counselors, advocating for their various roles, advancing the practice of genetic counseling, and fostering collaboration, education, and research to ensure equitable access to genomic healthcare.

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About *Perspectives*

Perspectives offers relevant and cutting-edge information in the field of genetic counseling, as well as news from NSGC in an online format. Publication of any article or advertisement in *Perspectives* should not be considered an endorsement of the opinions expressed or products advertised. Statement of fact and opinion are the responsibility of authors and advertisers alone and do not imply approval or endorsement on the part of the officers, membership or staff of *Perspectives* or NSGC.

Perspectives

Exploring insights and trends around genetic counseling

National Society of Genetic Counselors

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🟣 **Popular on Perspectives**
Articles that received the most page views within the first 30 days of publication.

🟢 **Editorial Committee Selections**
Articles selected through voting by the NSGC Board of Directors.

🟠 **Board of Directors Selections**
Articles selected through voting by the Perspectives Editorial Committee.

🔵 **Reader Selections**
Articles selected through voting by the NSGC membership.

LEADERSHIP MESSAGES

FEATURED ARTICLES

Letter From the President: Twenty Years, Many Perspectives

20 years. That's how long ago I entered the genetic counseling profession as a bright-eyed newbie full of energy to start the work that I had been dreaming of since 7th grade. That was also my first year as a full member of NSGC where I read *Perspectives* for the first time. Knowing I was going to write this piece for *Perspectives* this year as president, I couldn't help myself but look back at the articles that were **published in 2005**.

Some of the topical trends and insights at the time included the following: "A Genetic Counselor's Most Valuable Skills," "Achieving Genetic Counselor Licensure in Illinois: A Lesson on the Political Process;" "Nontraditional GC is Mainstream;" "Travels to Guatemala — Genetics as a Common Language," just to name a few of many articles. It's amazing to me that ***so much*** has changed since that time, yet some things remain the same.

Themes of conversation from then to now include translational GC skills, billing and reimbursement (CPT code work was initiated in 2005!), J.E.D.I. and underrepresented identities in our profession, licensure, and the global GC community. So, as we've seen with music and trends, what is "old" is "new" again, but with the benefit of knowledge gained over the years.

On the topic of underrepresented identities in our profession, I spoke about this as it related to me personally in my incoming presidential address last year being a person from a multicultural background. I was raised in a household with different religions and very different world origins and experienced different perspectives and lenses with which to see the world. This beautifully embodies the entire purpose of our *Perspectives* publication, and this year-end *Mosaics* issue — the ability to bring so many different subjects to the forefront that impact many of us, our practice areas and those we serve.

Looking back on the timeline this issue covers (2024-2025), so much has happened, and that is reflected in the article themes highlighted. Professional issues, such as concerns for fewer employment opportunities, have been a theme of conversation in not only our new graduates but also different sectors of our profession that have navigated increased turnover in recent years. In light of this, information on navigating career options for genetic counselors and creating new roles without a road map are incredible resources to consider multitudes of opportunities for professional growth. Inclusion and belonging topics, such as J.E.D.I.

PERSPECTIVES
in genetic counseling

Volume 27 Number 2 Summer 2005

national society
of genetic
counselors, inc.

nsgc

the leading voice, authority and advocate
for the genetic counseling profession

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Jessica Mandell, MS
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A Billing and Reimbursement Timeline in NSGC's History

Susan Manley, MS

Membership surveys have consistently indicated the most important issue for NSGC to address is Billing and Reimbursement (B&R). In NSGC's 2004-2006 strategic plan, Improvement of Outlook for Billing and Reimbursement was a key strategic initiative. Here's a history of progress made and a look at exciting things to come!

GeneAMP Highlights

B&R has long been in the forefront of NSGC activities. In 1996, President **Ann Boldt** initiated GeneAMP – Genetic Applied Marketing Project – which funded opportunities for member-driven projects in five categories: Primary Care Providers, Managed Care Organizations, Medical Professional Organizations, Consumers and Employers and Legal. In the program's seven years, two projects specific to Managed Care Organizations raised awareness of B&R issues:

- "One Message for Managed Care," funded for $2300
- "Measurable Outcomes of GC: Counselor and Consumer Assessment," funded for $2500.

Task Force Initiatives

In 2001, NSGC decided to move toward professional marketing, and a strategic membership survey ...to page 3

Now Available: A New Option for Professional Liability Insurance

Deepti Babu, MS

NSGC has negotiated a new program for professional liability insurance available to members in good standing.

Liability Backgrounder

Professional liability insurance is meant to protect the insured against allegations regarding their professional services. Liability insurance for genetic counselors safeguards against assertions of negligence and liability incurred from defense and/or settlement of claims. As Executive Director **Bea Leopold** suggests, "Counselors and students can go to work knowing they will be protected with a professional liability policy in place."

Genetic counselors' liability coverage through employers may vary depending on circumstances. All employees named in a lawsuit may share the benefits in some group policies, ...to page 8

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President's Beat

As summer arrives, bringing anticipation of vacations and a break from the office, I hope you can find time to renew your excitement about NSGC and the organization's activities. We continue to make great strides towards our strategic plan initiatives, and I encourage you to get involved in an area you feel passionate about.

B&R Achievements

NSGC has released a billing and reimbursement (B&R) "tool kit" on the website with helpful information and resources. NSGC, together with the American College of Medical Genetics, will present CPT codes specific for genetic counseling in early June. Many of you responded to our request for letters to SACHGS regarding their recent draft guidelines for reimbursement and coverage of genetic testing and services. View the webcast from the June 15-16 meeting when these guidelines were finalized. The B&R taskforce also has compiled an advisory committee of representatives from industry, health care and insurers that will meet this summer to develop a long-term plan.

Kelly Ormond, MS

Legislative Updates

NSGC has entered our third cycle for licensure state grants, with Florida, Illinois, Massachusetts, New York, Pennsylvania, Tennessee and Texas receiving grants. Licensure bills were introduced in Florida, Massachusetts, Oklahoma and Washington states this year. NSGC continues to play an active role in the Coalition for Genetic Fairness, promoting the Genetic Information Nondiscrimination Act of 2005 in the House of Representatives. The Social Issues Committee is monitoring other genetic counseling related legislation and developing a monthly legislative newsletter to help you learn about pending state and federal bills and how to get involved.

NSGC Builds Its Presence

We have sent liaisons to many important meetings over the past several months. **Jennifer Sullivan** presented public comments at the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, **Kristen Shannon** represented us at the Health Professionals Network meeting, **Nancy Warren** attended the Association of Schools of Allied Health meeting and **Wendy Uhlmann** represented us at the NHGRI Advisory Committee. **June Peters** and **Debra Eunpu** presented at the American Association for Marriage and Family Therapists meeting. In June, **Jennifer Hoksovec** will represent NSGC at the CDC's National Summit on Preconception Care, and **Kathy Schneider** will represent us at the Commission on Cancer meeting.

Upcoming Projects

NSGC's Board is currently evaluating its structure and effectiveness. It is about to complete the incorporation of a tax exempt "Genetic Counseling Foundation." The Foundation will support genetic counseling research, education and other activities that advance translation, understanding, application and delivery of genetic information. You will be hearing much more on this, and we hope everyone considers making a contribution.

Every Vote Counts

Finally, as we approach the upcoming NSGC election, I encourage you to make your voice heard by reviewing the candidates and submitting a vote. As genomics expands into all areas of medicine and biotechnology, NSGC needs visionary leaders who can help our organization continue to develop as the leading voice for our profession. In the meantime, I look forward to continuing to serve NSGC, and I encourage you to contact me or other members of the Board with questions, concerns or suggestions. ❖

Kelly E Ormond MS

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2004-2005 President
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☞ www4.od.nih. gov/oba/sacghs.htm)

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The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

Next issue ***September 15***
Submission deadline ***August 11***

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A Peek Back in Time *— The Q2 2005 issue of* Perspectives in Genetic Counseling *featured articles on billing and reimbursement, a genetic counselor's most valuable skills and the ethics of testing a child for a genetic condition without consent. Previous issues of Perspectives are available to all on the publication website.*

learnings from pulse surveys and experiences of genetic counselors with diverse identities, have spotlighted perspectives in important areas for reflection and growth.

As I reviewed the **2005 Q4 Perspectives issue**, the subject of one article was the initiation of our relationship with Smithbucklin as our association management partner — this year marks our 20-year anniversary with this NSGC staff partner! As I think about the work it takes to create every *Perspectives* issue, I want to call out with gratitude our Marketing Manager and Content Director Hannah Durnas and others who directly support this work. This and everything we do within NSGC would not be possible without the support of our staff partners, and I personally am grateful for them.

Enjoy this issue of *Perspectives* and refresh yourself on several important topics today!

Sincerely,

SARA PIRZADEH-MILLER, MS, CGC

President, National Society of
Genetic Counselors, 2025

Letter From the Editor: Introducing *Mosaics*

I am thrilled to share with you our year-end compilation of *Perspectives* articles. This issue in previous years was titled "Best of *Perspectives*." The *Perspectives* Editorial Committee selected *Mosaics* as the issue's new title to better encompass the value and diversity that this special issue showcases.

Additionally, the title serves as a nod to the genomic phenomenon of acquired variation within an organismal body. Just as cells diversify and adapt beyond their germ cells, so too have genetic counselors. It is the fluid and mutually respectful discussion between its constituents that makes up a healthy organization, which is what *Perspectives* aims to facilitate.

This is increasingly important in a landscape where writing and health care are becoming more reliant on generative AI. I was particularly struck by an early study out of the MIT Media Lab, which showed that the use of generative AI for writing decreases cognitive activity and self-reported ownership of one's work (Kosmyna et al., 2025). As someone who oscillates between being a Luddite and an AI super-user in both my writing and clinical work, I'm certainly not here to take sides — but I do think it's important to hold on to the nuances and identities that allow us to demonstrate our humanity and approach the work of genetic counseling in distinct ways.

When I assumed the role of *Perspectives* Executive Editor at the beginning of 2024, my mission was to elevate our publication by more clearly emphasizing positionality and making the publication process more transparent and accessible. I also hoped to capitalize on *Perspectives*' exclusively online, content hub format (no longer paywalled, and no longer a digital magazine or newsletter!) and broaden its reach. In the past two years, we have instituted clearer guidelines for authorship, conflict of interest and publishing. Three quarters into 2024, the number of page views on *Perspectives* exceeded the total number of views in all of 2023. And our 2025 pageviews are on their way to another high number, indicating a broadened impact of this publication — and of the voices of our contributing authors.

I am now stepping down and leaving *Perspectives* in the very capable hands of Christine Tallo and the rest of the *Perspectives* Editorial Committee. In these pages, I hope you will be inspired by personal narratives and moved by the calls to action. Here's to the incredible authors, editorial staff and volunteers who make *Perspectives* happen. ⬢

HANNAH LLORIN, MS, CGC

Executive Editor of *Perspectives in Genetic Counseling,* 2024-2025

“Black/African American” — Black Cultural Erasure in Genetic Counseling

By Timbria Burke (she/her)

As a Black first-year genetic counseling student, I am constantly delving into articles and papers for my coursework. Repeatedly encountering demographic information that categorizes participants as “Black/African American” in the “race/ethnicity” sections has become a source of frustration for me. Witnessing the persistent cultural erasure of every Black individual participating in these studies is disheartening, particularly when these categorization decisions are frequently guided by non-Black investigators.

I am Black ***AND*** African American. I have had the privilege of knowing and loving one great-great-grandmother and three great-grandmothers, but I cannot trace my ancestry beyond the Southern United States (U.S.). Despite recognizing and grieving the unfair and inhumane history of Africans being forced from their homes and into slavery, I take pride in the resilience of my ancestors who shaped and sustained African American culture, traditions, and language (Ebonics or AAVE — African American Vernacular English). However, it’s crucial to recognize that this specific label and cultural pride ***does NOT***

> I thought that this article was **very useful in my clinical practice**, and I have thought about it several times since I have read it. Thanks to the author for **underscoring such an important issue** that is part of genetic counseling daily.
>
> — *Perspectives Editorial Committee member*

extend to every Black person in this country. No one should be forced to categorize themselves in a way that is inauthentic to their cultural, personal, and societal experiences. Every Black person should have the autonomy to accurately label themselves, representing their unique cultural pride and ancestral history.

Race vs. Ethnicity: Why Does It Matter?

Race is based on common physical traits among people of shared ancestry (Flanagin et al., 2021). Ethnicity is a state of belonging to a group of people who share culture, including but not limited to "language, ancestry, practices and beliefs" (Flanagin et al., 2021). In this context, "Black" refers to a race while "African American" refers to an ethnicity. Yet, these two labels are frequently interchanged or merged, leading to the categorization of all Black people in the U.S. as African Americans without consideration for their distinct cultural histories and current practices. Other ethnicities of Black people in the U.S. that immediately come to mind are Afro-Latine/a/o/x, Caribbean American, Jamaican American, Haitian American and Nigerian American, amongst numerous other unique ethnicities. Unfortunately, African American is frequently used as the ostensibly "polite" and "politically correct" umbrella term for Black individuals, overshadowing the richness of their diverse ethnic and cultural backgrounds.

Race and ethnicity, while lacking precise biological foundations, are social constructs with significant relevance in studying systemic racism and health care disparities (Flanagin et al., 2021). Individuals often embody multiple racial and ethnic identities, highlighting the interconnected nature of these categories, making it essential not to discuss them in isolation (Flanagin et al., 2021). Without accurately collecting this more detailed information from Black patients, participants, communities and students, any conclusions drawn do not fully encapsulate the intricacies and differences within the Black experience.

Who Is African American?

From "Colored" to "Negro" to "Black" to "African American," Black people in the United States have been called an array of terms throughout history. In 1988, Rev. Jesse L. Jackson, Sr. suggested Black Americans should be called "African-Americans" to create and promote ethnic identity and cultural integrity (Martin, 1991). He argued that other ethnic groups in the U.S. had an identity label with "some historical cultural base," such as "Italian-Americans" and "Armenian-Americans" (Martin, 1991). Jackson supported his notion by saying that "African-American" would emphasize pride and a heritage connection to the country of origin and the current location (Martin, 1991). Within this historical context, African Americans are descendants of enslaved Africans in the U.S., unable to trace their lineage beyond this country due to the catastrophic multigenerational impacts of the transatlantic slave trade. Currently, some of those who fall under this definition do not identify as African American and may instead identify with "Black American" or "Black," especially if they do not share a direct connection to an African country.

The Responsibility to Know Better, Then Do Better

Perceiving and categorizing every Black student, patient, or research participant as African American is ***the erasure of Black histories and cultures***. Conflating these two interconnected but distinct labels compels every Black person to "self-identify" with an identity that does not align with their experience. Consequently, in research, the nuances of ethnic differences within the Black experience are often overlooked, undermining the accurate representation of this historically disadvantaged population. In genetic counseling programs, discussions around diversity, equity, inclusion and justice (DEIJ) disproportionately focus on the African American experience. In genetic counseling appointments, Black patients are often seen through a singular cultural lens, overlooking the fact that not all identify with the African American experience within the US. ***The solution to inaccurate labeling of Black people is to ASK how every individual defines their race and ethnicity.***

Questions to ask yourself as a member of the genetic counseling profession when interacting with Black people globally, but especially within the U.S.:

- How is race/ethnicity being used in this clinical setting or research study?
  - Is this information needed to achieve the intended goal?
- When interacting with a Black patient or student, am I automatically assuming they are African American, expecting them to be able to relate to a specific culture?
- During DEIJ discussions and initiatives, which populations and cultures am I actually referring to?
- Do I assume:
  - That any two Black individuals share the same cultural practices?
  - That all Black people use and know AAVE?
  - That every Black person speaks English as their first language?
  - That all Black people relate to American slavery?
  - That all Black people identify as an "American" before any other nationality?
- Am I capitalizing the "B" in Black when writing? (Coleman, 2020)

Black and *African American* are distinct labels. Recognizing and respecting this differentiation is essential in the genetic counseling profession to cultivate a more inclusive and culturally sensitive approach to student supervision, patient care and research. ⬢

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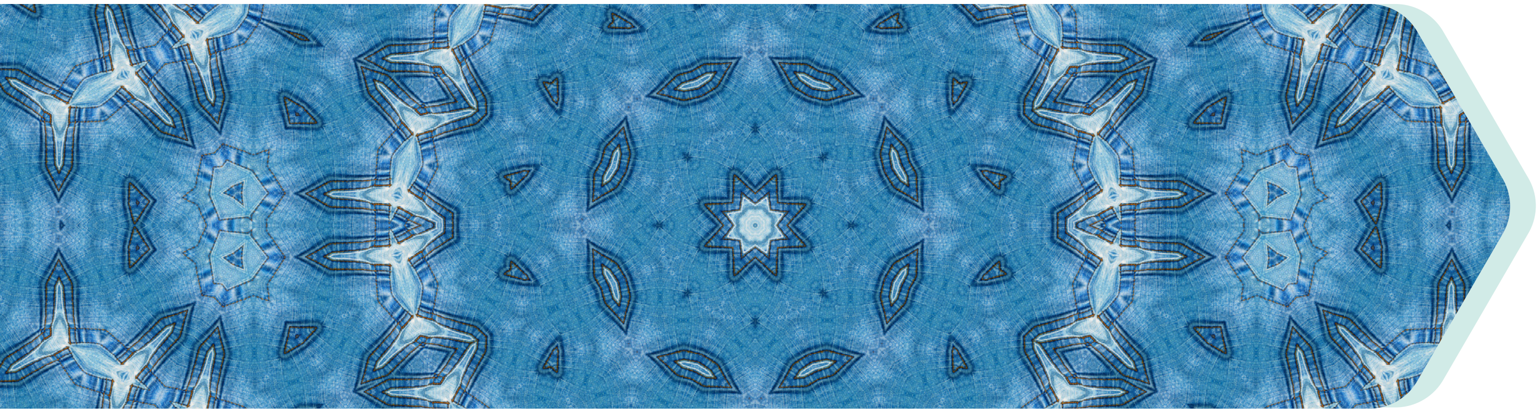

From Micro to Macro: Navigating Evolving Career Options in Genetic Counseling

By Kyle W. Davis, CGC, CMPP (he/him); Praveen Kaushik, CGC, CMPP (he/him)

Over drinks at the last NSGC conference, the two of us had a chance to catch up. We had met 10 years ago when one of us (Kyle) was a student and the other (Praveen) managed the student rotation at the lab. What would typically be a time to chat about new jobs, family and industry tidbits, instead turned into a conversation that would reframe how one of us (Kyle) understood our profession and the careers within it.

Over the past 15 years, Praveen had noticed a trend in our profession: the rise of "macro" positions. This framework places the work within a job on a continuum from micro to macro. I hadn't heard of this dichotomy before (trichotomy, actually). But as we talked, we found the framework resonated with the trajectories of our careers by pointing the way to ***how*** we liked to work, and which roles might be right for us as we navigate our careers. It also shed light on a tension in the genetic counseling community.

This idea of "micro" and "macro" jobs appears to come from **social work** and goes like this: Micro roles are defined by focusing on one-on-one encounters while macro roles focus on engaging small, medium and large groups. For genetic counselors, micro work might consist of counseling patients, researching and drafting lab reports, or working with students to affect individual outcomes. Macro work might entail addressing challenges across departments, clinical areas or policy at the state or national level to affect collective outcomes. There are also roles at the "mezzo" level, which operate between micro and macro roles and work with teams or small groups.

Essentially all genetic counselors complete their training and begin their career in a micro role. Most of these positions are on clinical teams that provide one-on-one care to patients and families. That's also what draws most students to enter genetic counseling programs. Many of us could have gotten a different professional degree, but we didn't (yet). We were drawn, at least in part, to the micro work that could have a large impact on a patient or family. Over time, people grow in their profession and can take on new roles at other levels (mezzo or macro) if they desire or do more challenging micro roles.

It's important to realize that while most of us — maybe all of us — like working across levels, many likely prefer work roles at a certain level and enjoy stepping outside that level in other professional capacities. For example, the counselor whose primary role is seeing pediatric patients may love their position at the medical center (micro) but may want the challenges of being an NSGC Board Member (macro). Alternatively, the counselor who works as a director of clinical operations at a commercial laboratory (macro) may also enjoy their part-time role teaching a class at their local GC program (micro).

But there is a tension here: trouble comes when we think we know what we want, or what we want conflicts with our role's work. To explore the first problem (we think we know what we want), we'll use Kyle's experience: He was on a clinical team at a lab and loved the team, his managers and the (micro) role drafting reports and talking to parents and health care providers. But after five years, he wanted to do more and use different skills. He was recruited to another lab to work as the manager of scientific communications (mezzo). There, he used different skills, had more responsibilities and had a higher salary commensurate with the work. He enjoyed many aspects, but in less than a year missed engaging with individuals (micro).

For the other problem (what we want conflicts with a role's work), we can use Praveen's experience: He noticed a trend where genetic counselors — whether in clinical or industry settings — wanted titles and pay commensurate with macro roles, but to keep doing micro work with the same responsibilities. Many of us aren't specifically trained for macro roles and must learn new skills, but we want the title or salary that comes with macro roles. This tension seems to have increased over the past 10-15 years as genetic counselors perform more jobs at the macro level.

This is reflected in our Professional Status Surveys (PSS). Over the years, different titles (individual contributor up to CEO), work locations (governments, private companies, academic institutions, etc.) and role types (direct care, "mixed", and nondirect care) have steadily increased. One needs only glance at the salary tables to see that nondirect care roles, which have more macro roles, have higher average salaries.

This rise of these opportunities is exciting but also disorienting. We've never had so many options for work and to affect change via clinic, policy, sales/marketing and education. When thinking about your current or future role, consider these questions: At what level do you like to work, micro (individuals) vs. mezzo (small groups) vs. macro (large/multiple groups)? For which roles are you (currently) qualified? And does the role you're looking for, or salary and title you'd like, make sense with the scope of the role? Knowing the answers to these questions will help you realize the roles where you'll fit best (for now).

To be clear, we don't think any level of work is better than another. We also believe all genetic counselors should continue to advocate for their benefits and pay regardless of their position. And we should continue to push the boundaries of where genetic counselors, with our unique training, are employed. We need genetic counselors operating at all levels to grow genetics and genomics in health care and realize its full potential.

KYLE W. DAVIS, CGC, CMPP (HE/HIM), is a genetic counselor and writer. His previous roles in the field of genetic counseling have been on a clinical team at a diagnostic laboratory (micro), marketing manager (mezzo), science communications specialist (mezzo), and he currently serves as the assistant director of fieldwork at the Vanderbilt University Master of Genetic Counseling program (mezzo and micro). He completed his graduate work at the Johns Hopkins University/NHGRI program. He lives in Austin, Texas with his family and cat where he is at work on a sci-fi novel (micro).

PRAVEEN KAUSHIK, CGC, CMPP (HE/HIM), is a genetic counselor and commercial leader. He is currently an executive director of product marketing at Veracyte (macro). His previous roles included genetic counselor in the medical services department at a diagnostic laboratory (micro), a manager of genetic counselors (mezzo) and various marketing and product management roles at a diagnostic laboratory (mezzo/macro). He lives in Denver with his family and tries to climb as many mountains as possible (macro).

National Society of ...?: The Hidden Costs of a Name Change

By Katherine Anderson (she/her)

There has been a recent resurgence of discourse surrounding changing the name "genetic counselor," including a debate at the NSGC 42nd Annual Conference, and subsequent posts from community members (Cohen, 2023; McGruder, 2023; Resta, 2023). As a genetic counseling student becoming aware of interpersonal relations and Diversity, Equity, Inclusion, and Justice (DEIJ) initiatives within the profession, I can't help but think there are bigger fish to fry. As we know from other health care professions, the material costs of a name change are significant. Take physician assistants, whose possible name change to "physician associates" is projected to cost their professional organization $22 million (Rau, 2021). Within genetic counseling, this funding, time, and energy could be better utilized to enhance belonging and diversity within the profession (Rau, 2021).

What Are the Costs?

A number of people have already highlighted reasons why renaming "genetic counselor" is not a valuable change for the profession. For one, psychosocial counseling and awareness is a key uniting factor as practice-based settings for genetic counselors continue to expand (Cohen, 2023; Means et al., 2020; Resta, 2023). Changing our title to something like genetic "specialist," "consultant," or "practitioner" could exacerbate harmful power dynamics with our patients, in addition to doing little to raise awareness of our skill sets (McGruder, 2023). ***Importantly, before we invest in this change, we must also consider how such resources might be better utilized toward pressing DEIJ initiatives within the profession.***

For example, the material costs that would go toward a name change could be better used to fund graduate scholarships and pre-genetic counseling experiences, such as internships and awareness days. Although most genetic counseling programs present themselves as devoted to DEIJ initiatives, many still do not offer scholarships and experiences specifically for those with underrepresented identities in genetic counseling.

In addition, this funding could be directed towards promoting diversified research initiatives and improved compensation for folks who conduct and participate in this research. A more concerted effort is needed to focus research on the needs of those who are BIPOC, LGBTQIA+, disabled, and hold other marginalized identities. It is crucial to consistently fund and compensate researchers who themselves belong to underrepresented groups (Thomas et al., 2021).

Lastly, it is not uncommon for genetic counselors and students with underrepresented identities to undertake DEIJ-oriented research projects, presentations, and publications to enhance belonging and awareness. Often, these endeavors extend beyond one's official responsibilities or coursework, without additional compensation for the extra time, effort, and mental toll. Changing the name of the profession could introduce confusion and inconsistency for prospective students and patients, jeopardizing the progress made by these individuals. The financial resources used for a name change would be better utilized to compensate individuals for their valuable contributions.

But, Who Are We?

With these initiatives in mind, it is important to question who we are as a profession, regardless of the title that seemingly unites us. As demonstrated by NSGC's 2023 Professional Status Survey, the Exeter Report, and the graduate admissions match statistics, we have significant work to do as a community to challenge the current homogeneity of identities among genetic counselors (The Exeter Group, 2021; National Matching Services, Inc., 2023; National Society of Genetic Counselors, 2023). I am a white, cisgender, and non-disabled genetic counseling student whose majority of identities are already well-represented in the profession. Given my own positionality, I want to emphasize that a deeper dive into what to call our profession, as well as what DEIJ initiatives should be uplifted in this space, must involve a diversity of perspectives. It is imperative for those of us that are following this career path to question the homogeneity among current genetic counselors and to think about effective avenues for fostering a more diverse community. Rather than focusing on unity at the level of a name, we should spend more time together on what it means to *be* a "genetic counselor." ●

KATHERINE ANDERSON (SHE/HER), is a first-year genetic counseling student at Boston University Chobanian & Avedisian School of Medicine. Anderson's interests in the development of the genetic counseling profession stem from growing up in a health professional shortage area and her graduate training in a safety-net setting.

Can We Only Be Successful If We Mask Our Disabilities?

By Amy Mook, MS, MPH (she/her); Lara Grether, MS, CGC (she/her)

This article represents only two perspectives of individuals with disabilities. We recognize that these experiences are ours alone and that others in the disability community may have different perspectives.

We were not prepared for the resistance we would meet as we began navigating the genetic counseling profession as individuals with disabilities. Our experiences culminated as we both found ourselves in the prenatal space. One as a new graduate; the other as a student in one of their final rotations. One with an invisible disability; the other with a visible disability.

I (Amy) have spent my entire life being my own best advocate, learning what I need and how to process the range of positive and negative interactions that I can have with others related to my disability. Before entering my prenatal rotation, I recognized potential biases I might encounter when others observed my physical disability. Would people assume what my thoughts would be on abortion because I have a disability? Would patients feel comfortable sharing with me their needs and desires for their family? I sought guidance extensively throughout the GC community and was simply told: “Survive your rotation and never go into prenatal” and “prenatal likely isn’t the best fit for you.” When facing the reality that I wanted (and needed) to truly explore the prenatal specialty, I was told one “option” would be to conceal and mask my disability, to sit behind a desk and have patients brought to me so patients would feel more *comfortable*.

Despite this harmful advice, I ended up loving my prenatal rotation. I was there for my patients to provide them with the best care possible. I developed my own counseling style and gained great experience. Although not entirely surprised, I still question why this aspect of my identity received so much attention in prenatal, but my very impactful experiences of cancer in my family were never brought up as a concern in my cancer rotation.

I have felt the isolation of being a person with a physical disability throughout my training. The acts of othering and damaging words continue to impact me. When I was hopeful to be met with open arms by this community of my future GC colleagues, I was instead met with a clear underlying message that I am an outcast. What has been most upsetting is the lack of willingness to engage in this conversation and the avoidance of our GC community to confront this intersection of the varying social perceptions of disability, the prenatal setting and trainees/professionals who identify as having disabilities. NSGC continues to promote important conversations regarding J.E.D.I., including how patients navigate the intersection of disability and reproductive justice, but how can we achieve these goals when there is disdain for disabled GCs in the reproductive space?

I (Lara) have often struggled with advocating for my needs and accommodations. Frequently, individuals are unaware that I have ADHD and struggle with memory, attention, anxiety, depression, time blindness and executive function. I mask my disability most of the time, and it is exhausting to do daily tasks. When preparing to enter the prenatal space, I received consistent pushback given my diagnosis: “I just want you to make sure this is the right fit for you” “Are you sure this is something you want to do?” “Are you sure you can manage the emotional toll of prenatal?”

They could not have been more wrong. The high-risk prenatal specialty is a good fit for me as the nature of prenatal allows me to drop the facade of perfection, and together with my families prioritize their care. Did I miss something in the session? *We can cover that in a follow up call.* Did I forget something in my office? *No worries, my families understand and are willing to wait, and sometimes even appreciate the extra time to process.* Did the session take longer than expected? *Not a problem, I was showing my families they are my priority, and together we created a plan for their care.*

One of the most frustrating aspects of having a disability in the workplace is that I try to think ahead and advocate for various needs and accommodations. On the surface, I can appear as though I glide through various tasks, but people do not see how hard I am treading water to complete all of the mental and background work to keep appearances. People often refuse accommodations until we “see how it goes.” In other words, they need proof of my failure before I can receive help. This breaks trust, forces me towards burnout and is not sustainable.

Why do both of us feel pressured to mask our disabilities? Honestly, we mask so that we can have a successful career in genetic counseling. We mask our disabilities to try to avoid being “othered,” as well as to spare ourselves from judgment, assumptions and mistreatment. It is not unusual for us to feel that we must mask as a tool to be treated with respect. Whether that is spending extra hours outside of work to keep up appearances or using different mobility aids to make a permanent disability seem temporary. The level to which one can mask their disability is a privilege, and changes what is “acceptable” to pursue as a career. The genetic counseling community continues to exclude disabled GCs. Instead, the two of us have created community with each other. We empower each other to pursue our goals, personally and professionally, and support each other when advocating for our own needs. We hope that we can extend that to all of you. ⬢

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On Unemployment and Professional Self-Actualization: Musings From a Recent Graduate

By Eden Brush, MS, CGC

I had grown used to the admiration, bordering on envy: "It must be so nice to know what you want to do" and, "Wow, what is it like to have a sense of purpose? Meaning? Direction?" We are encouraged from a shockingly young age to "find our passion" and "follow our dreams" — of course, this is usually intended in the capitalistic way wherein our worth is equated with what we produce, how much and how fast. But even so, discovering genetic counseling felt like that "aha" moment where my interests, values and strengths serendipitously converged into one unified purpose: I would be a genetic counselor.

While there are (thankfully) a growing number of resources to prepare one for graduate school applications, the challenges one might face during graduate school, and the job search/interview process after graduate training, there is nothing that could have prepared me for the unanticipated period of unemployment that has followed graduation. When your identity, time and space orientation, and purpose are inextricably intertwined with becoming, it can be psychologically and existentially (not to mention financially) tormenting to be unable to actualize the version of yourself you have spent unfathomable hours, resources and energy nurturing. I want to be a genetic counselor and I, like many, am stuck in this purgatory where I have become but cannot be.

I am the first to criticize the way our society's obsession with work has us dehumanizing ourselves and each other. The grind culture and the rugged individualism it engrains has cost many of us our senses of rest, well-being and community. But not being able to participate in the workforce like I had planned meant losing the one part of my life I felt I had some control over. My unemployment has generated a complicated grief where I'm grieving the fact that I have been socially conditioned to equate my purpose with my career *and* that I can't fulfill that purpose due to the nationwide lack of genetic counseling openings (despite the very real need for genetic counselors). There are layers of frustration and anguish. Even without a job, I am on high alert from 9 to 5 on Mondays through Fridays, because what if today is the day a potential future employer schedules an interview? Or, imagine that, offers me a job? Friday evening offers a twisted sense of relief with a twinge of pity: another weekend without the career I care so desperately about nor the income I have given so much to deserve.

I know I am a genetic counselor and will get to actualize that version of myself eventually — just not in the way I had anticipated. I felt entitled to, or at least hopeful for, a certain future on a certain timeline. But isn't that a common thread in many of our clients' stories? Stories about reconciling what life was supposed to be like with what life actually is? The contexts and impacts are notably different, but maybe the underlying feelings, sensations and/or cognitions are similar; maybe this period of uncertainty, grief, shock and disappointment is equipping me with the lived experience to better empathize with my future clients. Maybe my unemployment is shaping me into a more adaptable and resilient person and counselor. Maybe this standstill is exactly what I needed to reclaim my love of reading, actually train for that marathon and finally learn how to cook — three goals that I had neglected in the name of pedestalizing becoming a genetic counselor. Maybe my pendulum needed to swing to sheer nothingness and surrender after 27 years of all-consuming striving and reaching in order to grant me the sense of balance and integration my spirit has been aching for — the sense of wholeness that will ensure my humanity and the humanity of my clients and colleagues is always centered. Maybe this all-encompassing uncertainty will help me to say "I don't know" with certainty. I don't know. But I do trust. I have to. ⬢

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Bridging Gaps: A Genetic Counseling Student’s Experiences Working in Rural Communities

By Evelyn Ramirez (she/her)

As a first-generation Mexican American, my personal experiences with health care disparities have driven my passion for advocating for underserved communities. Growing up on the South Side of Chicago, I saw how organizations offering low-cost medical care became lifelines for families like mine. These early experiences shaped my commitment to ensuring others, especially those from backgrounds like mine, have access to the best care possible.

In 2023, working as a genetic counseling assistant in Charlottesville, Virginia, with rural populations introduced me to new challenges. While I had experienced barriers related to low-income urban populations, I had not considered how different rural barriers to care would be. In rural regions, transportation, technology, and distance make health care even harder to access. While cost was a barrier for my family, we never had to travel far to see a provider. In Virginia, some patients lived hours from the nearest genetics clinic with no public transit options. Telehealth can help bridge gaps, but many rural families lack internet access, making virtual care unreliable.

A year later, I had the opportunity to work alongside another rural community, but this time as a genetic counseling student. In the Fall of 2024, I rotated at the Clinic for Special Children in Gordonville, Pennsylvania, and I learned new lessons while serving Amish and Mennonite patients, collectively referred to as the Plain community. These organized religious groups often reject modern conveniences like phones and computers. In contrast, those who embrace contemporary technology are referred to as part of the English community by Plain community members.

Few patients we saw through the Clinic for Special Children had cell phones; in some cases, patients had home phone lines where they could be contacted. Others, however, had no access to a telephone, and because of this, lots of meticulous planning went into scheduling a phone call via a local public telephone. This experience made me realize I had never stopped to ask patients if they had access to a phone. I assumed that, given this is the 21st century, everyone has a phone. Serving patients from Amish and Mennonite backgrounds made me realize that even people outside these communities may not have the financial means to have a cell phone.

Both of my experiences in rural communities made me reflect on how often health care providers assume all patients want or have access to phones or other technology. Even in Virginia, we would often call the number in patients' medical records, only to learn that the number listed was not a private phone or that the line had been disconnected. Whether in Charlottesville, Virginia or Gordonville, Pennsylvania, rural patients face many obstacles to receiving care. Travel to a clinic can be difficult, with patients needing to arrange childcare, take time off work and commute long distances. In Virginia, some patients drove over an hour for genetics appointments, while Amish patients often paid high sums for drivers or traveled by horse and buggy.

Outreach clinics make a tremendous impact in the Plain communities by offering low-cost genetic testing and serving as a medical home base where patients can access both comprehensive genetics care and primary care. Its location reduces travel time and expenses, making care more accessible to rural patients. The low cost of testing and appointments provides affordable care to a population that is largely uninsured. The Clinic for Special Children is a powerful example of a clinic that has beautifully integrated itself into the communities it serves. This clinic has built a firm infrastructure catering its services to serve this rural, culturally distinct population on its terms. The outreach clinic is very beneficial, and working there holds new challenges and learning opportunities for staff members. Providers often travel far themselves to reach patients and learn to adapt their language and care to fit the local culture. In a conservative community like the Plain community, using words like "partner" as opposed to "husband or wife" was not encouraged. Although it was confusing for me to break away from the language taught in school, it became clear that this was critical. To be a culturally competent genetic counselor, embracing different communities involves mirroring their preferred language.

Through my experiences as both a genetic counseling assistant and a graduate student at the University of Pennsylvania, I've gained a deeper understanding of the barriers rural patients face in accessing care. I am fortunate to be a student in the University of Pennsylvania's Genetic Counseling Program and a Fellow in the Warren Alpert Alliance in Genetic Counseling, which has provided me with the resources to participate in these unique outreach opportunities. This fellowship has provided the chance to connect with other students from diverse backgrounds and reflect on how our

identities shape us as providers. As a fellow, I meet monthly with other fellows to discuss outreach initiatives and hear lectures from professionals focused on patient education and community engagement. These monthly discussions have deepened my understanding of how ethnicity, culture, geography and socioeconomic status influence health care experiences. Having a clear understanding of how a patient's identity and resource accessibility influence decision making is essential when supporting patients through choices about genetic testing and medical care.

All of my experiences have shown me that genetic counselors must work to overcome barriers people in rural communities face by expanding mobile genetic services, increasing funding for rural health care initiatives, or reassessing how we structure appointments to accommodate patient needs. True inclusivity in genetic counseling means considering all aspects of a patient's life, including the unseen barriers they navigate daily. We and the institutions we work in must adapt and become more flexible in delivering care, from developing community-based outreach programs to building strong partnerships with local health care providers. Inclusivity also means being mindful of the cultural, technological, and financial challenges that many of our patients face when making decisions about their health care.

After all, genetic counseling is not just about conveying complex genetic information — it is about ensuring information is accessible, understood, and actionable, regardless of where someone lives or their financial situation. By bridging these gaps, we can ensure that all individuals, regardless of their background or origin, can access the care and support they need. ⬢

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Are You Checking Your Bias Toward Disability When Nobody's Watching?

By Madison Le, MS, Board-Eligible GC (she/her)

As genetic counselors, we take pride in offering equitable, empathetic and informed care. We're taught to approach our patients without judgment, be nondirective and center our patients' lived experiences. But in our pursuit of developing our professional excellence, are we taking enough time to examine the biases we carry? Especially when it comes to those related to disability?

There's a disconnect I've noticed which lingers in my mind as I near graduation and gear up to enter the workforce, one that feels both uncomfortable and urgent: the tendency for genetic counselors to publicly advocate for people with disabilities while privately holding ableist views and values. It's one thing to support disability inclusion in front of colleagues and supervisors. It's another to carry those values into our personal lives — into the spaces where

no one is watching. How do we act in a space where no one will call us out?

This disconnect matters because if we are serious about ***inclusion, diversity and equity***, we cannot just perform allyship only when it's convenient or professionally beneficial.

The following story is an example from my experience in the GC field so far. During one of my clinical rotations, I participated in a session with a patient experiencing various symptoms who shared an emotional toll: Over the years, they've felt unheard by medical providers. I strongly validated the patient's experiences and expressed empathy for how difficult that must have been. After the session, I received feedback from my supervisor that I may have exhibited countertransference. Countertransference refers to the emotional reactions a health care provider may have toward a patient, often rooted in a provider's own experience. I respectfully disagree with that interpretation of my approach. I did not feel that my response stemmed from my personal experiences, but rather from a genuine recognition of the patient's pain and a desire to offer the empathy she had been missing in previous encounters with health care professionals.

In contrast, I felt that during the session, my supervisor wasn't fully acknowledging the patient's concerns, which could only reinforce the patient's experiences of being dismissed. I was told, "There's nothing we can do for her; we aren't the right providers to be able to help her with her symptoms." But that doesn't mean we couldn't offer her compassion and a supportive space for her to share her feelings. At the end of the day, it felt to me like my supervisor didn't care about the patient, her symptoms or her story.

For me, this patient's story was a powerful reminder of how important it is to deeply listen; her years of struggling through the medical system spoke clearly to her need for validation, not a diagnosis. Failing to acknowledge her experience and the experiences of others like her not only perpetuates emotional harm but also reflects the ableism that too often silences and invalidates patients with complex and misunderstood conditions.

An article published in 2019 called "Examining Genetic Counselors' Implicit Attitudes Toward Disability" by Gould et al. sheds light on how prevalent this issue may be. 90% of study participants demonstrated an apparent bias toward ability, while only 10% showed either no bias or a bias in favor of disability. That means the majority of participants harbored implicit ableism, even if they believed themselves to be objective. I think everyone, in one way or another, holds certain biases — whether they relate to disability or other characteristics. But the presence of bias isn't the problem. What matters most is how we recognize, manage and reflect on those biases. Bias doesn't have to define our actions, but it can impact our counseling if left unchecked. Just because you think one way about something does not give you the right to push your values and beliefs onto others.

If a genetic counselor is able to acknowledge their own bias, put it aside and create a space where patients feel heard and respected, then that bias doesn't have to interfere with the quality of care for our patients. Unfortunately, that's not always the case. Some providers do allow personal beliefs to shape how they treat patients. This is where the true harm begins.

One area where this tension is evident is in the space of reproductive genetic testing. As advances in technologies, like noninvasive prenatal testing (NIPT), expanded carrier screening and preimplantation genetic counseling, become more widespread, so do the ethical dilemmas they present. These tools can empower patients with information, but they can also unintentionally reinforce ableist narratives that suggest lives with disabilities are less valuable or should be avoided. This challenges us, as genetic counselors, to ensure our counseling doesn't just focus on risk and prevention, but also affirms the dignity and worth of all lives, whether disabled or abled. All in all, being able to ground our work in the framework of reproductive justice means supporting the individual's right to make informed decisions based on maintaining their autonomy while actively challenging systematic biases that devalue disability and limit reproductive freedom.

This work of reflection, of accountability and of continuous learning must become a part of our professional culture. Training programs should make space for deeper conversations around disability, identity and bias. Supervisors and mentors should model vulnerability and self-awareness. And as individuals, we should regularly ask ourselves, "Am I embodying the values I promote?"

Disability is not a pathology to be solved or erased. It's a natural part of human diversity. People with disabilities deserve to be ***seen, respected and included*** both in our clinics and in our lives.

As someone with Crouzon Syndrome, a rare genetic condition characterized by the premature fusion of the skull bones leading to distinctive facial features and various other medical challenges, I've spent a lifetime navigating social perceptions and internalizing ideas of what it means to live with a visible disability. My experience has given me insight into how powerful and pervasive ableist attitudes can be, even among well-intentioned providers. It's also what drives me to foster empathy and accountability in our field. My lived experience isn't separate from my professional identity; it informs it.

So let's take a look in the mirror. Let's do the work. Inclusion isn't a statement or a role to play — ***it's a practice*** that we must learn to implement into our lives in order to care for our patients in the way they deserve and need. ⬢

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Genetic Counseling in Somatic Oncology: Creating a Role Without a Roadmap

By Antonina Wojcik, MS, CGC; Sam Wiley, MS, CGC; Karina Chuah, MS, CGC; Amber Pryzbylski, MS, CGC; Rhianna Urban, MS, CGC

Mayo Clinic launched its first solid tumor next-generation sequencing (NGS) assay in 2014, and genetic counselors' (GCs) input and expertise in somatic oncology quickly became invaluable (for a snapshot of this history, check out a previous **article**). A decade later, as our understanding of somatic mutations in cancer continues to grow, so has the demand for more complex and comprehensive testing.

Consider a patient with metastatic breast cancer whose tumor sequencing revealed a somatic PIK3CA mutation. This result makes them eligible for an FDA-approved targeted therapy, an option they would not have had based on traditional pathology alone. Targeted treatment often leads to a meaningful clinical response, underscoring how somatic testing can transform patient outcomes. This is why many tumor-specific NCCN (National Comprehensive Cancer Network) guidelines now recommend biomarker testing, and a growing number of FDA-approved targeted therapies have made solid tumor testing the standard of care in oncology. Biomarker results optimize patient care by providing clinicians with essential diagnostic, prognostic, and therapeutic information, all of which rely on accurate detection, classification, and interpretation of somatic alterations.

These advances led to the rapid expansion of our somatic oncology test menu and the subsequent addition of team members. Furthermore, the increase in order volume and interpretive nuances has also necessitated the development of workflows distinct from our hereditary-focused colleagues. Today, our somatic team, which consists of seven GCs and two variant scientists, is the largest in our work unit. We now support 38 assays with several more tests currently in development. Our team has continued to grow, and we foresee further expansion, despite the recent volatility of the laboratory genetics job market (**Stoll, 2022**).

Our Role in Somatic Oncology

As somatic oncology-focused laboratory GCs, we play an integral role in variant curation and report writing for tumor-based molecular testing. Most importantly, we drive our lab's initiatives to scale reporting workflows and meet the demands of increasing volumes. Our GCs lead a multidisciplinary committee that reviews and creates reporting comments and automates reporting workflows; co-own IT tools such as internal knowledge bases and external reporting platforms; teach genetic counseling students, medical residents and fellows; and serve as liaisons between lab directors, technical specialists, test developers and IT specialists. We also play a role in test development, requiring a thorough understanding of testing methodologies, limitations, clinical implications of results and reporting workflows that must meet rapid turnaround times.

Training and Challenges

For GCs entering the field of somatic oncology, there is no clear training pathway. Many have either not considered entering this space or are unaware roles like this exist. Background knowledge of somatic oncology, including tumor profiling and somatic variant curation, is not routinely covered in genetic counseling training programs, leaving many GCs to learn on the job. Even GCs who came to this role at our organization with a laboratory background felt out of their depth with prior experience focused on hereditary genomics, test utilization, results counseling, marketing and client support. None of these tasks are a significant part of our current role. Despite this, we share a commitment to advancing the field of laboratory genomics, upholding the value of personalized medicine, and learning new skills in an ever-evolving environment, from deciphering FDA labels to the intricacies of tumor testing methodologies. While the lack of formal training can make this role intimidating, it also presents a unique opportunity for professional growth.

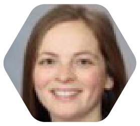
While GCs have a history of pioneering nontraditional roles, somatic oncology presents unique challenges. With increasing demand for somatic oncology testing, the systems and tools required to manage these tests are under significant pressure. Historically, IT tools were designed with hereditary genetics in mind, making it difficult to integrate alternate variant classification guidelines. Building and selecting new tools must allow for scalability of workflows and flexibility to accommodate rapidly changing guidelines and recommendations from professional organizations, such as the

Food and Drug Administration, the Association for Molecular Pathology, the American Society of Clinical Oncology, the College of American Pathologists and the World Health Organization. Another challenge is balancing the need for personalized reporting with the drive for standardization. Personalization in somatic oncology reporting ensures that findings are relevant to each patient's unique clinical situation, yet achieving standardization across a wide range of assays and platforms is necessary for operational efficiency. GCs must navigate these competing demands while supporting clinicians in delivering timely, actionable insights.

What Is Next for Our Team?

Looking ahead, GCs must continue adapting their expertise to strike a balance between variant interpretation solely for therapeutic and prognostic purposes versus reporting variants with potential hereditary implications. This balance requires adherence to professional guidelines and careful judgment, as the role of somatic mutations in cancer therapy becomes increasingly intertwined with hereditary considerations, and as paired tumor-normal testing becomes more widely available. Additionally, our diverse skillset and understanding of health care systems may allow expansion of our role to billing and marketing of somatic tests as they become better integrated into oncology care. This expansion will further enhance our value to laboratory clients and oncology clinicians.

Our experience reflects the GC profession's adaptability in taking skills gained in graduate school training and transforming them to meet the expanding needs of both patients and the health care field. While the exact roadmap may not be clear, the role of GCs in somatic oncology is here to stay. Our unique expertise and drive to learn ensure we will continue to shape the future of oncology and patient care. As oncology precision medicine advances, we may need to draw on our hereditary skills once again, bringing full circle our unique path as GCs. ⬢



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I Am a Genetic Counselor, Even if I Don't Feel Like One Yet

By Ileana Matta, MS, CGC (she/her)

I am a genetic counselor in the most technical sense of the term: I graduated from an accredited program, I passed the ABGC board exam and I received a license to practice in my state.

I had always imagined that my career as a genetic counselor would be linear. The plan was to move back home after graduation in June, having secured a clinical genetic counseling role in my favorite specialty at my favorite institution.

The reality was that upon graduation, I found myself in a period of unemployment. As anyone who has ever been unintentionally unemployed can tell you, it was brutal. I applied to the very few genetic counseling jobs that had been posted in my city, and I wondered whether those "You are no longer under consideration" emails were because there were other applicants with many more years of experience, or if my experiences were simply inadequate. With each new rejection email that flashed in my inbox, I reflected on my skills and wondered if the years I had spent working towards my goal of becoming a genetic counselor were insufficient. Apparently, I could be a certified genetic counselor in name but not in practice.

One of the aspects of the genetic counseling field that spoke to me as an undergraduate student looking to learn more about the profession was the job prediction data reported by the U.S. Bureau of Labor Statistics (BLS). The 2018 NSGC Professional Status Survey referenced a 29% growth rate from 2016 to 2026 for the genetic counseling profession based on data from the BLS. The current job outlook for genetic counselors has fallen to a projected growth of 16% from 2022 to 2032[1]. While this value remains higher than the average for all occupations reported by the BLS, it is evident that the days of an entire graduating class securing a job offer before graduation are no more.

I was in middle school during the 2008 recession, and I witnessed the devastating effects it had on our society. I learned from an early age that job stability was priceless. In 2022, while I was completing my summer rotation, a major genetic testing company announced a restructuring plan that gutted its workforce[2]. Social media postings and news circulating amongst classmates confirmed even more layoffs across different laboratories in the following months. The applicant pool for genetic counseling positions was growing, and it was daunting to realize that recent graduates would be competing with an influx of highly experienced industry genetic counselors for these positions.

Throughout different periods of my life, I was able to focus primarily on my schoolwork and was not preoccupied with the implications that these economic shifts would have on my own employment. Being a student during these turbulent times provided a temporary safety net from an uncertain job market. The current economic climate offers none of the promises of job security that seemed to be echoed by the genetic counselors I shadowed and met with during informational interviews just a few years ago.

I constantly scour job postings for genetic counselors, and I recall seeing one that required a minimum of one year of experience working as a genetic counselor in the past five years. Did my hard-earned genetic counseling skills have an expiration date? When the market is tough, the only thing one can do is make themselves more marketable. Learn new skills, follow up with your network, and do not lose confidence.

Since my path to genetic counseling was clearly not the linear journey I had envisioned, I decided to embrace this detour and explore other possibilities outside the field of genetic counseling. During my graduate training, I had a wonderful experience rotating with a research genetic counselor and enjoyed collaborating on study startup activities, from helping create provider information sheets to discussing universal consent and the ethics of reporting certain genes to participants. After several months of job hunting, I accepted a role on a clinical research team focused on characterizing the symptoms of long COVID in children.

In terms of gaining new skills, I am learning how to coordinate a clinical research study and how to engage with research participants. I quickly realized that clinical research has its own lexicon, and my knowledge of genes and syndromes was supplemented with new terms and acronyms: Reportable New Information (RNI), Note to File (NTF), Delegation of Authority (DOA), and many more. However, there are also aspects of my current job that parallel the role of a genetic counselor: obtaining informed consent, thorough documentation, and presenting data to health care providers. I keep in touch with supervisors from my previous rotation sites and reached out to the genetic counselors at my current institution to express my interest in a genetic counseling position. I frequently remind myself that everyone's path looks different. I know I am a genetic counselor, even if I don't feel like one yet.

I can't control what jobs will open up in my city and when. But when a position does open, I know I'll be ready. I was not the second-year student with a genetic counseling job lined up just before graduation. I will be almost a year out from that full-time student lifestyle, but I will have earned a collection of skills and work experience that make me uniquely qualified to take on a genetic counselor role. ⬢

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It's Time to Start Trusting Our Disabled Genetic Counselors

By Andrea Schelhaas, MS, CGC (she/her); Devin Shuman, CGC (she/her)

The authors deliberately chose to capitalize the "D" in "Disabled" genetic counselor to signify identity-first language, inclusive of a shared identity and community of genetic counselors with disabilities.

For Rare Disease Awareness Day, two genetic counselors with rare genetic conditions have one request: Please stop asking genetic counselors with disabilities if we are comfortable counseling patients with our own diagnoses.

There is one question every genetic counselor gets asked during a job or graduate program interview: "How did you hear about genetic counseling?" If you are a genetic counselor with a genetic condition, there is a second question that creeps its way into every interview: "Would you be able to counsel patients with your diagnosis?"

One of the most difficult parts about being asked this question repeatedly is that there is an expected answer: "No." The expectation in our field is that a genetic counselor with a genetic condition or a disability cannot objectively counsel about their own condition. There are unfounded assumptions that a Disabled genetic counselor will experience countertransference and that patients will likely feel uncomfortable, especially if a shared diagnosis is visible. Most often, the question asked is along the lines of, "Are you able to counsel a patient who is considering terminating a pregnancy with your condition?" Sometimes, either implicitly or explicitly, genetic counselors with visible disabilities or genetic diagnoses are told we should avoid working in prenatal roles altogether.

But why do individuals in positions of power feel entitled to ask such invasive questions? Genetic counselors who have children are not asked if they are capable of remaining objective when working in pediatrics. Genetic counselors are not asked about their history of pregnancy loss and whether it impacts their ability to impartially counsel individuals considering termination. In fact, many genetic counselors find their way to the profession due to a personal or family connection, and this is often viewed as an incredible asset.

It is not uncommon for an oncology genetic counselor to enter the profession due to a personal or family history of cancer. Most rare disease organizations are founded and run by parents of individuals with genetic diagnoses, and we applaud their achievement for turning a personal experience into an impactful organization. Why does it feel different to have Disabled individuals working in medicine, and why is it standard fare to question their abilities and intent? Instead of generating barriers based on hypotheticals, the genetics community would benefit from seeking the expertise of Disabled providers with lived experiences. Unfortunately for many, it feels like a constant uphill battle as we fight to demonstrate our value within the field.

Genetic counselors are trained to be self-aware, to be mindful of countertransference and to remain non-directive regarding a patient's decisions about their body and their family. Yet, ableism rears its ugly head with these types of questions. Often asked with "good intentions," these questions and the assumptions beneath them have the potential to cause lasting harm to Disabled genetic counselors and the profession overall. Experiences of Disabled genetic counselors are an asset, not a liability. As a profession, we do not need to distance ourselves from disabled bodies and identities. Implying or directly telling genetic counselors with visible disabilities that they do not have a place in certain spaces of the profession likens back to America's Ugly Laws where disabled bodies should be hidden away and not "imposed" onto others with our mere presence. It is time to trust that a Disabled genetic counselor is in fact capable of counseling in whatever setting they choose.

So on this Rare Disease Day, as two of the only 41 GCs who reported having a genetic diagnosis on the last PSS we ask you — please never ask these types of questions again. Take a moment and reflect on why we view the disabled body so differently, trust that Disabled genetic counselors are able to make choices about their own career paths based on their personal and professional interests and experiences, and ask yourself what you can do to address the ingrained ableist biases in your graduate program and/or workplace. ⬢

ANDREA SCHELHAAS, MS, CGC, (SHE/HER) is a Disabled genetic counselor at Genetic Support Foundation and Nemours Children's Hospital. She is a graduate of the genetic counseling program at Augustana University. In addition to seeing patients clinically, as a genetic counselor with achondroplasia and parent of children with achondroplasia, Andrea finds it important to address factors that may influence a Disabled individual's experiences in society and within the medical system and to increase Disabled representation within the genetics profession. Andrea is a member of the Little People of America Medical Advisory Board and has received remuneration for consulting related to patient advocacy and clinical trials with Tyra Biosciences.

DEVIN SHUMAN, CGC, (SHE/HER) is a Disabled LGBT genetic counselor at Genetic Support Foundation. She graduated from University of California Irvine's GC program and Smith College. Her mitochondrial DNA depletion syndrome has driven her to be an active participant in the mitochondrial disease community and she is passionate about Disability advocacy and rights. She has no financial disclosures, beyond accepting free CEUs from various genetic testing companies and being a part-time FDA employee.

My Career Pivot From Genetic Counselor to Environmental Geneticist

By Rachel Mador-House

The genetic testing industry, while promising in its potential to advance health care, has also been plagued by challenges such as layoffs, budget cuts, and uncertainty. My journey in this sector began with enthusiasm but eventually led to burnout and apathy. Seeking to reignite my passion for genetics and make a meaningful impact, I embarked on a career pivot towards the environmental field. This article chronicles my transition, emphasizing the importance of transferable skills, embracing change, and finding joy in new endeavors.

Burnout in the Health care Sector

Leaving behind my clinical oncology position for an MSL role marked the start of a journey to reclaim my love for genetics and contribute to positive change in the world. And for a while, I enjoyed the new challenges associated with an industry role and was thrilled to be part of a fast-moving and exciting industry. However, amidst the recent tumultuous landscape of the genetic testing industry, I recognized familiar and insidious feelings of burnout and apathy creeping back into my career life and recognized the need for a shift. My decision to pivot stemmed from a desire to align my expertise with a field that resonated with my values and offered renewed inspiration.

Transferable Skills and Versatility

The knowledge we build as genetic counselors qualifies us as experts in the field of genetic testing, however genetic testing is not solely reserved for health care. As I began investigating career pivots outside of clinical genetic testing, I realized that our unique knowledge and skills could be used in several different non-clinical fields such as agriculture, animal sciences, forensics, and environmental sciences. Indeed, any field that uses genetic testing could benefit from a genetic counselor. However, these fields remain largely unexplored by our profession. There are many examples of roles that we may be qualified for, and yet may not have ever been held by a genetic counselor, such as an agricultural role as a plant breeding and genetics expert (all positions found on Indeed.com) or a crop molecular improvement specialist.

When considering forensics, I have the privilege of knowing a genetics specialist nurse who works in the Ontario Forensic Pathologist Office as the coordinator of molecular autopsy and genetic diagnosis department, a position that a genetic counselor would easily fit into. And finally, in animal sciences, a genetic counselor seems aptly suited for a role in animal breeding programs, animal microbiologist, geneticist, or research scientist. In fact, as I was exploring my options, I was tempted by a role posted for a local farm needing a part time geneticist to aid in their livestock breeding program. Anyone else tempted by tiny baby goats?

But genetic counseling also equipped me with invaluable soft skills such as empathy, effective communication, and active listening which are also invaluable to diverse industries. As I explored alternative careers, I discovered the relevance and value of these skills in every industry. Embracing my versatility empowered me to pursue avenues aligned with my passion for genetics while transcending the confines of a singular career trajectory.

Finding Purpose in Environmental Impact

Joining a company in the environmental field represented a pivotal moment in my career journey. Here, genetic testing serves a different purpose – evaluating biodiversity and contributing to environmental conservation efforts. The vibrant atmosphere, characterized by enthusiasm and positivity, reignited my sense of purpose and joy. A great example of this is highlighted during my interview where each interviewer took the time to tell me about their personal passion related to environmental sciences. And although I joined the team with cautious optimism, I was delighted that the atmosphere did represent the image that had been portrayed; each team member has a similar internal mission, which leads to easy teamwork and a sense of urgency to further the team purpose with stress replaced by excitement and enthusiasm.

In addition to a positive and motivating work culture, environmental genetics also presents me with new challenges and opportunities to make a tangible difference, reminding me of the profound impact we can achieve beyond the confines of traditional roles. For example, in clinic I knew I was helping each of my patients. In my genetic testing industry role, I knew I was having an impact on the health system mainly through provider education related to genetic testing. Now, I get to impact the health of my community by engaging in activities that monitor biodiversity in an attempt to help protect nature. In my day to day, that may look like meeting with large company CEOs to discuss strategies on how they can measure and decrease their impact on nature or present recent research at conferences. I also work with non-governmental organizations (NGOs) to further their goals related to biodiversity. Considering that the World Economic Forum states that the impact of ecosystem collapse is already being felt and is expected to cause an annual decline in global GDP of 2.3 per cent, or $2.7 trillion by 2030, I feel that my work continues to have a profound impact on the health and well-being of my community.

A challenge I have experienced in my new role is learning about an entirely new field. For example, I previously had no idea how difficult it is for biologists to figure out which fish live in any given body of water. Well, now I know how fish surveys are done, along with a host of new knowledge. You may be interested to know that reptiles shed less DNA into the environment than other animals or that elephants have 28 pairs of chromosomes and may have low levels of cancers because they have around 40 copies of TP53 (although many are inactive retrogenes). And this new knowledge includes the guidelines and regulations for this field. As a previous cancer genetic counselor, citing NCCN guidelines became second nature. Now, however, I have a whole new set of regulations, guidelines, and governing bodies to become accustomed to. I think anyone who has completed a genetic counseling program can say with confidence they have the skills necessary to learn a new field, however the discomfort with being a non-expert and taking the time to build expertise can be challenging, especially to those of us who have enjoyed the comfort and ease of knowledge afforded by experience and specialization.

Embracing Change and Relishing the Unknown

My transition underscores the importance of embracing change and approaching the unknown with curiosity rather than fear. While the path ahead may be uncertain, it is also brimming with potential and possibility. By reframing challenges as opportunities, we can navigate career transitions with resilience and optimism. Through my journey, I encourage others to embrace their multifaceted talents, pursue their passions, and find fulfillment in unexpected places.

Conclusion

The trajectory of my career reflects a journey of self-discovery, resilience, and adaptability. From the challenges of burnout in clinical genetics to the ups and downs and associated uncertainty in the genetic testing industry, finally to the revitalizing energy of the environmental field, I have learned the value of embracing change and following my passion. My experience highlights the varied strengths and skill sets inherent in genetic counselors. We are genetics experts with counseling training. These two facets actually make us ideally suited to a number of fields using genetic testing, not just health care. As such I would encourage anyone else who is ready for a change not to be afraid of the unknown and to allow your career to be defined not by one specific title, Genetic Counselor, but by the skills embedded in your training and experience.

As I continue to explore new horizons, I am reminded that our true potential knows no bounds when we dare to embrace the unknown and pursue our passions with unwavering determination. ⬢

Disclaimer: The content of this article was written with assistance from ChatGPT, an AI language model developed by OpenAI. While ChatGPT provided suggestions and guidance, the final text was edited and reviewed by Rachel Mador-House to ensure accuracy and alignment with personal perspectives and experiences.

RACHEL MADOR-HOUSE is a genetic counselor, molecular biologist, and an MBA candidate. Her passion is to use cutting edge genetic testing techniques to improve the health and wellbeing of her community. She has done this clinically as a cancer genetic counselor and director of a newborn screening program. In addition to her clinical experience, she has also participated in training programs in the U.S. and Canada by providing workshops about diversity, equity and inclusion, the lived experience of health care providers with disabilities and the perspectives of international clinicians in the U.S. Currently, Mador-House uses cutting edge genetic testing techniques to monitor biodiversity changes in our environment as the Head of Scientific Affairs for North America at NatureMetrics.

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AI/ML in Genomics and Genetic Counseling: Insights From NSGC's Genomic Technologies SIG AI/ML Subcommittee

By AI/ML Subcommittee of the Genomic Technologies SIG

We are excited to introduce everyone to the AI/ML Subcommittee — a team of diverse genetic counselors with a wealth of expertise and united by a shared passion for advancing the intersection of artificial intelligence (AI), machine learning (ML) and genetic counseling. Our mission is to bridge the gap between cutting-edge AI/ML technologies and their practical, ethical and clinical applications in our field. We believe genetic counselors (GCs) are not just participants but essential creators, trainers and users of AI and ML technologies in clinical genomics.

The Broad Implications

AI and ML are transforming genomics, offering new opportunities for diagnosis, risk prediction, patient care and communication. Genetic counselors play a critical role in addressing challenges like ethical considerations, algorithmic bias and equitable access. By actively shaping the development and use of these tools, we can ensure they enhance — rather than overshadow — the human element of genetic counseling.

While AI is already impacting a wide range of professions, including genetic counseling, experts predict its role will be to enhance effectiveness and efficiency rather than replace us altogether (Kearney, 2019). In fact, as AI reshapes traditional roles, it is expected that the value of uniquely human attributes — including empathy, adaptability and others already mastered by GCs — will become even more evident. Meanwhile, AI literacy, model training and optimization are becoming increasingly demanded skills in the workforce (Levanon, 2024). To stay competitive not only within genetic counseling but also across science and healthcare, genetic counselors must acquire new skills and develop these emerging competencies.

A Call to Action for Genetic Counselors

Integrating AI/ML into health care has sparked both excitement and skepticism. Adopting an opportunity mindset enables us to view these technologies as a means to enhance our profession. By working with AI/ML — not against it — we can automate time-consuming tasks, freeing up time for patient care, research and other critical activities that require empathy and human judgment. While these technologies offer tremendous potential, they also pose risks, so we must actively engage in understanding and mitigating them. By participating in their development and adoption, we can ensure these tools align with our profession's ethical standards and values. This perspective can empower GCs to spot innovative ideas and embrace advancements that support the core values of our practice.

1. ***Upskill for Impact:*** AI/ML literacy is essential, even for those skeptical of its current uses. As subject matter experts, we should aim to understand these technologies, evaluate their outputs and develop informed opinions that drive meaningful discussions and generate new project ideas. While AI engineers develop models, it is — in our opinion — our uniquely positioned role to guide their application in healthcare and specifically in genetic counseling.

2. ***Stay Ahead:*** Keep up with AI/ML advancements in genetics to make informed decisions and provide the best possible care for our patients.
3. ***Join the Conversation:*** Engage with our Subcommittee, share insights and help shape how AI/ML is integrated into our field. We invite you to **suggest content or share use cases for future discussions**. Equally important, we welcome discussions on the challenges, risks and limitations of AI/ML, as these perspectives are crucial for maintaining a well-rounded view within our community.

Identifying Education and Resource Gaps

This past summer, our Subcommittee conducted an online survey within the genetic counseling community using a mix of closed and open-ended questions. The survey was promoted through the NSGC listserv and LinkedIn to gain a deeper understanding of the profession's needs related to AI/ML. We asked about the current state of knowledge, comfort levels and access to relevant AI/ML resources in both professional and personal contexts. The feedback from 67 respondents was consistent: ***while many GCs are curious about AI/ML, there is a clear and pressing need for accessible education, hands-on resources and real-world examples of these tools in action.***

Based on survey results, 89.6% of respondents indicated that long-form learning opportunities would be the most beneficial. To this end, the AI/ML Subcommittee is considering the following possible options for programming:

- ***Webinars*** featuring experts in AI and genomics to discuss real-world applications and case studies.
- ***Workshops*** to help genetic counselors upskill and gain confidence in using and evaluating AI/ML-driven tools.
- ***Collaborations*** with other SIGs and professional organizations to create multidisciplinary opportunities for learning.

Introducing Our Newsletter!

One of our major initiatives this past year was the launch of our new newsletter, AI/ML for Genomics and Genetic Counseling, in November of 2024. This resource informs readers about the latest advancements in AI/ML related to our field. You'll find curated articles, research highlights, ethics discussions, and more. Whether you are a seasoned professional or a student exploring the landscape, our newsletter is here to guide you. Check out our **second issue** and **subscribe here** to join our growing community of 400+ subscribers!

Moving Forward Together

Remember, our collective engagement is not just about staying relevant — it's about ensuring that GCs' unique insights and expertise are at the forefront of these technologies, whether those in development or already live in our healthcare systems. We're committed to supporting our peers in navigating these technologies and their impact on our profession. Your voice matters, and we encourage you to share your insights.

This article was written by members of the AI/ML Subcommittee of the Genomic Technologies SIG. The Subcommittee members are:

- Amy Gaviglio, MS, CGC
- Katya Orlova, PhD, CGC, MPH
- KT Curry, MS, CGC
- Lara E. Sucheston-Campbell, PhD, MS
- Marlena Ahn, MGCS, LCGC
- Ping Gong, MS, CGC

While AI-assisted tools contributed to the creation of this article, AI/ML Subcommittee members carefully reviewed and edited all content to ensure accuracy and relevance. We believe in AI as a collaborator, not a replacement, and we always prioritize veracity, ethics, and transparency.

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