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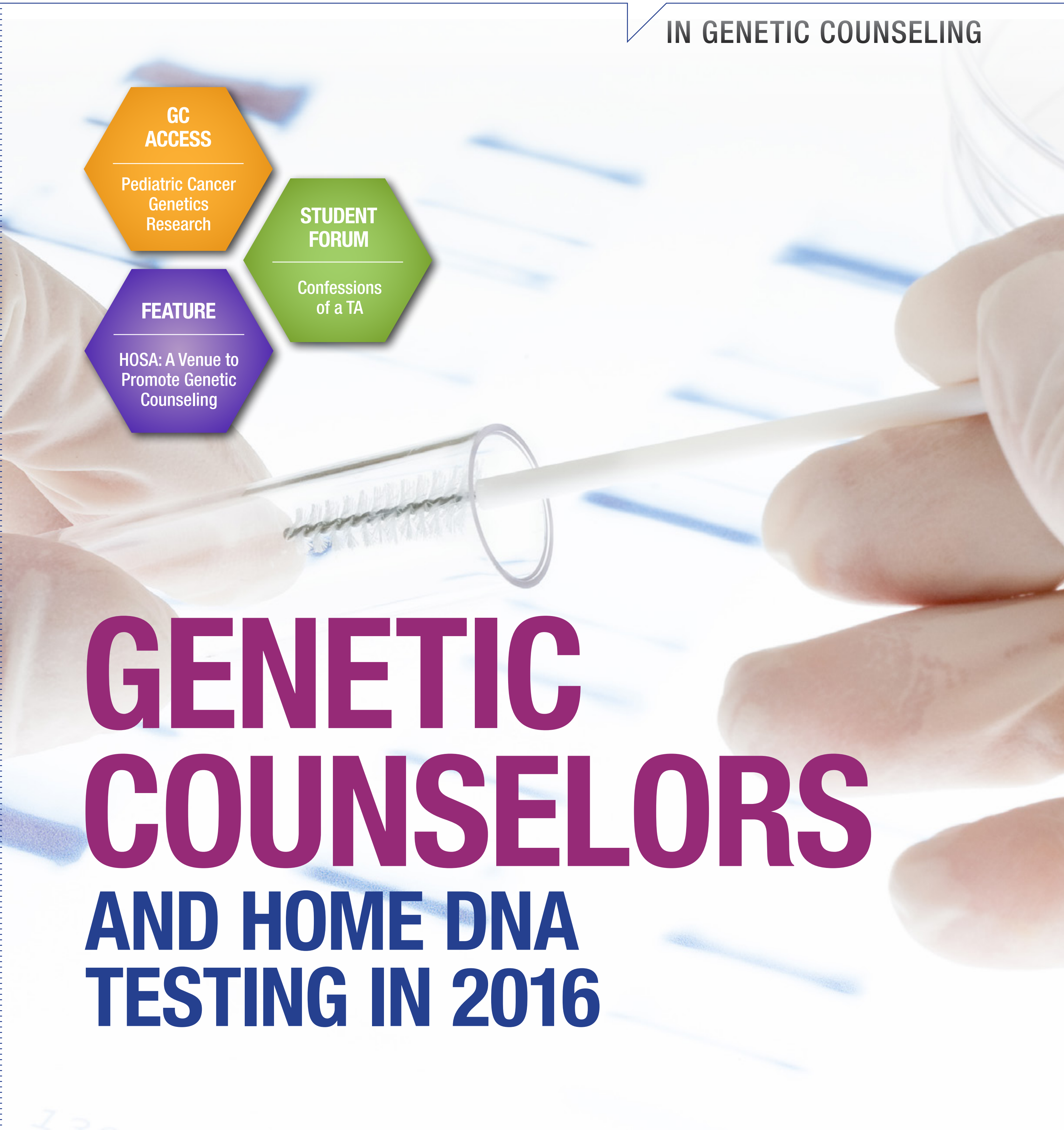
QUARTER 3, 2016 • VOL. 38 • NO.3

PERSPECTIVES

IN GENETIC COUNSELING



GC ACCESS

Pediatric Cancer Genetics Research

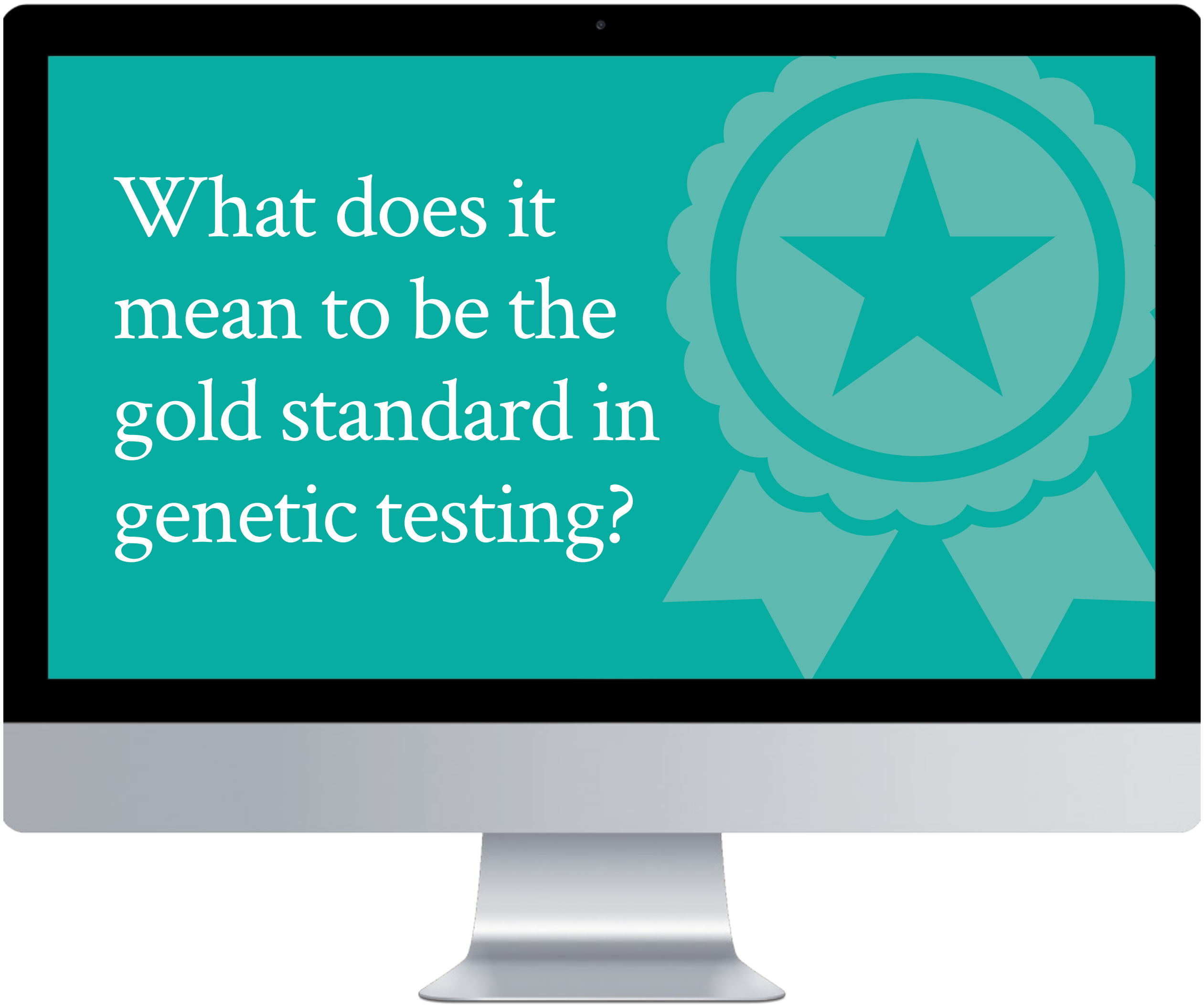
STUDENT FORUM

Confessions of a TA

FEATURE

HOSA: A Venue to Promote Genetic Counseling

GENETIC COUNSELORS AND HOME DNA TESTING IN 2016



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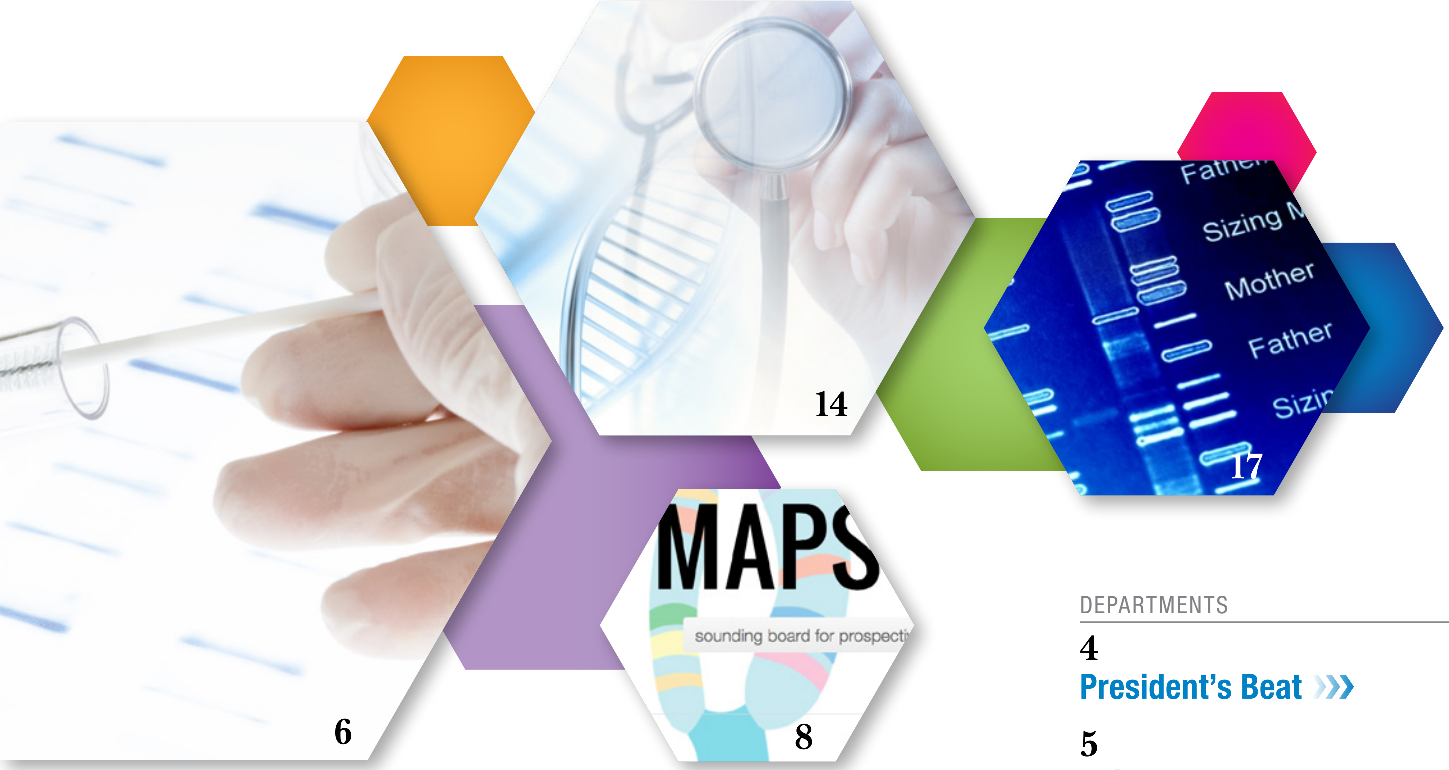

COVER STORY

FEATURE

DEPARTMENTS

Celebrating 35 Years of the NSGC Annual Education Conference History


Jehannine Austin

As genetic counselors, our histories share a common element: our training. While we were driven toward this training by values that we share, our individual career paths have taken us in different directions.

Our Annual Education Conference (AEC) is an opportunity to recharge and reconnect with our professional family, restoring our energy and enthusiasm. This is our chance to connect to our roots, our history and the values that we share, while acknowledging and celebrating our different career paths and evolutions, both as individuals and as a profession. This year, our conference will be even more special — it will be our 35th Annual Conference. The very first NSGC AEC was in 1981 in San Diego, with 182 attendees. Thirty-five years later, we are back on the West Coast and expect more than 2,000 attendees!

We plan to make this year's conference not only our biggest and best yet, but also want to celebrate our profession's history. There are a few ways in which you can get involved.

First, we'd love for you to share your photos from past AECs or a selfie (using one of these downloadable AEC frames, if you like!) on the NSGC Facebook page using the hashtag #nsgc16. Use the comments section to tell us what you are looking forward to this year and why you love attending the AEC. We will be displaying some of these photos during the AEC and on social media. Learn more here. Do you have memories of important events or pivotal moments from past AECs, or from the NSGC's history more broadly? We'd love to hear about them! Please use this survey link to tell us about your recollections. We want to collect narratives of important events or memories of our profession to help document the history of genetic counselors and our AEC. You will see your contributions used throughout the AEC.

REGISTER TODAY

We have come so far in 35 years and we have so much to celebrate. I'd love for you to be in Seattle for our AEC to recharge and celebrate with us. Hope to see you there — register today! ●

National Society of Genetic Counselors

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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.

NSGC Executive Office

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WWW

Connect with the NSGC Community

Embrace the Possibilities

"Possibilities do not add up. They multiply."
— Paul Romer

The 2016 Q3 issue of *Perspectives in Genetic Counseling* is packed with yet another set of genetic counselors who are using their skills in transferrable and interesting ways. Much like the quote from economist and entrepreneur Paul Romer says, these genetic counselors have identified possibilities that led them to success. Learn about your colleagues' involvement in home DNA tests, the promotion of genetic counseling through educational outreach to Health Occupations Students of America and the creation of a blog for prospective genetic counseling students. Listen to the benefits of being a teaching assistant in graduate school in our Student Forum, plus a new graduate's adaption to her position at a research institute. Our Global Genetics column explores a fertility genetic counselor's experience with LGBTQ patients from Israel; our featured genetic counselor publication involves the pediatric cancer subspecialty; and the Book Review column explores a story of learning one's BRCA1 positive status. Learn about the use of healthcare mobile apps from the Health IT SIG, as well as new resources for licensure in the GC Access column. Finally, President Jehannine Austin outlines the compelling reasons to look forward to the NSGC's Annual Education Conference (our 35th!) in the fall.

Genetic counselors have so many possibilities ahead. Enjoy the stories in this issue and please consider sharing your experiences with us in a future article of Perspectives in Genetic Counseling!

Kirsty McWalter, MS, CGC
Certified Genetic Counselor,
GeneDx

CONNECT WITH KIRSTY: ✉ in

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

CONNECT WITH KRISTEN: ✉

PERSPECTIVES
IN GENETIC COUNSELING

GENETIC COUNSELORS AND HOME DNA TESTING IN 2016

BY BRIANNE KIRKPATRICK, MS, LGC

In Jehannine Austin's "5 Hot Genetics Issues to Watch in 2016" blog post, home DNA tests ranked third. Recent headlines, most notably the 2015 FDA-approval of 23andMe's limited carrier screen, have brought the topic of home DNA testing and genetic counseling into the limelight. Many wonder what the National Society of Genetic Counselors (NSGC) is doing to educate genetic counselors and consumers about this topic.

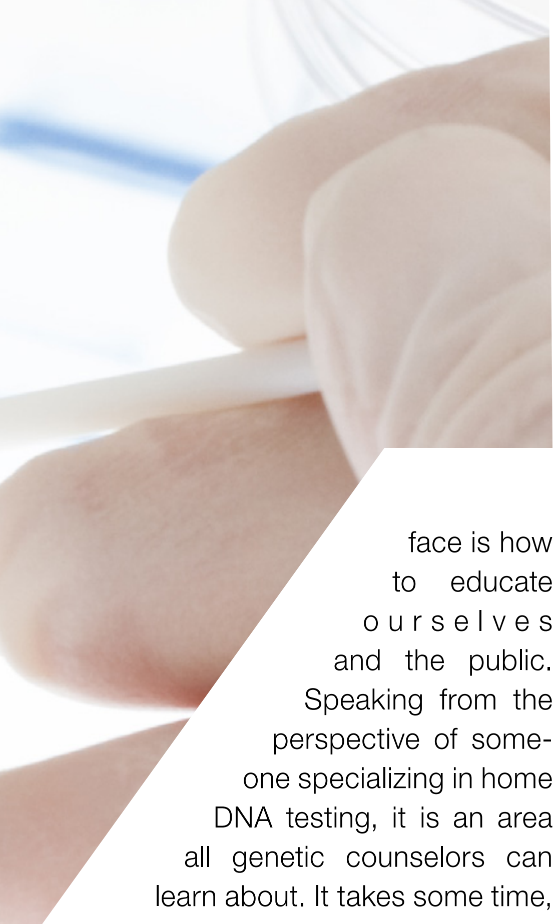
In 2014, the NSGC Public Policy Committee formed a task force to assess the society's position and address the educational needs of consumers considering home DNA testing. Discussions culminated in a revised position statement (see sidebar) and a consumer-friendly article titled "5 Questions to Ask before Ordering an At-Home DNA Test." The article is meant to be shared with individuals who ask about direct access genetic testing. It encourages the reader to seek guidance from a medical genetics professional, such as a certified genetic counselor. NSGC blog posts over the past year have addressed home DNA testing topics, including:

- Jason Flanagan: "Understanding Pharmacogenetics: What Everyone Should Know and Consider"
- Brianne Kirkpatrick: "DNA, Ancestry Testing and You"
- Susan Hahn: "Is Direct-to-Consumer Genetic Testing Right for You?"

These posts are appropriate for the general public, and a common thread is the value genetic counselors can provide to those considering and/or pursuing testing. Dr. Oz The Good Life magazine's article on home DNA tests (June 2016 issue) can be another great resource. It highlights the benefits and limitations of home DNA testing and encourages consumers to consider genetic counseling when contemplating a genetic test.

WHAT CHALLENGES DO WE FACE?

Genetic counseling for a DNA test, whether home- or clinic-based, can't be provided without informed and passionate genetic counselors. One challenge we



face is how to educate ourselves and the public. Speaking from the perspective of someone specializing in home DNA testing, it is an area all genetic counselors can learn about. It takes some time, effort and self-education (one of the identified core skills of genetic counselors!) to become equipped to respond to questions about home DNA testing. The demand exists and we are fortunate to have this opportunity to engage with the wider public and individual consumers who want to learn and understand more about their genetic code.

HOW CAN I LEARN MORE?

A 2014 webinar and a 2015 Annual Education Conference (AEC) workshop addressed ancestry testing, a home DNA test for which over 3 million test kits have been sold. The webinar is freely available and the video-recorded workshop is available for purchase as part of the 2015 AEC online Continuing Education Unit (CEU) package.

NOW WHAT?

What will come next? This depends on you! Will you create a video about home DNA testing and post it to YouTube? Write an article or blog post? Submit a journal manuscript? Investigate which home DNA companies have certifications like CLIA and CAP and post your findings to an NSGC discussion forum? The options are limitless.

If you are interested in home DNA testing and want to be involved in efforts to make genetic counseling services available to the growing consumer base, the PM SIG is a great first stop. Learn more in the "Member Center" section of the NSGC website and consider joining for benefits (discussion forum, grant opportunities and a CEU-earning webinar series). ⬢

Brianne Kirkpatrick, MS, LGC, *founder and president of a private practice called WatershedDNA, provides tele-consulting for ancestry, home DNA testing and raw data analysis. She was the lead of the 2014–15 Direct Access to Genetic Counseling Task Force and continues to lead efforts to prepare genetic counselors for the growth of the home DNA testing market and to educate consumers about the benefits of genetic counseling services. Learn more at www.watershedDNA.com.*

CONNECT WITH BRIANNE: ✉

Comments on the Direct Access to Genetic Testing Position Statement

NSGC Position Statements are drafted by task forces, commented upon by the membership and ratified by the Board of Directors. They are meant to represent the NSGC as a whole, with recognition that there is often a range of beliefs and opinions within the membership. Statements are reviewed every few years and reaffirmed, revised or retired.

The 2015 update to this position statement reflects the NSGC's support of a person's right to access, understand and be empowered by their genetic information. Another focus of the statement is the recognition and assertion that genetic counselors can serve as resources and healthcare allies for these individuals.

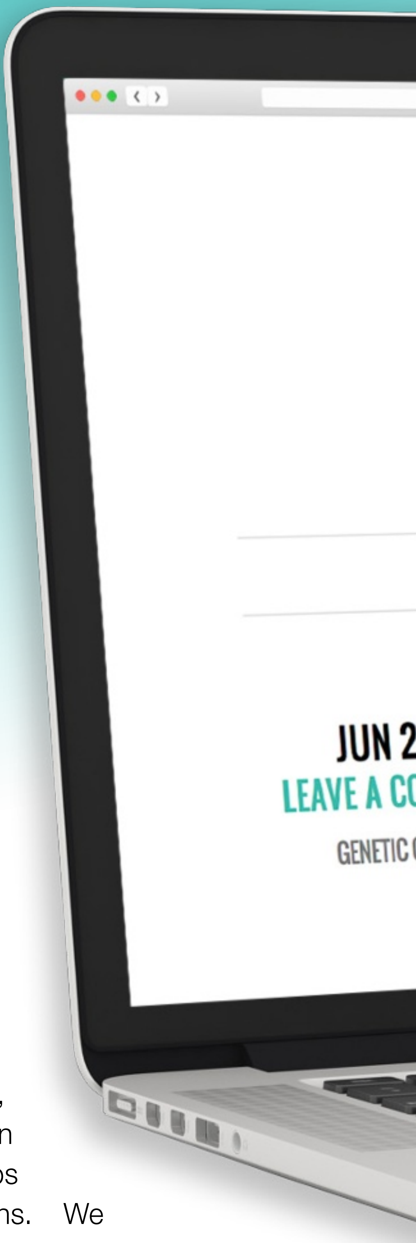
"The National Society of Genetic Counselors believes that people interested in at-home DNA testing — also known as direct-to-consumer (DTC) or online genetic testing — have a right to make an independent, informed decision about whether or not to pursue this form of testing. Companies that offer direct access to genetic testing have a responsibility to offer consumers easy access and/or referrals to appropriate resources and qualified genetics professionals, such as genetic counselors."

Direct Access to Genetic Testing Task Force Members

- Janice Berliner
- Laura Hercher
- Brianne Kirkpatrick
- Elissa Levin
- Melanie Myers
- Karen Powell
- Ilana Solomon
- Jill Stopfer
- Elizabeth Varga

THE IMPETUS AND EVOLUTION OF THE MAPS & GENES BLOG

BY JADE MUKRI MS, CGC, CHES



The Maps & Genes blog, started in 2011, was the result of bouncing a brewing idea off a new friend. I was 23 years old and attending a graduate school interview at the University of South Carolina (USC). During a meet-and-greet for prospective students, I met Olivia Tan. We connected quickly through our shared interest in travel and polymerase chain reactions.

Just two years prior, genetic counseling was unknown to me. I was a lost soul badly wanting to be a scientist without being a “fill in the blank” — doctor, nurse, physician assistant, occupational therapist — these just did not click with me. So, like a typical lost soul, I moved back in with my parents and developed a Google addiction, desperate to carve out a life plan. Internet resources unmasked the profession of genetic counseling. Still, there was not a lot out there in 2009.

During the USC interview, I cornered Olivia and pitched a blog idea for prospective genetic counseling students: “There doesn’t seem to be enough resources for people wanting to enter this career. I think we can help a lot of people. I think this will be fun. Maybe — if we dream really big — the DNA Exchange will feature us on their side panel.”

Olivia, who I met only 16 hours prior, went all in. We created a WordPress account the next week. Ultimately, Olivia attended Sarah Lawrence and I attended USC. This allowed us to share our different worlds of learning on the blog. It was nice to have a side project, a creative outlet and, importantly, a distraction from thesis work. Our readership was meager. If anything, we just posted content that perhaps our classmates would enjoy.

In 2013, we put on our caps and gowns. We had new jobs and new cities requiring our attention, and only 50 email subscribers and a few blog comments. This motivated us to pass the blog on to a new generation of students. Sarah Brandenberger, still an editor today, increased social media presence and included buzzworthy graphics. Our readership increased tremendously. Olivia and I were impressed, but we also noticed less consistency of material and interaction with commenters. This is only natural when a blog

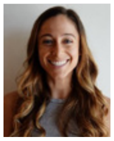
CONFESSIONS OF A TA ((CAMILLE))

With out-of-state tuition costs swimming through my mind, I quickly accepted that what was once just a "busy" semester might now entirely overwhelm me. In addition to the mounting coursework and clinical rotations, I had decided to squeeze a 20-hour per week teaching assistantship into my already overflowing schedule. A small price to pay, I thought, for complete tuition remission and a monthly stipend. However, as the semester wore on, I soon recognized teaching for the university to

> *I feel this — to engender uprising motivation in the field — is one of my greatest achievements as a genetic counselor to date.*

passes through so many hands, but we desired more continuity. Olivia and I are now back as editors. Our modest project has gained traction over the past six years. We feel devoted to this student-centered platform that provides support for a comparatively small-guild profession.

My most fulfilling moment occurred earlier this year. I dug up our old Maps & Genes email account and logged on to clear out junk mail. There was no junk. Over 100 thoughtful, motivated prospective students had emailed us. I emailed everyone back that day and included an apologetic post to address the most common questions. I feel this — to engender uprising motivation in the field — is one of my greatest achievements as a genetic counselor to date. And it all started with a crazy, spontaneous pitch during a graduate school interview. ⬢



Jade Mukri, MS, CGC, CHES, *is a board certified genetic counselor living in Jacksonville, Florida, and currently works as a cardiology report writer for GeneDx. She received her Master of Science in genetic counseling from the University of South Carolina in 2013, and also earned a Bachelor of Science in health education and a Bachelor's in Spanish from the University of Florida in 2009. She is a member of the Florida Alliance of Genetic Counselors as well as a Jacksonville running club. Visit the Maps & Genes blog.*

Reproductive Genetics in Israel's LGBTQ Community

BY EMILY MOUNTS, MS, CGC

My role as director of the genetics program at a fertility clinic recently presented me with the opportunity to visit Tel Aviv, Israel. Many gay Israeli men start their families by traveling to the U.S. to access donor egg and gestational surrogacy programs. During my trip I met with some of the 165 such patients who have recently, or will soon, come to Oregon for this purpose.

Tel Aviv is a modern, global city with a large LGBTQ (Lesbian, Gay, Bisexual, Transgender or Queer) population. Israeli national healthcare pays for heterosexual couples to have in vitro fertilization (IVF). However, it does not pay for, or permit, such treatments for single or gay men wishing to have children via egg donation and surrogacy. Many European and Asian countries similarly prohibit fertility treatments for single individuals and LGBTQ couples. Hence, U.S. surrogacy practices are desirable to many patients. These factors, combined with improved organization and outreach by U.S. clinics, have facilitated a dramatic increase in international LGBTQ patients traveling to the U.S. to start their families. For gay couples who prioritize having their own genetic children, using one egg donor and fertilizing half of the eggs with each man's sperm allows them to have biological half-siblings, either through a twin or sequential singleton pregnancies.

Many gay Israeli men report that coming out was more difficult knowing that having a family would not be easy; Israeli society is highly family-oriented. Those who have children have said this has facilitated family acceptance and support. Customs such as Friday night Shabbat dinner, which I was fortunate to attend at a patient's parents' home while in Tel Aviv, are family- and child-centered. Having previously taken my patient's formal family history during a genetic counseling session, watching a lively but traditional three-generation Jewish pedigree come to life around the dinner table was a highlight of my trip.

The genetic counseling I provide to these men as they start their family-building journeys — including assessing the family histories of the intended parents and egg donors and discussing the benefits and limitations of genetic screening — is a crucial part of the preconception IVF process. Israelis tend to be eager and sophisticated consumers of genetic services. Expanded carrier screening is readily pursued out of interest in interrogating genes not routinely tested by standard Israeli panels. Results are easily digested, likely due to the cultural familiarity with recessive conditions. Family histories tend to be offered with abundant detail and are instantly supplemented via text messages to family members back home. Egg donor profiles are examined with care and scrutiny. Many choose preimplantation genetic screening to reduce the risk of transferring an aneuploid embryo, a particular concern in complex, expensive surrogacy cycles.

I am extraordinarily proud of the work my team has accomplished with the brave LGBTQ populations in the U.S. and abroad. I am equally excited about the potential applications of genetic counseling services to new and eager global populations.

Emily Mounts, MS, CGC, *is a genetic counselor at Oregon Reproductive Medicine (ORM), a globally recognized fertility clinic. She is the Director of ORM Genomics, a program dedicated to the integration of clinical and laboratory genetics into fertility care.*

CONNECT WITH EMILY: ✉ WWW f

Feature Article: Pediatric Cancer Genetics Research

BY SARA SPENCER, MS, CGC

Wolfe Schneider K., Jasperson K. Unique Genetic Counseling Considerations in the Pediatric Oncology Setting. Current Genetic Medicine Reports. 3(2):65-73. 2015.

There are few worse things for a parent than a cancer diagnosis in their child except, of course, if the cancer could have been inherited. In the featured article, genetic counselors Kami Wolfe Schneider and Kory Jasperson provide their perspectives from experience with genetic counseling in pediatric oncology; they consider psychosocial, ethical and medical management issues. According to the 2016 Professional Status Survey, only 90 members of the National Society of Genetic Counselors reported Pediatric Cancer Genetics as their specialty. Schneider and Jasperson publish to offer support and consistency to this small, but intricate, specialty.

Schneider is busy producing manuscripts on pediatric oncology genetics. She co-authored a review article on pediatric cancer genetics with four other genetic counselors; at press time, the manuscript was under review for publication. She has been involved with publishing on genetic counseling in the setting of bone marrow transplantation, as well as researching physician perspectives of testing minors for Li-Fraumeni syndrome. She has also published on the collaborative experience of evaluating genes on next-generation sequencing panels with other cancer genetic counselors. There is no doubt Schneider's research endeavors and the collaborative efforts of pediatric oncology genetic counselors will benefit this specialty.

It is clear that Schneider invests a lot of time in publications. Like many genetic counselors, her position is mostly clinical with a small amount of time allotted for administrative responsibilities, inclusive of research. Schneider finds research very enjoyable. She states, "I value research/publishing and have made it a priority to integrate it into my career. There is something special about publishing that is different from clinical work in that it marks your work in a more measurable way. I find that doing both publications and clinical work makes for a rewarding professional balance." Her experience with publishing began during her graduate training at the University of Cincinnati in 2005, when she was required to produce a thesis in publication manuscript format. Schneider states, "In graduate school, I was glad to be challenged to do a project and I was determined to get it published, which took about four years after graduation to get done, but I did it. Since getting my first publication, the process has been much less intimidating."

Schneider has some words of advice for genetic counselors or new graduates interested in contributing to research in our field. She states, "We are all doing research/publication-worthy work. It may take some extra hours beyond clinic/job hours, but it is worth it. It gets easier the more you do it." ⬢

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National Society of Genetic Counselors. Professional Status Survey, 2016.

Sara Spencer, MS, CGC, *graduated from Sarah Lawrence College in 2006 and was certified by the ABGC in 2007. She was a genetic counselor at Memorial Sloan-Kettering Cancer Center from 2006-2009. She is currently a genetic counselor in the Division of Clinical Genetics at Northwestern Medical Faculty Foundation and serves as a Core Faculty Member for the Northwestern University Graduate Program in Genetic Counseling.*

CONNECT WITH SARA: in

From the Health IT Special Interest Group

Mobile Genetics Apps: Is More Always Better?

BY MEGAN FRONE, MS, CGC; AND WILLONIE MENDONCA, MSC, MS, LGC

Health information technology (IT) provides an opportunity for genetics practices to lower costs, reduce per-patient workloads, reach more patients, increase referrals, and improve quality and coordination of care and more. Mobile applications have great potential to deliver information and services on creative platforms with the literal push of a button. However, there are also important limitations and risks that must be considered. In some studies looking at health apps, only about half were based on scientific validation.[1] Many apps are created without the input of medical professionals or without undergoing analysis for effectiveness.[2] Simply delivering information is often not enough to change behavior, suggesting that apps may need to be supported with additional clinical actions.[3,4] Also, many health apps have incomplete privacy protections. As in other areas of health IT, there continue to be problems integrating information collected by apps with other health IT systems, such as electronic medical records. Finally, with so many health apps available, patients may not know how to choose the best app for their particular needs.

To address these issues, some groups have proposed developing rating systems to help patients, though no system has been widely adopted thus far. In September 2013, the U.S. Food and Drug Administration (FDA) issued guidelines for the oversight of mobile medical apps. While a few lists of healthcare apps are currently maintained by the FDA and the National Health Service, consumers and providers are not always aware of these resources. The Office of the National Coordinator for Health Information Technology (ONC) is a great resource for healthcare providers who are interested in learning more about the secure use of health IT to optimize patient care.

Genetic counselors need to think critically about how health IT is used and how it can be improved. The Health IT SIG will be distributing its annual survey through the National Society of Genetic Counselors discussion forum to evaluate how genetic counselors' health IT use is changing over time. The goals are to establish the meaningful use of health IT within the genetic counseling profession and positively influence the use of health IT for the personalization of care for patients. For more information about the annual survey or implementing health IT into your practice, contact the Health IT SIG co-chairs at megan@cagene.com or wmendonca@genedx.com. ⬢

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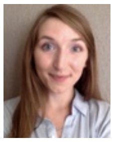


***Megan Frone, MS, CGC**, works as the Genetics Specialist for CancerGene Connect, and is co-chair of the Health IT SIG.*

CONNECT WITH MEGAN: ✉ in

***Willonie Mendonca MSc, MS, LCGC,** currently works at GeneDx Laboratories and is co-chair of the Health IT SIG.*

CONNECT WITH WILLONIE: ✉

Confessions of a TA:

The Benefits of Teaching in Graduate School

BY CAMILLE FISHER, BS

With out-of-state tuition costs swimming through my mind, I quickly accepted that what was initially a busy semester might now entirely overwhelm me. In addition to the mounting coursework and clinical rotations, I decided to squeeze a 20-hour per week teaching assistantship into my already overflowing schedule; a small price to pay for complete tuition remission and a monthly stipend, I thought. However, as the semester wore on, I realized that teaching would be an invaluable part of my graduate education and growth as a genetic counselor. Founded in communicating complex information with finesse and clarity, genetic counseling is a profession that truly relies upon an ability to educate others. Teaching six discussion sections for an introductory zoology course afforded me countless opportunities to hone this essential skill.

First and foremost, teaching requires understanding material well enough to explain it to others. To survive as both a teaching assistant and graduate student, I learned to efficiently gather information on a topic. Distinguishing what is and what is not essential is a critical component of quickly acquiring familiarity with a subject. I have observed genetic counselors do this as they juggle countless patients and side projects. As an individual prone to getting hung up on technical details, learning to focus my efforts and manage my time more efficiently have become indispensable skills.

While working with students, I also found a platform to exercise my core counseling abilities. As with patients, students have variable learning styles and differences in understanding. To be an effective educator, it is important to first assess how a student may approach the material. By discerning an individual's current level of understanding, I can operate within their frame of reference. This is a skill that directly applies to working with patients and families. Ultimately, teaching has afforded me frequent opportunities to practice effective communication and refine my counseling techniques. This has resulted in greater confidence in my abilities and permitted me to dive into patient interactions with less hesitation.

Additionally, working as a teaching assistant allowed me to practice my presentation skills almost daily. An asset in any profession, public speaking and presenter skills are best maintained through consistent use. Class and case presentations are no longer quite so nerve-wracking with teaching as a part of my weekly routine. Undoubtedly, these skills will continue to serve me as a practicing genetic counselor.

What I once thought would overwhelm me has become instrumental to my training and provided endless opportunities for counseling and professional skill building. Without the flexibility and support provided by my training program, a teaching assistantship might not have been possible. It is with great appreciation for the professional and financial benefits that I look forward to teaching again next semester. ⬢

Camille Fisher, BS, *is a second-year genetic counseling student at the University of Wisconsin in Madison. Originally from Texas, Camille completed her Bachelor of Science in human biology from the University of Texas at Austin. Camille is joining the Perspectives team as the column editor for Student Forum (since she has so much free time in her schedule!)*

CONNECT WITH CAMILLE: ✉

HEALTH OCCUPATIONS STUDENTS OF AMERICA

A VENUE TO PROMOTE GENETIC COUNSELING

BY LAUREN BEAR, MS, LCGC; AND GAYUN CHAN-SMUTKO, MS, LCGC

With the rising demand for genetic counselors, connecting with future healthcare professionals about our ever-growing field is exceedingly important. Genetic counselors join the profession from various disciplines and at different times in their professional lives, so many never had early exposure to our field. We are both genetic counselors at the Center for Cancer Risk Assessment at Massachusetts General Hospital and are interested in sharing our profession with a new generation of local students. To this end, we connected with organizers of our local Massachusetts (MA) chapter of the Health Occupations Students of America (HOSA). HOSA is an international student organization whose mission is to "promote career opportunities in the healthcare industry and to enhance the delivery of healthcare to all people," according to the organization's website. Members of HOSA represent a motivated group of students (mainly high school and post-secondary/collegiate) with a special interest in careers in the healthcare industry.

In April, we attended the 2016 MassAHEC (Massachusetts Area Health Education Center) HOSA State Leadership Conference, held at the University of Massachusetts Medical School in Worcester, MA. This annual event featured seminars, activities, hands-on stations in medicine and research, competitions across healthcare/scientific disciplines, as well as speed networking with healthcare professionals. By participating in the networking event, we met with many motivated high school and college students to promote the rapidly growing field of genetic counseling. We discussed the graduate school application process, training programs, genetic counseling specialties and a day in the life of a genetic counselor.

> *This was a targeted effort to increase the visibility of the profession and if we helped inspire even one future genetic counselor, then we feel that our mission was a success!*

The students had poignant questions and showed a keen interest in the field. Many had not heard of genetic counseling before, but they were not shy in asking questions to develop a better understanding. This was a targeted effort to increase the visibility of the profession and if we helped inspire even one future genetic counselor, then we feel that our mission was a success!

Through this event, we also met educators interested in learning more about the professional applications of the genetics they teach in their classrooms. We discussed future collaborations for in-person visits to the educators' schools to meet with more students. Hopefully these relationships will allow us to continue to connect with the next group of budding healthcare professionals and share information about our growing and versatile field.

Students involved in HOSA are focused, intelligent and motivated. With a chapter in every state, HOSA is a resource that we encourage other genetic counselors to investigate. We can increase the visibility of our profession and help inspire the next generation of genetic counselors. Locate your local HOSA chapter at www.hosa.org. ⬢

Lauren Bear, MS, LCGC, *joined the Center for Cancer Risk Assessment (CCRA) at Massachusetts General Hospital after earning her master's degree from the Genetic Counseling Program at Brandeis University in 2014. As part of the CCRA, she provides risk assessment and genetic counseling services in the Breast/Ovarian and GI Cancer Genetics clinics. Her research interests include familial myelodysplastic syndromes and acute myeloid leukemia.*

CONNECT WITH LAUREN:

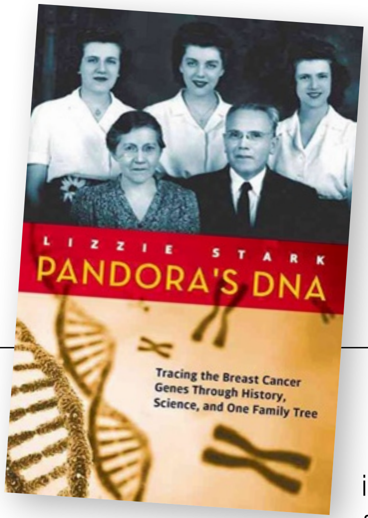
Gayun Chan-Smutko, MS, LCGC*, earned her master's degree from the Genetic Counseling Program at Brandeis University and joined the CCRA at Massachusetts General Hospital in 2002. She provides educational outreach and genetic counseling services in various clinical settings including the Familial Renal Cell Carcinoma and von Hippel-Lindau (VHL) disease program. She has co-authored the VHL Handbook: Kid's Edition, a publication of the VHL Alliance. Her interests include the hereditary basis of renal cell carcinoma and associated syndromes; psychosocial care of young adults with tumor/cancer predisposition; and genetic counselor training and education. She is the assistant director of the Genetic Counseling Program at Brandeis University.*

CONNECT WITH GAYUN:

Pandora's DNA:
Tracing the Breast Cancer Genes Through History, Science, and One Family Tree

REVIEWED BY CARLEIGH ROBERTSON, BSC, MSC

Author: Stark, L.
Publisher: Chicago Review Press, Chicago, IL (2014)
Pages: 336 pages
Retail Price: $19.56
ISBN-10 : 1613748602

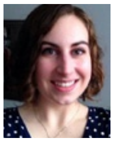


The decision to remove healthy breasts and ovaries is not a choice that an otherwise healthy woman in her late 20s typically has to make. In "Pandora's DNA: Tracing the Breast Cancer Genes Through History, Science, and One Family Tree," author Lizzie Stark is faced with this very dilemma. Stark carries a BRCA1 mutation, a daunting legacy passed through her maternal ancestors that has shaped the lives of women in her family. With grace, wit and passion, Stark recounts her family's experience with cancer while detailing the history of the BRCA1 and BRCA2 gene discovery, breakthroughs in the diagnosis and treatment of breast and ovarian cancer, advancements in genetic testing, and the ethical, legal and cultural impact of these mutations.

"Pandora's DNA" clearly explains medical terminology and statistics, making it well-suited for a general audience. Stark's journey is emotional at times but the author describes her experience with humor and clarity. She skillfully chronicles her despair following her positive genetic test results, the ambiguity and ethical concerns of genetic medicine, and her hope for the future despite the genetic hand she has been dealt.

A reporter by trade, Stark consulted a wide variety of sources to explore the landmark 2013 lawsuit against Myriad Genetics and its patents on the BRCA genes, including Joy Larsen Haidle, immediate past president of the National Society of Genetic Counselors. The author also drew from several authorities, such as Siddhartha Mukherjee (author of "The Emperor of All Maladies"), and strove to provide a balanced and accurate representation of the biology of cancer, as well as the evolution of the legal and societal events that have shaped cancer management. She also reveals the personal stories of other women affected by hereditary breast and ovarian cancer and explores risk reduction strategies and the difficult trade-offs that are closely intertwined with cultural ideas of femininity and one's identity as a woman.

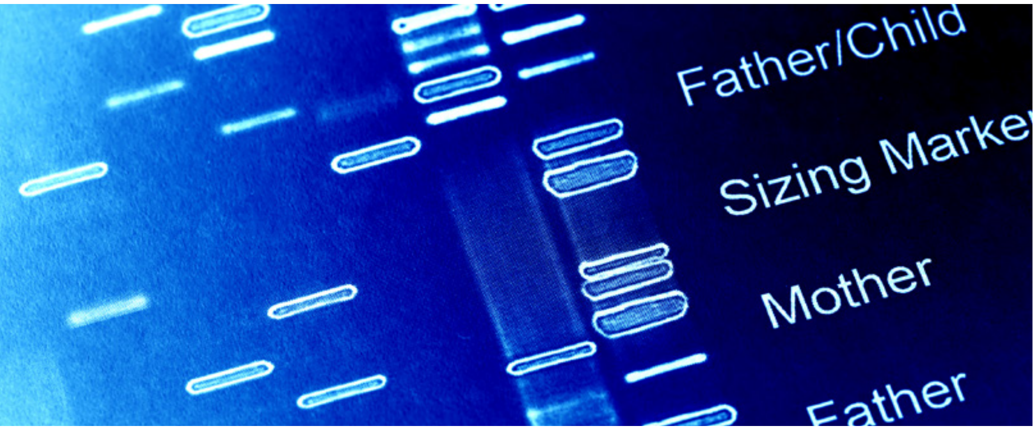
"Pandora's DNA" provides a glimpse into the experience of carrying a cancer-predisposing genetic mutation. As such, it is a valuable tool for those who work with these families. The book offers an intimate, honest and compassionate look at the emotional impact of genetic testing, the onerous task of regular cancer screening and the difficult decision to undergo prophylactic surgery. Though the science may be old hat to genetics professionals, "Pandora's DNA" is relevant and worthwhile reading for genetic counselors and general readers alike.



Carleigh Robertson, BSc, MSc, *is a second-year genetic counseling student at McGill University in Montreal, Quebec, Canada.*

Genetic Counseling Skills:
Not Just for Patients

BY WHITLEY KELLEY, MS, CGC



While in graduate school, I occasionally wondered if genetic counseling was the right career choice for me. Would I be able to find a job? What if I didn't like it? What if I burned out right away? After working for a year at the HudsonAlpha Institute for Biotechnology, I am comforted and encouraged to realize that, as a genetic counselor, my two biggest assets are a deep knowledge of genetics and a strong set of communication skills — assets that will continue to increase in value in a variety of settings.

Our profession is a small, fairly homogenous field that requires extremely specialized training. We seem to fill a specific niche in the career landscape. Many people (even in healthcare) still don't know what we do or who we are. Each of us, at least once, has had to give the 20-minute discourse to a new acquaintance to explain our job title. However, when you consider two basic components, knowledge of genetics and the communication skills to explain it, suddenly our role becomes more broadly applicable.

Working in the education department of a research institute isn't exactly like spending my days counseling patients. Although I do a fair amount of patient education and counseling through research studies and an affiliated genomic medicine clinic, I also spend time educating healthcare providers, teachers, students and the general public. Initially, the prospect of such a wide range of audiences intimidated me. As it turns out, what these audiences need is not so different from what our patients need: thorough, accessible genetic information explained in a way that is relevant and makes sense.

This work isn't done in isolation. At HudsonAlpha, I have opportunities to work closely with educators, scientists, bioinformaticians, and marketing and legal teams to ensure that the education provided is of the highest quality. Similar to the insight that is shared among different members of a multidisciplinary clinical team, my own team of multidisciplinary professionals strengthens me as a genetic counselor by providing a broader perspective of the end goals we have in mind. As a new graduate, this has been especially empowering because my colleagues are just as eager to learn from my knowledge and experiences as I am to understand theirs.

As genetic medicine continues to transform healthcare, genetic counselors can expect to have roles that expand beyond the scope of what many of us were exposed to during our training. The value of our critical skills will allow opportunities for our impact to extend even further beyond individual patient care and relationships. ⬢

Whitley Kelley, MS, CGC, *received her Master of Science in Genetic Counseling from the University of Alabama at Birmingham in 2015. She works on pediatric genomics research projects and at the Clinic for Genomic Medicine at the HudsonAlpha Bioinformatics Institute.*

GC Access: New Resources for Licensure

BY ASHELEY SUPIK, MS, CGC; DAWN ALLAIN, MS, CGC; AND JOHN RICHARDSON

The Access and Service Delivery Committee is responsible for monitoring and making recommendations for 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 Colleen Campbell (colleen-campbell@uiowa.edu) and/or Sara Gilvary (sgilvary@sarahlwarence.edu).

The Licensure Access and Service Delivery Subcommittee is charged with providing continuous education to National Society of Genetic Counselors (NSGC) members, legislators and key stakeholders regarding state licensure for genetic counselors. The subcommittee's primary role is to administer NSGC state licensure grants on a semiannual basis. These grants support state licensure efforts in a variety of ways and range from small awards (less than $500) that can help with traveling to key meetings or creating and printing supporting documents, to larger awards ($7,000-$15,000) that support state-based lobbyists. Any NSGC member in good standing is eligible to apply for grant funds. Members seeking licensure support need to provide a clear plan for how awarded funds would move their state's licensure effort.

The number of states that have obtained licensure continues to grow. As of June 1, 2016, 22 states have passed laws; 19 of these states are issuing licenses and many other states have active efforts.

John Richardson, the NSGC's Director of Policy and Government Relations, with the support of the Licensure Subcommittee, brings the collective knowledge of past successful efforts to members pursuing licensure. Obtaining licensure is unique to each state; through close communication with Richardson and the subcommittee, states can gain valuable insight into how others have managed similar challenges.

For further support, the Licensure Subcommittee has redesigned the NSGC's Licensure webpage. As part of this redesign, the subcommittee created several resource templates to help states develop their own materials.

The Licensure Subcommittee members hope that you will visit the new Licensure section of the website and invite you to contact John (jrichardson@nsgc.org) with any licensure-related questions. The subcommittee will open the first grant cycle for 2017 in the fall of 2016. Look for an announcement later this year.

***Asheley Supik, MS, CGC**, is a cancer genetic counselor with InformedDNA. Asheley has been involved in licensure efforts in Virginia where she led the successful effort to enact a licensure law and nationally as the current chair of the NSGC Licensure Subcommittee.*

***Dawn Allain, MS, CGC**, is an associate professor in The Ohio State University's (OSU) Department of Internal Medicine and is director of OSU's Genetic Counseling Graduate Program. She has more than 20 years of clinical expertise, currently providing adult medical genetic services. She was also one of the genetic counselors who led Ohio's successful licensure efforts and OSU's credentialing efforts.*

CONNECT WITH DAWN:

***John Richardson** is the director of Policy and Government Relations at the NSGC. He has been involved in state and federal genetic counselor licensure efforts.*

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