National Society of Genetic Counselors

QUARTER 2, 2017 • VOL. 39 • NO.2

PERSPECTIVES

IN GENETIC COUNSELING

WHY IS THAT GENETIC COUNSELOR HOLDING A BUSINESS MEETING IN AN UBER?

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Planning for Conference

GC PUBLICATIONS

Mosaicism in Embryos

Spinal Muscular Atrophy (SMA)

Invitae now offers analysis of *SMN1* and *SMN2* in a single test

SMN1 loss of function results in spinal muscular atrophy (SMA), an early-onset debilitating neuromuscular disorder characterized by loss of motor neurons in the spinal cord.

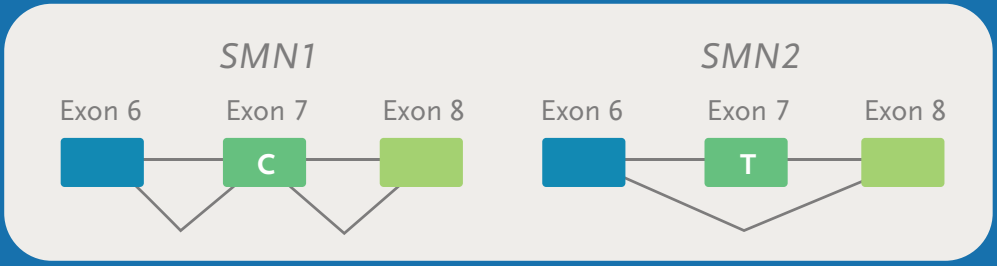
SMA can be caused by:

- Deletions of *SMN1*
- Gene conversion of *SMN1* to *SMN2*
- Rare inactivating sequence variants in *SMN1*

In addition, *SMN2* copy number is **highly variable** and can significantly modify the severity of SMA, with more copies of *SMN2* correlated with decreased SMA severity.

What makes *SMN1* and *SMN2* challenging?

SMN1 and *SMN2* are nearly identical—the coding regions differ by a single nucleotide or **"gene-determining variant (GDV)"** in exon 7.



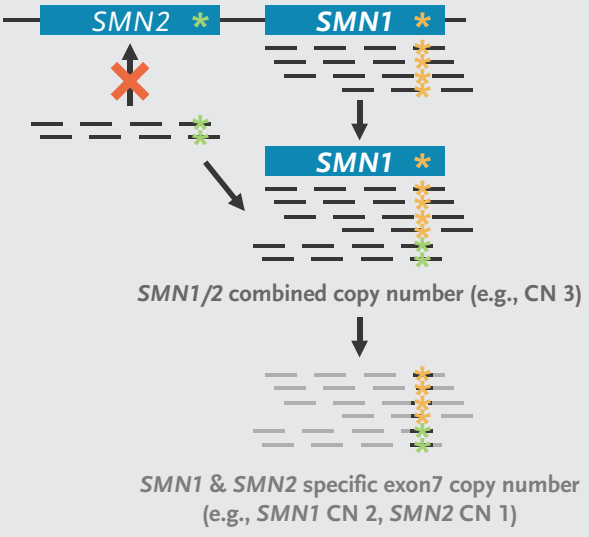
How we determine copy number:

Invitae's approach:

NGS-based approach with customized bioinformatics to accurately detect pathogenic changes in *SMN1* and determine both *SMN1* and *SMN2* copy number in the same test.

Reads from *SMN1* and *SMN2* are aligned to *SMN1* to get combined copy number.

SMN1- and *SMN2*-specific exon 7 copy number is resolved by counting reads with the GDV in exon 7.



What's the clinical impact?

- Simplifies SMA testing and provides a diagnosis with a single test
- Accurate detection of SMN2 copy number can provide critical information for disease progression

Visit our website to learn more and download the technical whitepaper.

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Learn more

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National Society of Genetic Counselors

PERSPECTIVES

IN GENETIC COUNSELING

Location, Location, Location!


Mary E. Freivogel, MS, CGC

Have you ever wondered how the National Society of Genetic Counselors (NSGC) decides on the locations for our annual conferences? It is not as easy as it may seem. The NSGC staff typically starts a search by issuing a request for proposals (RFP) to cities with convention center space that meets our criteria. These criteria include our preferred dates, plenary room size, exhibit hall square footage, number of breakout and meeting rooms, and hotel rooms nearby.

Space for large meetings, especially in desirable cities, is at a premium. Competition is fierce, and cities can be selective when responding to an RFP. They carefully evaluate the full economic impact of a conference. Our conference is a bit unique in that many attendees choose to share hotel rooms. While helpful for our individual budgets, it actually makes us less attractive to some cities, since the hotel revenue is low compared to the number of attendees.

To remain competitive, NSGC has started searching for locations earlier. Our annual conference has grown rapidly over the past several years, and it is difficult to accurately project our future space needs. While we are starting earlier, we still may not sign contracts more than two years before the annual confernce. We use this time to explore where we can be flexible and where we need to hold firm to ensure the best fit for our attendees and exhibitors. Once we sign a contract, NSGC is essentially "locked in." We make every effort to ensure that we enter into a contract that will work before we commit to a location.

We recognize that the annual conference is extremely important to NSGC members. Our goal is to provide you with a meeting that is strong in educational content and rich in professional development opportunities, but also takes place in a city you will enjoy. As you can see, there are many logistics to consider, and advance planning is necessary. We are extremely grateful for the NSGC staff for their expertise as we navigate these decisions. We are equally grateful to you, our members, for supporting our annual conference year after year. I look forward to seeing all of you in Columbus in the fall!

Mary Freivogel, MS, CGC
President, NSGC

CONNECT WITH MARY

National Society of Genetic Counselors

Board of Directors

About NSGC

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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WWW

Connect with the NSGC Community

Exploring new territories

"Exploration by real people inspires us." — Stephen Hawking


Kirsty McWalter


Kristen Hanson

The 2017 Q2 issue of *Perspectives in Genetic Counseling* highlights genetic counselors' explorations of new territories, from a competitive Uber ride with feature article author Ellen Matloff, to the novelty of a home office for New Graduate Life author Kyle Davis.

Student Forum author Katie Compton discusses how her background in medical communication led her on a winding path to genetic counseling. Mentor Match Program participant Lindsey Byrne recalls how her mentor helped her explore new opportunities and strategies for a new professional role.

Read about colleagues involved in research about mosaicism in preimplantation genetic diagnosis, and their exploration of how genetic counselors can contribute to guidelines and policies in this area. Learn about the Access and Service Delivery Committee's charge to identify service delivery models and create resources for NSGC members.

Gain insight from President Mary Freivogel as she describes the process of choosing NSGC's annual conference location each year. Consider reading the book featured in our Book Review, which focuses on women's value in the workplace.

Hear from Neeraja Reddy, as she shares her experience as an international student in a genetic counseling program and a new culture. The Neurogenetics SIG addresses the wide range of neurogenetic indications potentially seen by a genetic counselor, and presents a valuable resource tool for those working with patients with neurologic disorders.

Are you inspired to start some explorations of your own? If so, please share your experiences with us! We encourage you to reach out with ideas and topics for future issues of *Perspectives*.

Kirsty McWalter, MS, CGC
Certified Genetic Counselor, GeneDx

CONNECT WITH KIRSTY:

Kristen Hanson, MS, CGC
Certified Genetic Counselor, University of Michigan, Cancer Genetics Clinic

CONNECT WITH KRISTEN:

PERSPECTIVES
IN GENETIC COUNSELING

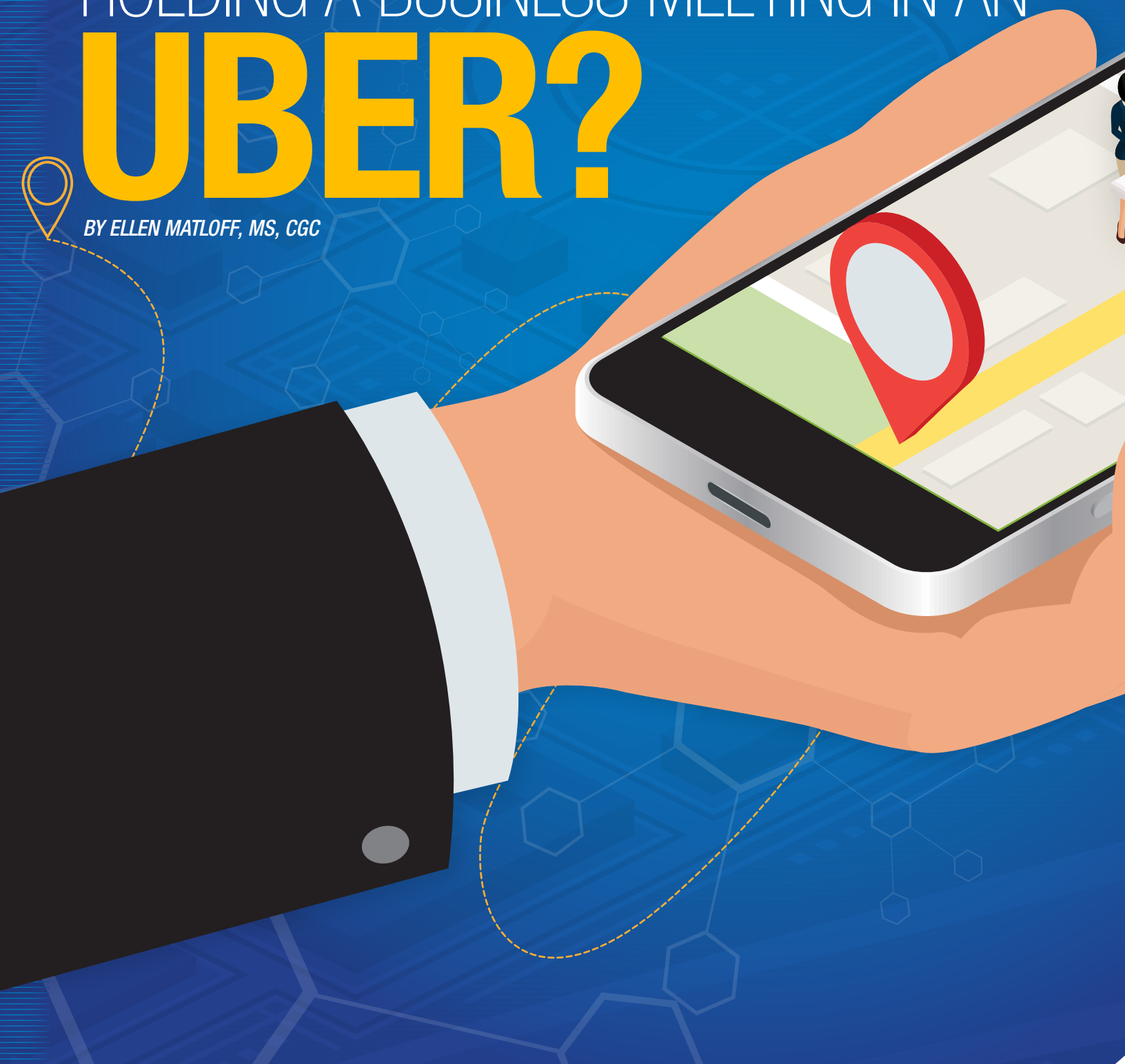
Editorial Staff

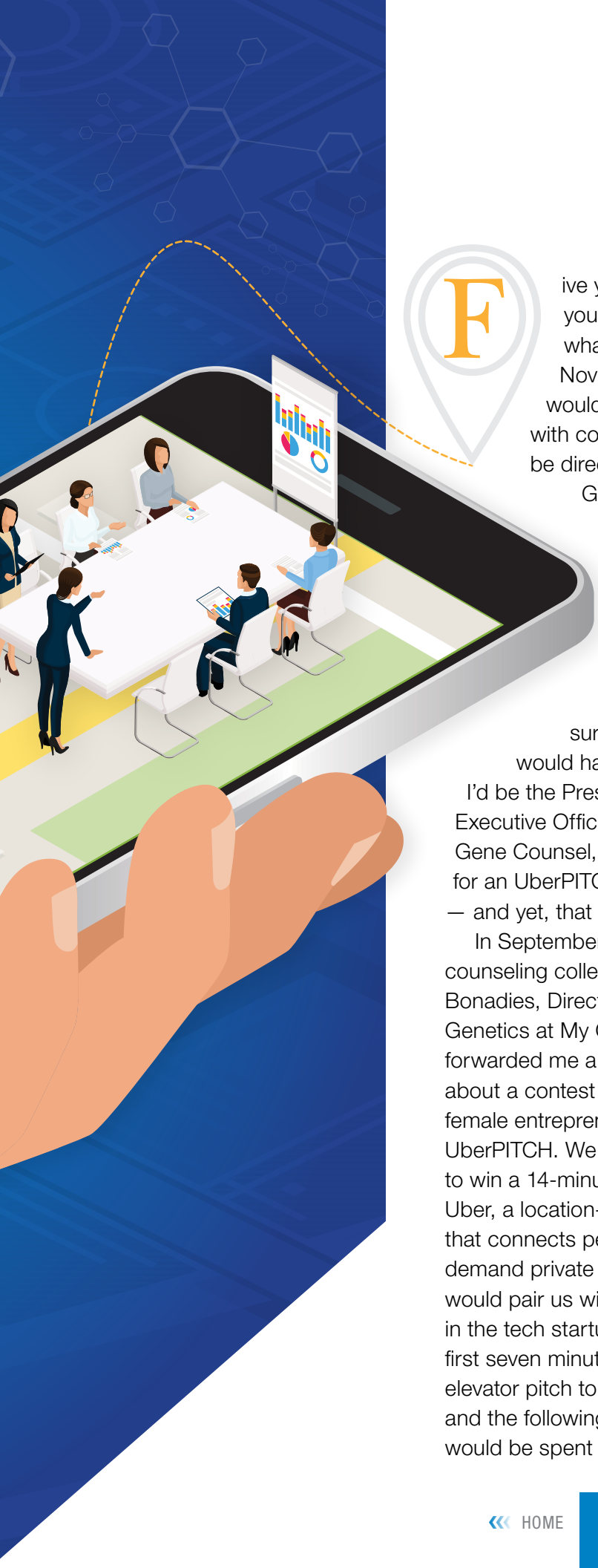
About *Perspectives in Genetic Counseling*

Perspectives in Genetic Counseling (PGC), the flagship digital magazine of the National Society of Genetic Counselors (NSGC), is published digitally four times a year. Publication of any article or advertisement in *PGC* should not be considered an endorsement of the opinions expressed or products advertised. Statements 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 *PGC* or NSGC. Original articles and letters are welcome. To submit items for consideration, contact any of the *PGC* editors via email (see contact information above).

WHY IS THAT GENETIC COUNSELOR HOLDING A BUSINESS MEETING IN AN UBER?

BY ELLEN MATLOFF, MS, CGC





Five years ago, if you had asked me what I'd be doing in November 2016, I would have told you, with confidence, that I'd be directing the Cancer Genetic Counseling Program at Yale School of Medicine, as I had since its inception in 1996. I can assure you that I *never* would have predicted that I'd be the President and Chief Executive Officer (CEO) of My Gene Counsel, and preparing for an UberPITCH competition — and yet, that is the reality.

In September, my genetic counseling colleague, Danielle Bonadies, Director of Cancer Genetics at My Gene Counsel, forwarded me a notice about a contest aimed at female entrepreneurs called UberPITCH. We could apply to win a 14-minute ride with Uber, a location-based app that connects people with on-demand private drivers. The ride would pair us with an investor in the tech startup space. The first seven minutes would be our elevator pitch to the investor, and the following seven minutes would be spent answering detailed questions about our company and business plan. As a digital health company that links current, evidence-based information to people's genetic test results, we decided to throw our hat in the ring.

Little did we know, more than 275 female-led tech startups applied from across the country, but My Gene Counsel was one of 150 companies chosen for the competition. We were instructed to go to New Haven on October 26 and order an Uber through their app between 11 a.m. and 2 p.m. As the CEO of a small company, I've given many an elevator pitch over the past three years, but never in a competition, let alone an Uber! I was excited, but also a bit nervous, standing on Chapel Street in New Haven on that beautiful, sunny morning.

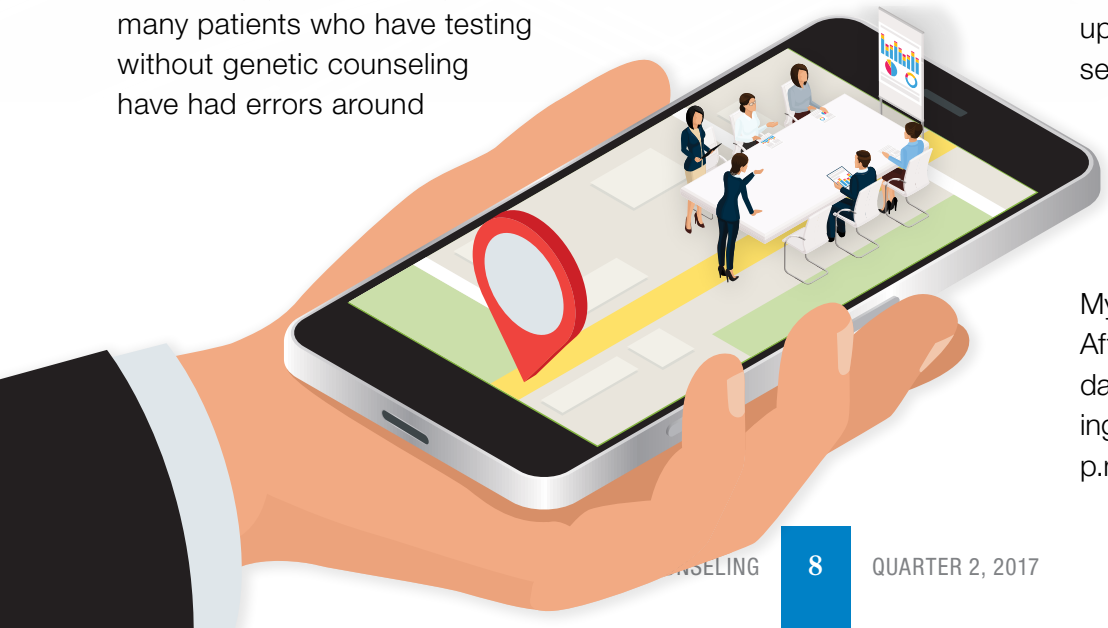
GIVING THE UBERPITCH

At 11 a.m. we went onto the Uber app, and an option for "Pitch" magically appeared next to the car options. We entered our code, and a few minutes later an Uber pulled up. Inside the car were the driver, a **reporter**, and an investor. I jumped into the back with Cynthia Tseng from Hartford-based Fairview Capital and began my pitch — seven minutes isn't much time to outline your **background**, your

vision, and your business plan! But I did, and then Cynthia asked me detailed questions about our financials, the market need, and our short- and long-term strategies.

Our pitch focused on the trends we've encountered in the industry over the past decade: Namely, the cost of genetic testing is dropping, more people are having genetic testing, and many patients who have testing without genetic counseling have had errors around result interpretation. This can be damaging, and even fatal, for patients and their family members. Our product provides first-line genetic counseling information to clinicians and patients, and helps them find a certified genetic counselor near them.

Six days later, we received an email congratulating us on advancing to the semi-finalist round! Only 25 of the 150 companies were chosen, and we would be given the opportunity to pitch in front of a panel of judges on the morning of November 16 in Stamford, Connecticut. Ten companies would advance to the finals that evening. The competition was stiff, but that afternoon we received an email that we'd been chosen for the finals. We showed up for a cocktail hour and poster session at 6 p.m. The final pitches in front of an audience and a panel of judges began an hour later.



THE FINALS

My Gene Counsel pitched first. After such a long and stressful day, I honestly thought I'd be falling asleep by the last pitch at 9:15 p.m., but instead, I was on the

Our product provides first-line genetic counseling information to clinicians and patients, and helps them find a certified genetic counselor near them.

edge of my seat. The other finalists were *incredible* — pitching companies that find and match job candidates for companies, make cancer immunotherapy vaccines for dogs, or attract customers to try new brands of alcohol.

The winners were announced at 9:45 p.m., and My Gene Counsel was honored and thrilled to be in the **Winner's Circle**! We were awarded third place and a cash prize to further our digital genetic counseling product line. We will use our prize money to help bring our direct-to-consumer product to market.

After 20 years of serving as a traditional genetic counselor, I never imagined that I would someday be an entrepreneur, but here I am. And what a wild ride it has been so far.

Ellen T. Matloff, MS, CGC, *is a genetic counselor and the president and CEO of My Gene Counsel. She was the founder and Director of the Cancer Genetic Counseling program at Yale, where she served for 18 years. Matloff was also a plaintiff in the 2013* BRCA *gene patent case that went to the Supreme Court, moderates the tweet chat #GenCSM, and has authored more than 50 articles, book chapters, and books in genetics.*

MAKING THE LEAP:

ONE MEMBER'S EXPERIENCE BEING A MENTEE IN A TIME OF TRANSITION

BY LINDSEY BYRNE, MS, LGC

As I began my new job in a different hospital system, I was full of excitement and terror. I was taking on the role of the program's clinical lead and supervising genetic counselor. I began searching for any resources that could help me get settled in my new role. I came across a webinar from the National Society of Genetic Counselors (NSGC) called "I'm in Charge, Now What? Experiences of Genetic Counselors in Management Positions," which was exactly what I needed. There were pointers, books, and resources given during this presentation that lessened my anxiety.

Most importantly, there was a brief discussion about the NSGC mentor program and how having a mentor who has management experience was helpful for new genetic counselors in leadership. I had heard about the mentor program before, but viewed this program for new genetic counselors and students linking up with experienced genetic counselors. I never would have thought this would end up being the most helpful piece of information I received from the webinar.

So, I took the plunge and went onto the mentorship program website to create my application as a mentee. As I thought more about this process, I wondered if I could find a mentor who had leadership experience in the NSGC, since I

Using the "mentor finder" tool on the website, I was able to find just what I was looking for, and requesting a mentor was as easy as sending a note through the website.

wanted to get more involved. Using the "mentor finder" tool on the website, I was able to find just what I was looking for, and requesting a mentor was as easy as sending a note through the website.

I chose to be paired with Sara Riordan, who has both NSGC leadership experience and extensive management knowledge. Once Sara accepted my request to be her mentee, we began our mentee/mentor relationship. We scheduled calls once a month to talk about the given topic by the mentorship program, but also about anything that was on my mind or hers. I cannot say enough about how great this experience has been. Sara has provided me with amazing guidance through my transition in my new role, and will continue to be an important person in my journey as a genetic counselor.

Though I have been a genetic counselor for eight years, I didn't know the best ways to get involved with the NSGC, and I struggled to discern which opportunities were right for me. Sara knew exactly how I felt, and she listened to my interests and helped me take the right steps toward becoming involved in a way that was most rewarding. Sara guided me through the beginning of my NSGC volunteering as an at-large member on the awards subcommittee. I was so nervous and excited for my first big opportunity with the NSGC, but also relieved that Sara was there for me for any support or questions I had along the way.

As my work with the awards subcommittee came to an end, I thought about how to stay involved with the NSGC. Sara gave me the courage to apply for numerous opportunities in the membership committee. Now I get to work on the nominations and the professional status survey subcommittees. I also work on the mentor program, the program that made my involvement in the NSGC possible!

As I look back on this last year, I can say that I would not be where I am without the mentor program. I am so excited and honored to be able to contribute to this amazing program through the work of the committee. Connecting with my mentor has shown me that I can provide this same experience to other mentees, and I plan to sign up to be a mentor soon. I am sure that others reading my story can relate to having people in their lives that helped guide them through various challenges. I hope that you will read my story and think about how having a mentor or a mentee could enrich your life. Consider going to **www.nsgcmentor.org** to sign up for this incredible benefit offered by the NSGC.

Lindsey Byrne, MS, LGC, *graduated from the Sarah Lawrence College Genetic Counseling Program in 2008. She is currently the senior genetic counselor and clinical lead of the cancer genetics program at Mount Carmel Health in Columbus, Ohio. Lindsey is on the executive committee for the state of Ohio Partners for Cancer Control, and is active with The Ohio State University Genetic Counseling Graduate Program. She was on the NSGC CEU review committee and the NSGC awards subcommittee, and is currently on the membership committee.*

Challenges of Becoming a Genetic Counselor: Perspective of an International Genetic Counseling Student

BY NEERAJA REDDY, MS, LCGC

Diversity Dialogue is an open forum for discussion of diversity in genetic counseling. The purpose of this column is to share the voices of genetic counselors from various background identities and experiences, particularly those underrepresented in the field or in society. If you are interested in authoring a future article, email Kate Dempsey.

I grew up in India with a keen interest in a career in healthcare. For three years, I served as a volunteer for several local schools for children with special needs, and grasped the taboo and misconceptions surrounding disabilities and genetic conditions. The common theme in all my interactions with families and school systems was the need for awareness and education. My drive to bridge this gap brought me to genetic counseling.

The field of genetic counseling in India was in the early stages of development, and there were no graduate-level programs in the country. Though the National Society of Genetic Counselors and the American Board of Genetic Counseling provided a wealth of information online, there was limited guidance for potential international students. The first challenge was to truly understand the role of genetic counselors and determine whether this was the right fit for me. I sent out emails to many genetic counselors to understand their daily activities. Their responses and passion for the profession reaffirmed my career choice. After completing all my prerequisites, I began applying to graduate programs. Following multiple interviews, I was waitlisted by three universities. Unfortunately, I was not admitted. Feedback from programs included suggestions to shadow genetic counselors and try to attend interviews in person; however, all of these programs acknowledged the difficulty of international applicants to satisfy these recommendations.

I was fortunate to shadow a fertility genetic counselor for three months prior to the next application cycle. As an international student from a modest background, I could not afford to travel abroad for interviews, but I was able to work with programs to personalize the interview process by using video conferencing. This time, I was successful and looked forward to the challenge of attending graduate school in a new country in which I would develop my skills to become a genetic counselor.

After completing nearly insurmountable paperwork and navigating through the visa process, I was thrilled to start school. Soon I came across major challenges as an international student: understanding academic expectations, learning under a new format of teaching, and acclimatizing myself with a new accent and professional expectations. I had a stark awareness of my culture and its influence on all my interactions and the process of counseling. Inadvertently, self-awareness toward cross-cultural competency became an essential part of the training process. During the early days of internships, I was concerned if patients would understand me and accept me as their healthcare provider. Over time, however, I experienced that acknowledging cultural differences and recognizing personal biases has allowed me to hone my skills as a genetic counselor and grow as an individual.

Neeraja Reddy, MS, LCGC, *graduated from Brandeis University in 2015. She currently works as a genetic counselor at the Penn Telegenetics Program at the University of Pennsylvania, providing genetic counseling in clinical and research settings.*

Bringing Awareness to Mosaic Diagnosis in Embryos with Genetic Guidance

BY CHRIS STALLMAN, MS, LCGC


Andria Besser, MS, CGC


Emily Mounts, MS, CGC

Besser, A.G; Mounts, E.L. Counselling considerations for chromosomal mosaicism detected by preimplantation genetic screening. *Reproductive BioMedicine Online* (2017). doi: 10.1016/j.rbmo.2017.01.003.

In vitro fertilization (IVF) is an increasingly available option for patients who need assistance to achieve pregnancy. Preimplantation genetic screening (PGS) can be performed on embryos to identify chromosome number, sex, some forms of polyploidy, and mosaicism. Most results have established outcomes, making it straightforward to determine which embryos are considered for transfer. However, results indicating mosaicism make such decisions less clear-cut.

As genetic counselors working in the field of assisted reproductive technology, **Andria Besser, MS, CGC,** and **Emily Mounts, MS, CGC,** are familiar with the problematic nature of embryos with mosaicism. "In late 2015, a study reported healthy babies born from embryos diagnosed as mosaic. This sparked discussion in the community about how to interpret a mosaic diagnosis and what to do with these embryos," said Besser. The pair identified a need for provider guidance in these scenarios.

"Although the phenomenon of mosaicism is not new, its diagnosis in embryos has been rapidly increasing as PGS technologies become more sensitive," said Mounts. Besser and Mounts provide a summary of current data and discuss genetic counseling recommendations when the results reflect mosaicism.

Now employed at NYU Fertility Center, Besser counsels patients about preimplantation genetic diagnosis/screening, works in the clinic's donor egg program, and develops clinical policies, protocols, and educational tools. She also is a part-time genetic counselor for Counsyl. Mounts is a clinical genetic counselor and Director of Genetic Services at Oregon Reproductive Medicine: She is a team lead in genetic policy/protocol development and liaison with egg and embryo donation programs. Besser and Mounts aim to bring awareness to the potential of under- or overestimating the risks associated with transferring embryos diagnosed as mosaic. "Our paper is the first to explicitly address considerations for counseling patients about mosaic results in preimplantation embryos, and serves to initiate a crucial dialogue between reproductive medicine and genetic counseling communities," Besser said.

The authors are hopeful that this study will have lasting effects beyond helping providers better interpret mosaic PGS results. "Ultimately, we would like to influence the development of clinical policies regarding transfer and storage of these embryos," Mounts said. "We want to demonstrate the value of genetic counselors and improve patient care by increasing our understanding about the benefits, risks, and limitations of PGS."

Chris Stallman, MS, CGC, *has experience in cardiovascular genetics, teratogen exposures, prenatal and PGS genetic counseling. She works at the University of Arizona as a Teratogen Information Specialist at MotherToBaby Arizona.*

CONNECT WITH CHRIS:

A Comprehensive Resource to Navigating Neurogenetics Initiatives

BY WEIYI MU, SCM, CGC, AND KRISTA QUALMANN, MS, CGC

Neurogenetics is a rapidly expanding specialty in the genetic counseling profession. According to the National Society of Genetic Counselors' Professional Status Survey, 8% of genetic counselors in 2016 reported neurogenetics as a specialty area, compared to only 1.1% in 2014. Studies suggest that neurologists frequently order genetic testing,[1] often without available genetic counseling expertise. Specialty neurogenetics clinics, which occur in a variety of settings, enhance collaboration between specialties and bridge gaps in expertise by bringing together genetic counselors, neurologists, and other providers.

In response to interest from the Neurogenetics SIG membership, 2016 co-chairs Jennifer Roggenbuck, MS, LGC, and Amanda Bergner, MS, CGC, asked us to organize a workgroup to create a comprehensive resource guide for establishing or expanding a neurogenetics specialty clinic. Based on a similar document created by the Cancer SIG, this practice resource is tailored specifically for genetic counselors working with neurologic disorders.

We were struck by the wide variety of indications currently seen by Neurogenetics SIG members, which range from adult neurodegenerative diseases to epilepsy and structural brain malformations. Neurological disorders may overlap with cancer, cardiology, pediatric, and adult indications, creating a specialty with as much variety as a general genetics position. Common themes within neurogenetics include unique biological, psychosocial, and ethical concerns that arise when working with patient populations who have a disorder centered within the nervous system.

Some highlights of this 23-page resource packet include:

- Detailed descriptions of different neurogenetics clinic settings
- Anecdotes outlining the importance of genetic counselor involvement for better patient outcomes
- Justification for a program, and points to consider when developing a program
- Genetic information confidentiality concerns
- Research responsibilities for genetic counselors within a neurogenetics protocol
- More than 60 primary literature references

With the ever-increasing call for genetic counselor workforce expansion, alternative models of care delivery are becoming a necessity. We hope this resource guide will not only be useful for genetic counselors looking to justify new positions in a neurology setting, but also for counselors looking to improve an established neurogenetics clinic, better delineate their roles, and expand their practice.

RESOURCES

1. Arthur KC, Doyle C, Chiò A, Traynor BJ. Use of Genetic Testing in Amyotrophic Lateral Sclerosis by Neurologists. JAMA Neurol. 2017;74(1):125-126. doi:10.1001/jamaneurol.2016.4540.
2. "Practice Resources for Starting a Neurogenetics Clinic" may be accessed by Neurogenetics SIG members at www.nsgc.org.

Weiyi Mu, ScM, CGC, *is a clinical genetic counselor with the Institute of Genetic Medicine at Johns Hopkins University, specializing in pediatric neurogenetics and adult neurodegenerative cases.*

CONNECT WITH WEIYI:

Krista Qualmann, MS, CGC, *is a clinical and research genetic counselor with the Memorial Hermann Mischer Neuroscience Institute and the University of Texas Health Science Center at Houston, where she specializes in brain aneurysms, neuro-oncology, and other adult neurogenetic indications.*

CONNECT WITH KRISTA:

How a Career in Science Communication Led Me to Genetic Counseling

BY KATIE COMPTON

My decision to study genetic counseling started with a single sentence.

At the time, I was working as a writer and editor at the Canadian Institutes of Health Research (CIHR). Our communications team was publishing a series about personalized medicine research, and I had been tasked with editing the text. One of the articles, written by Dr. Bartha Knoppers and Dr. Denise Avard, detailed their work on the legal and ethical issues surrounding genomic research. The article described the barriers to addressing these issues, including the lack of health professionals with a background in genetics. The researchers stated, "Beyond the ethical questions [associated with genomic research], there are concerns that primary care providers are not equipped to deal with the flood of information that whole-genome sequencing produces, and there are nowhere near enough genetic counsellors to help them."

As an undergraduate, I studied biology, and became fascinated by the ways that people write and talk about science, particularly in the realm of health. I took courses on writing for the sciences. When I completed my Honours research project, I realized that I had enjoyed writing the thesis more than doing the actual lab work. At that point, I decided to become a science communicator.

I went on to complete a graduate degree in science communication — a field focused on demystifying complex concepts and explaining scientific ideas in very concise ways. When I went to work at CIHR, I was excited by the challenge of increasing Canadians' science literacy and appreciation for health research. I had the opportunity to talk to scientists in many different areas of health research, and present their work in ways that were relevant to non-scientists. Gradually, I found there were specific topics that I felt more drawn to than others, and genetics was at the top of that list. I also wanted to have a more immediate, tangible impact on patients using my skills in science communication.

When the personalized medicine articles came across my desk, and I read about the need for health professionals who can talk to patients about genetics, it seemed like the perfect next step. Returning to school after working for a number of years has been challenging; leaving the security of my job at CIHR was nerve-wracking, and getting back into an academic mindset was difficult at first. But I've gained a new community, made up of my classmates and supervisors; and talking to them about their own motivations for entering the profession has been inspiring.

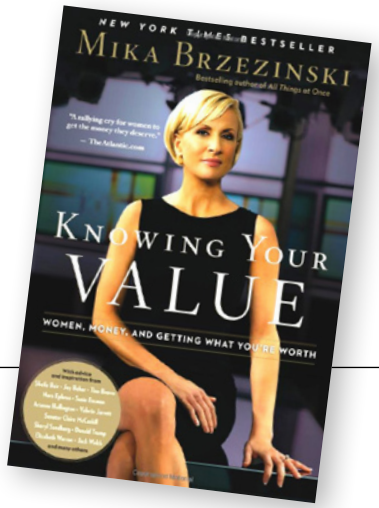
Now I've entered the second year of my program, and I am taking on more responsibilities in the clinic. When I'm sitting across from a patient, thinking about the best way to communicate the information I have to share, I feel nervous, exhilarated, and so glad that I edited an article on personalized medicine three years ago.

Katie Compton *is a Genetic Counselling MSc candidate at the University of British Columbia. She has an undergraduate degree in biology from the University of Prince Edward Island and a master's degree in science communication from Drexel University.*

BOOK REVIEW

Knowing Your Value: Women, Money, and Getting What You're Worth

REVIEWED BY SARA WIYRICK, MS, LCGC



Author: **Mika Brzezinski**
Publisher: **Weinstein Books (2011)**
Pages: **194 pages**
Retail Price: **$22.95 hardcover**
ISBN-10: **978-1-60286-134-3**
E-Book ISBN: **978-1-60286-142-8**

You may know Mika Brzezinski as the co-host of MSNBC's *Morning Joe*, or as the author of the *New York Times* bestseller *All Things at Once*. Like many in our profession, Brzezinski balances roles in her career and at home, as a wife and a mother. From her personal experience as a journalist, she came to appreciate some of the complexities of knowing a woman's value in the workplace.

Brzezinski recalls her own story of initially being grateful for the opportunity to co-host *Morning Joe*. She aggressively put her reporter skills to work and poured every ounce of her energy into the show's success. Over time, her frustration grew, as she was significantly underpaid compared to her male counterparts. She eventually reached her breaking point, which caused her to reflect, investigate, question, and learn from others' experiences.

Morning Joe is known for being smart and unpredictable, and telling things like they are. Brzezinski's style is similar; she reports on the topic of women's value in the workplace. A criticism might be that Brzezinski's reporting is light on the rigor of research to which many genetic counselors are accustomed. However, through a series of key interviews she uncovers many valuable insights.

Brzezinski shares commentary and advice from successful women like Suze Orman, Sheryl Sandberg, and Elizabeth Warren, as well as notable men like Donny Deutsch and Donald Trump, such as, "if you're not paid for it, don't do it" and "speak up, and make sure your ideas are heard." These words of wisdom are helpful as we consider our journeys through the workplace.

How does advice of "if you're not paid for it, don't do it" fit with genetic counseling? Our profession is relatively young, and many genetic counselors are early in their careers. Doing everything to demonstrate our value seems important so that we become more essential. Instead, perhaps we should continually sharpen our focus on efforts that represent the most value-added aspects of our role.

Knowing Your Value gives ideas for taking a seat at the bargaining table and asking for increased compensation. Let's do what we can to not arrive at the same point of frustration as Brzezinski found herself. *Knowing Your Value* has ideas on other things we can do proactively; for example, creating strategic alliances. Our profession already has an active mentoring program, and we can begin identifying "sponsors" who will advocate for our advancement both among and outside of the profession.

Now is an incredibly exciting time for our profession. The topics Brzezinski discusses may help us navigate the many opportunities ahead so that we are able to more fully demonstrate our true value.

Sara Wiyrick, MS, LCGC, *works as an Area Manager at Myriad Genetics. During the past nine years, she has held a variety of roles at Myriad. Sara is happy to work for a company that supports her professional development and where there are many women succeeding in their careers. Sara previously worked at the University of Washington and the MD Anderson Cancer Center. Sara is an alumnus of the University of Michigan (Go Blue!). Her proudest accomplishments are those outside of work: her three children, Marielle (5), Hattie (3), and Graeme (3 months).*

From Homework to Working from Home: Remote Genetic Counseling as a New Graduate

BY KYLE DAVIS, SCM, LCGC

Nothing can describe the feeling of finding what seems like the perfect position — especially when it's right out of graduate school. Fortunately, I found a fascinating position at a growing company that valued my skills, included a team of genuinely good people, and offered a 30-foot commute (estimated distance from bedroom to home office). Most important, though, was that this position fit into my family's lifestyle: I could literally pack my office as needed when my wife's job might take us to New York or Los Angeles with perhaps a month's notice (or less!). But in all my excitement, I didn't realize the many challenges that came with working in a remote position as a new professional.

A phrase I heard often in my training program was that we were learning how to learn. I knew this was true to an extent — that as new graduates our knowledge base was wide yet shallow — but I didn't appreciate the phrase until my first two weeks of work. On-site training was bittersweet, because I saw what I would soon be missing: hallway discussions of interesting findings or difficult cases, a whiteboard with hastily drawn chromosomes showing translocations, and reflection about the genetics field with our resident scientists.

I adapted and relied on active self-teaching or purposely reaching out to colleagues via phone or chat.

Although my co-workers helped me acclimate, I increasingly realized I would need deeper knowledge as training became work and the specter of the board exam loomed. It turns out learning how to learn is easier in the right environment, where knowledge can passively grow. And then there were the other things I would be missing, like the inside jokes and office pranks, impromptu happy hours, and leftover food from executive-level meetings.

After I returned home from training, all was quiet in my home office. The leftovers from breakfast or lunch were my own, and therefore unexciting. The benefits and drawbacks of working from home came into focus. I constantly chatted online with my team, but I kept thinking about my classmates in their workplaces: bumping into other genetic counselors, doctors, or professionals; working in cancer, prenatal, and adult genetics; and yielding professional growth and knowledge in different and possibly faster ways than a remote genetic counselor.

I adapted and relied on active self-teaching or purposely reaching out to colleagues via phone or chat, which is somehow harder than swiveling your chair around to nag a colleague with a question that's most likely just a Google search away. I grew over weeks and months, and after passing the boards (fireworks emoji!), I did feel that through my daily work, research, self-learning, and team-based collaboration, the remote environment was no longer such a challenge. But I didn't appreciate the difficulty of getting to that point when I first accepted a remote position. Knowing what I do now, I wouldn't change a thing.

Kyle Davis, ScM, LCGC, *received his master's in Genetic Counseling from John Hopkins in 2016. He lives in Austin and works at Lineagen, Inc. He loves reading new genetics research, science writing, creative writing, and, at times, a combination of all three.*

CONNECT WITH KYLE:

Service Delivery in Genetic Counseling

BY SARA GILVARY, MS, CGC, AND LAURA PANOS SMITH, MS, CGC

The Access and Service Delivery Committee is responsible for monitoring, making recommendations for, and addressing issues related to increasing access to genetic counselors. Specific issues of interest include service delivery models, payer coverage of genetic services, state licensure, coding and credentialing, and patient outcomes. If you have any questions or are interested in getting involved, please contact Sara Gilvary and Laura Panos Smith.

The Genetic Counselor Workforce Working Group's **Workforce Study**, shows that despite a projected 72% workforce growth rate over the next 10 years, a shortage of genetic counselors involved in direct patient care will still exist.

The Access and Service Delivery (ASD) Committee is helping to increase payer recognition of genetic counselors, genetic counselor licensure and credentialing, genetic counselors' efficiency and productivity in clinical care, and alternative service delivery models utilization.

The ASD has been charged with engaging key stakeholders within the National Society of Genetic Counselors to identify effective models of service delivery and develop practice resources to help members implement these models. We are excited to announce the ASD's Service Delivery Work Group, led by Stephanie Cohen, MS, CGC. Between 2012 and 2013, Cohen was the lead author on two papers that defined, identified, and evaluated the service delivery models in use at that time.

A service delivery model is "the method in which genetic counseling services are delivered by genetic counselors."[2] The four basic models are: 1) in-person genetic counseling; 2) telephone genetic counseling; 3) group genetic counseling; and 4) telegenetics.[2]

The Service Delivery Work Group will explore the current landscape of genetic services to update the existing data on identified models, as well as highlight novel models that have recently been implemented. The Work Group will also collaborate with the Outcomes Task Force and the Research Special Interest Group to identify metrics for measuring the effectiveness of existing and novel service delivery models.

If you are providing clinical genetic services in a unique way, the Service Delivery Work Group would love to hear from you. Please contact Stephanie Cohen at **SACohen@stvincent.org**.

REFERENCES

1. Cohen, S.A., Marvin, M.L., Riley, B.D. et al. J Genet Counsel (2013) 22: 411.
2. Cohen, S.A., Gustafson, S.L., Marvin, M.L. et al. J Genet Counsel (2012) 21: 645.

Sara Gilvary, MS, CGC, *is the Fieldwork Placement Coordinator for the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College. Prior to her current position, she was a prenatal and pediatric genetic counselor at NYU Langone Medical Center and Bellevue Hospital. Sara is currently the co-chair of the NYS Genetic Counselor Licensure Task Force and the co-chair of the Coding subcommittee of the NSGC Access and Services Delivery committee.*

CONNECT WITH SARA:

Laura Panos Smith, MS, CGC, *is a genetic counselor at Ambry Genetics, living in Dallas, Texas. She has a personal interest in cancer genetics, genetics/genomics public policy, and furthering the application and innovation of genetics technology.*

CONNECT WITH LAURA:

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