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“Prospectives” in Genetic Counseling

“Perspectives in Genetic Counseling” for prospective genetic counseling students

Welcome!

We at the Student/New Member Special Interest Group are so excited you are thinking about a career in genetic counseling. We are here for you throughout your journey. Inside this newsletter, you'll learn about new genetic technologies - direct-to-consumer genetic testing - read a story highlighting the intense emotions experienced in a genetic counseling session; and hear about the day-to-day life of a real genetic counselor. We hope you will find this information helpful! Please keep your eye out for more resources to help you organize your applications and decide which program(s) are the best fit for you!



Tia Moscarello, MS & Erin Syverson, MS
Prospective Students Task Force Leaders 2016

Direct-to-Consumer Genetic Testing

With the recent explosion of efficient, cost-effective genetic technology and consumer-driven healthcare, individual genetic information is now more accessible than ever. These developments have laid the foundation for the emergence of direct-to-consumer (DTC) genetic testing. A number of commercial laboratories, including 23andMe and deCODE Genetics, are

offering tests which analyze thousands of genetic markers to provide information about disease risk, physical and behavioral traits, and ancestry. These tests can be performed without a physician's order, and the results are typically sent directly to the consumer. In 2013, the U.S. Food and Drug Administration

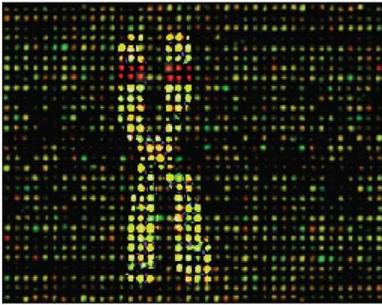
ordered several DTC genetic testing companies to discontinue providing information regarding disease risk on their test results; however, this information continues to be readily available through third-party services that provide interpretation of the raw data reports. 23andMe

has since received FDA approval to include information regarding disease carrier status on their reports.

DTC genetic testing has been hotly debated within the genetic counseling community and the healthcare community at-large. Proponents of DTC genetic testing argue that individuals have a right to their own genetic information, and

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DTC companies use SNP arrays to look at certain nucleotides in a customer's genome and compare the results with reports of their associations with disease.

Photo from
<http://www.genengnews.com>

“This increased access to genetic information is not without its drawbacks.”

that DTC genetic testing can 1) motivate individuals to adopt health-promoting behavior and 2) increase access to genetic testing for individuals who may not

have a readily available healthcare provider to order such testing. This increased access to genetic information is not without its drawbacks. Many of the disease-associated markers analyzed through DTC genetic testing confer only a small increased disease risk or their cumulative role in disease may be unclear. The interpretation of these complex results will be left to the consumers' physicians (or even of the consumers themselves), many of whom do not have the genetic expertise to properly interpret them. This has the potential to lead to inappropriate risk assessment and unnecessary screening or preventive procedures.

“...the key to unlocking this potential is the interpretation of these genetic testing results by qualified genetics professionals, such as genetic counselors.”

DTC genetic testing has the potential to be an immensely powerful healthcare tool, but the key to unlocking this potential is the interpretation of these genetic testing results by qualified genetics professionals, such as genetic counselors. Genetic counselors are skilled at using their expert knowledge of genetics, scientific literature, and genetic risk assessment to help patients and their families understand their DTC genetic testing results, and use this information to make informed decisions about their healthcare. Genetic counselors can bring this expertise to DTC genetic testing companies in the role of a laboratory counselor, helping to develop useful tests and interpret test results. Genetic counselors can also aid physicians and patients in interpreting their DTC genetic testing results in a variety of clinical settings. Genetic counselors will continue to be an integral part of the growing DTC genetic testing

market, ensuring that consumers and healthcare providers understand the implications of DTC test results in health.

A High-Anxiety Appointment

By Lauren
Puryear

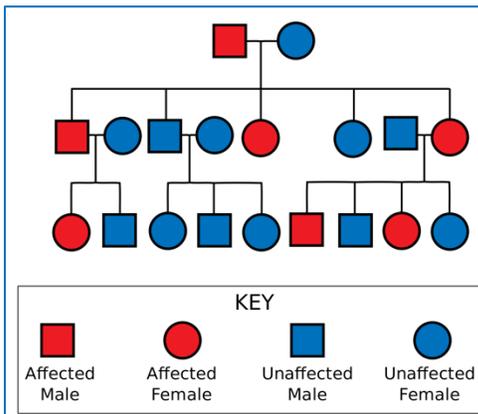


Genetic
Counselor at
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Medical Center

I saw a family to talk about testing the 15-year-old daughter “Jessie” for a familial cancer syndrome identified in her mom. The referral form said “daughter has high anxiety about this upcoming visit” so I knew it might be an emotional appointment. When the family arrived I greeted them and asked how they were doing. Jessie started to cry. I took a deep breath, passed tissues around, and made an empathetic comment about how much the family had been through. I let her sit and compose herself instead of jumping in to ask questions.

When Jessie had calmed down a bit I asked her what she was most worried about. She said she was worried about her mom being okay. I

explained that part of my job was to give her some information about how we take care of someone and her shoulders went down about two inches as she said yes. I told her that my goal was to help her leave the appointment feeling much less anxious than when she came in.



About 10-15% of cancer is hereditary, meaning that there is a genetic reason for the cancers clustering in a family. This family history (pedigree) is typical of many hereditary cancer syndromes and shows an autosomal dominant inheritance pattern.

Photo: commons.wikimedia.org

As we talked, Jessie relaxed more and asked questions. When we talked about testing and the possibility of Jessie having a hereditary cancer syndrome, she said that knowing for sure would be much better for her than not knowing. Now that she understood the screening and preventive guidelines, she felt like testing would be empowering. Before the family left to get Jessie’s blood drawn, I asked her if she was feeling

less anxious. “Yes!” she said with a big sigh, “so much better.” When patients don’t have much information they often imagine the worst. Part of our job can be to provide a reality check and help them let go of their unnecessary anxiety.

GC Spotlight: Shelby Rosomer, MS, CGC

Shelby shares her day-to-day life as a new genetic counselor and how she got her start.

A “DAY IN THE LIFE”



Shelby Rosomer, MS, CGC shares what it's like to be a pediatric genetic counselor at a major medical center

As I approach my one-year anniversary of graduating and starting my first job as a general genetic counselor in the Department of Pediatrics, Division of Medical Genetics at the University of Iowa, I am happy to reflect and share my typical "day in the life as a general/pediatric genetic counselor" at a large university medical center. I typically see between 20-30 patients per month both in the pediatric specialty clinic at the University of Iowa Hospitals and Clinics and at various outreach clinics across the state of Iowa. Therefore, I also consider myself to be an "outreach genetic counselor". In a typical month, I may have 2-3 clinics at the University of Iowa Hospital and one outreach clinic per month. Typically, I see 12 patients at outreach clinics and 5-6 patients at half-day clinics at the hospital. I will travel between 1 hour and 3 hours to various outreach sites across the state in order to see a very full day of patients, which can make for very long days, but I actually enjoy those days the most because I get to counsel patients all day long. When I'm not in clinic seeing patients, I spend most of my days at my desk doing a variety of care coordination, prepping and follow-up tasks. This may include calling patients with test results, writing patient letters, coordinating blood/DNA specimens to send for testing, working on insurance prior-authorization for genetic testing, calling patients to complete telephone intakes prior to their appointment, and gathering resources, articles and counseling aids for my upcoming patients. As a general genetic counselor, I have learned that my role is not only to educate and provide support to the families and patients I see, but to help coordinate their often complex medical

care. This includes trying to refer them to various specialty providers, arranging echocardiograms or renal ultrasounds locally for them, or following up on overdue labs or previous recommendations. I often feel that I am the patients "go-to" resource for all care related to their genetic diagnosis. The days that I spend at my desk are often filled with patients calling with questions or concerns or just to touch base and give me an update on how they are doing. I love being the trusted point of contact for these patients and enjoy the opportunity to build rapport and relationships with patients and their families.

Typical work-up for a general genetics patient includes reviewing their medical records and pulling out the most important information and past labs/imaging studies. I then call every patient before clinic to review their medical, family and social histories. I document these intakes as progress clinic notes in our electronic medical system. I then meet with the geneticist and review our differential diagnosis, plan and recommendations for the patient. I then gather educational summaries, resources and counseling aids to use in clinic. I see every patient alongside the geneticist who will complete the physical exam and make their recommendations for the patient prior to my education and counseling. For patients that have known diagnoses, known family histories or receive a genetic diagnosis when genetic test results come back, I will see by myself for "genetic counseling only visits." After clinics, my follow-up tasks usually include placing orders for labs/imaging studies, requesting prior-authorization for genetic tests, re-drawing pedigrees, completing clinic note documentation, and tracking each patient's pending recommendations or orders.

As for meetings, every Wednesday morning we have a division-wide journal club meeting where everyone in the division takes turns presenting a

recent research article to review and discuss with the group, and we have division case conferences every Friday where challenging, unique or rare patient cases are presented either to spark discussion about possible differential diagnoses or to educate others on a particular genetic condition. In addition, I attend genetic counselor meetings every other week with the other general genetic counselors in the division and monthly hospital-wide genetic counselor meetings with the prenatal, cancer, neurology and cardiology counselors in the hospital.

What I love most about being a general genetic counselor is the very wide variety of patients that I get to see and counsel and the rare, unique, interesting and challenging diagnoses that I learn about daily. What I love most about my particular job at the University of Iowa Hospital, Division of Medical Genetics is the support, experience and expertise that my colleagues provide. I get to share an office space with three other genetic counselors, work right across the hall from four medical geneticists and our cytogenetics lab director and have all the support systems I need surrounding me. As a brand new genetic counselor, I have learned so much from my colleagues' experience and expertise and value their constant support and help in all aspects of my daily work.

I am also actively involved in NSGC by volunteering within the Student/New Member SIG prospective student task force and outreach task force. I enjoy meeting with prospective genetic counseling students at my work as well as volunteering to provide educational presentations about medical genetics to local high school and junior high students.

After work, I often find myself making supper with my husband, going for long runs (I recently finished my second half-marathon), working on house projects and of course dedicating my Monday nights to watching the Bachelor/Bachelorette as I am a huge fan! In my first year of working as a new genetic counselor, I passed my boards, got married, moved to a new home, had my research published, and became a first-time aunt to my precious baby nephew. I have realized the importance of establishing a work/life balance early in my career and setting up habits and daily routines to prevent long-term work or emotional burnout. Most importantly, throughout my first year of working as genetic counselor I have gained tremendous confidence in my genetic counseling skills and have enjoyed trying out and establishing my own genetic counseling style. I love that my days are always challenging, exciting, unpredictable and rewarding. I am never bored.

ABOUT SHELBY

Shelby is from rural southeastern Iowa. She graduated from Wartburg College in Waverly, Iowa with a bachelor's degree in Biology and a minor in Psychology. As an undergraduate, Shelby volunteered as a certified crisis counselor at a domestic violence and homeless shelter, was as a Special Olympics team leader, campus peer counselor, and completed a research project that sequenced mutations in a gene of interest in fruit flies. Shelby also spent her summers working with families affected by cleft lip/palate and other craniofacial anomalies while working as a research assistant at the University of Iowa. She gained exposure to genetic counseling through job shadowing a variety of genetic counselors in Iowa and Wisconsin and attending Northwestern University's summer internship in genetic counseling. Shelby graduated with her Master's degree in Medical Genetics from the University of Wisconsin Genetic Counselor Training Program in 2015 and is currently working as a pediatric genetic counselor at the University of Iowa Hospitals and Clinics.

Want to learn more about genetic counseling?

If you want to learn more about the genetic counseling profession and application process, there are so many resources out there!

SOME OF OUR FAVORITES...

NSGC: Explore a Career as a Genetic Counselor

<http://nsgc.org/p/cm/ld/fid=44#masters>

Master Genetic Counselor Series: Tape-recordings of genetic counseling sessions!

<http://nsgc.org/p/cm/ld/fid=248>

List of schools with accredited genetic counseling programs

<http://gceducation.org/Pages/Accredited-Programs.aspx>

Become A Genetic Counselor: the ins and outs of who genetic counselors are and how to become one

<http://www.becomeageneticcounselor.org>

The DNA Exchange: a blog about newsworthy genetics stories, written by genetic counselors

<https://thednaexchange.com>

Journal of Genetic Counseling: peruse our peer-reviewed journal!

<http://www.springer.com/biomed/human+genetics/journal/10897>

Stay tuned for a comprehensive list of all ACGC-accredited programs and their application deadlines curated by the Prospective Student Task Force (out Fall 2016): <http://nsgc.org/p/cm/ld/fid=248>



Krista Grosse, MS, CGC shows us a typical prenatal genetic counseling session.