

The PAGC  
Newsletter is  
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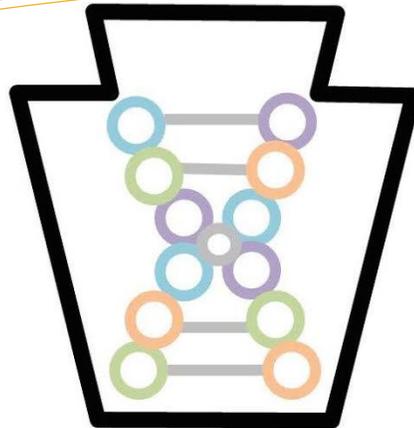
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## Featured Genetic Counselor: Tara Schmidlen

Anyone who attended the 2019 National Society of Genetic Counselors Annual Conference may have gotten to know Tara. She is the well-deserving recipient of the NSGC Strategic Leader Award and has been active within NSGC for several years. We thought it would be interesting to get to know a bit more about this ambitious genetic counselor.

Tara was originally drawn to the field of genetic counseling during her undergraduate training at Penn State because of the intersection of her favorite subjects; genetics and psychology. "Like many GCs, I loved the science of genetics but also the complex and rewarding interactions with people that counseling offered," said Tara. She learned about the genetic counseling profession from an adjunct professor (Kathy Peters) who was a genetic counselor. Tara describes this as her "light bulb moment," knowing that she found the correct career path. Tara went on to earn her Masters in Genetic Counseling from Arcadia University (now Upenn) and graduated 2006.

When asked about a pivotal occurrence that opened a career opportunity, Tara described what, at the time, she felt was a major setback, but turned out to be the career change she needed. "I had worked with external collaborators for several months on an R01 grant proposal that we were

excited to submit," said Tara. "At the 11<sup>th</sup> hour, my employer withdrew their support (our IT resources and my time) for the submission." Tara explained that this resulted in a scramble to find another institution to fill the IT void in the proposal and her dropping from Co-Investigator to a consultant role. Devastated and, "frankly, angry," Tara admits, that her efforts to bring in funding were not supported. The following Monday, fortuitously Tara received a recruitment email from Geisinger. She responded to Andy Faucett with interest and shared her cover letter and CV. The rest, as they say, is history! "After talking with him, I realized that to go further in my career I needed mentors and support that I didn't have but that Geisinger had in abundance," shared Tara.

Tara is now employed by Geisinger as a research genetic counselor providing genetic counseling for adult onset complex disease through the MyCode Community Health Initiative and through a traditional cancer genetics clinic. As a research counselor, Tara develops and executes research protocols, writes patient and provider educational materials, abstracts and manuscripts, and contributes to applications for grant funding. Her personal research interests involve the development of alternative genetic counseling service delivery models, especially those that

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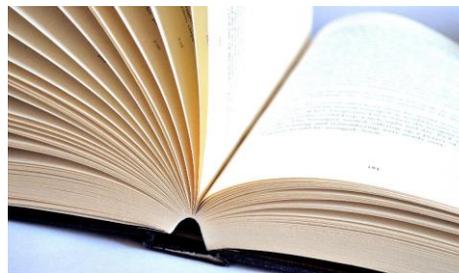
*Amy Biery Kunz, MS, LCGC*



This Fall the PAGC sponsored an essay contest for students from a genetic counseling graduate program in Pennsylvania. Students were asked to select from two prompts to explore how the popularity of genetic testing is impacting the practice of genetic counseling. The PAGC awarded first

## The PAGC Student Essay Contest

place to Brooke Meader, Class of 2021 at Thomas Jefferson University, who won a student membership to NSGC/PAGC and a \$500 travel scholarship to put towards an upcoming genetics meeting. Two Honorable Mentions were awarded a student membership to NSGC/PAGC. Honorable Mentions were given to Kennedy Richardson, Class of 2020 from Thomas Jefferson University, and to Casey Ryan, Class of 2020 from Thomas Jefferson University. Congratulations to all the award winners for their thoughtful responses to the essay prompts and thank you to all the students who participated in the contest. The essay from our first place winner is featured in this newsletter on pages 3 & 4.



Dani Shapiro, the author of "Inheritance: A Memoir of Genealogy, Paternity, and Love", experienced the unexpected result of non-paternity when she submitted her DNA for genealogy analysis. What started out as an endeavor motivated by curiosity turned into a search for identity and for uncovering long-buried family secrets. It is a remarkable story in that the author finds answers to almost all of her questions about her biological heritage, but the answers to "How did this happen?" and

## Inheritance: A Memoir of Genealogy, Paternity, and Love by Dani Shapiro

"Did my parents know?" are more elusive once she discovers she was conceived through fertility treatments. The writing is honest and relatable, although, at times, the author becomes a bit melodramatic as she describes her journey towards realizing that genetics are not the only basis for defining family and the love for her father. Any genetic counselor who has discussed an unexpected result with a patient or has helped a patient struggling with identity of self after a genetic diagnosis will be engrossed in this story. It touches on the part of us that hopes our expertise and our compassion are enough to see the patient through to finding acceptance and peace.

Book review by Susan Walther, MS, LCGC

## Student Essay Contest Winner

### Direct-To-Consumer Genetic Testing Increasing in Popularity

-By Brooke Meader

Direct-to-consumer (DTC) genetic testing has seen increased popularity over recent years. This change has sparked various discussions surrounding the best practices for DTC testing and its impact on society. One of the biggest concerns with this type of testing is what happens to patient data. Many DTC companies sell or share the genetic data of their subjects with outside sources, which can impact participating groups differently. The effect of these practices on the patients, medical researchers, and law enforcement varies drastically. testing. From 2004 till 2010 I was a member of the Human Genetics faculty at Emory University, splitting my time between Emory and the CDC. At Emory I launched one of the first online patient registries with genetic information and worked on moving rare disease testing

The biggest issue considered with patients and their DTC genetic data is their safety. And safety here has many meanings. Acquiring DTC testing is beneficial for patients because it gives them autonomy with their health information and doesn't require seeing a clinician who may or may not advise them on testing. Being able to order the test directly to their home and obtain the results online or over the phone adds convenience to

an already independent task. Many of these tests can be cost effective for patients who want the information but may not be able to see medical professionals. Another benefit is the knowledge that is obtain by patients, it can make them feel empowered and more aware of their health status or family ancestry. While the benefits to patients are clear, there may be unseen limitations or harm to patients who undergo this testing. Studies have found that patients can experience adverse psychological outcomes when this testing is not mediated by a clinician (Hendricks-Sturup & Lu 2019). From a genetic counseling standpoint, imagining patients receiving genetic results with little to no explanation or counseling is concerning and likely to cause unnecessary anxiety within the patient population. Another controversy regarding patients and DTC genetic data is the consent process and how patients can just click through online claiming they understand without reading the fine print. Hendricks-Sturup and Lu (2019) point out that the company Ancestry issues warnings that DNA information may be used against you or a genetic relative. Whether or not patients truly read that and understand the potential consequences with the sharing of their data with law enforcement agencies is unknown. It also brings up the rights of the relatives to have potential consequences for testing that they didn't consent to. These are conversations that need to keep happening in order to continue protecting patients and their health information.

Another group that can see the benefits and limitations of DTC genetic testing is medical researchers. Coming from a research background it is easy to understand how gaining access to thousands of patient samples is beneficial to many avenues of research. Obtaining large, well-documented cohorts of patients where one can categorize subjects by different traits, backgrounds, or genetic information is advantageous and convenient for researchers. The availability of the data is a clear benefit of data sharing with DTC companies and medical research facilities. While it can be quick and easy to access these patients' data, a limitation for medical researchers is that they can not be positive that everything input by the patients is accurate. They run the risk of using incorrect information and therefore making wrongful conclusions. Another limitation is whether the data is freely shared, or researchers need to purchase the data. Depending on the cost of obtaining that amount of genetic data, this could be a limitation for researchers.

Lastly, and likely most interesting from a societal view, is the data sharing relationship between law enforcement agencies and DTC companies. It has been highly publicized that law enforcement agencies are using data shared from DTC companies to solve active and cold cases through genealogy. Using this strategy to catch dangerous criminals is beneficial to society but



## EYE ON IT

### PAGC Membership

Remember to renew both your NSGC membership and your PAGC membership for 2020. Being a current member of NSGC is required to be eligible to hold a full PAGC membership.

Enjoy the benefits of being a member of PAGC, including discounted registration fees for the annual Spring conference, access to our quarterly newsletter, and more! Scroll to the bottom of this [website page](#) to renew today!

New members welcome!

calls into question where law enforcement should draw the line. Kennett (2019) discusses the public opinion on using genetic data to solve violent versus non-violent crimes. While many people find using genealogy to solve violent crimes and missing person cases is okay but not non-violent crimes. This public opinion stems from concerns for privacy and a need for regulation (Kennett 2019). Another issue is that

*continued on page 4*

*Tara Schmidlen cont. from p. 1*

leverage the use of technology to facilitate communication with patients. Many of us may have heard about her work with chatbots during presentations at national genetics meetings. Tara has been focusing on developing and testing novel chatbot tools to facilitate research consent, cascade testing and patient follow up.

Over the course of her career, Tara said that she has seen a tremendous evolution in the opportunities for genetic counselors. Like many GCs with several years experience under their belt, when Tara first discovered the field, most GCs were in clinical practice primarily in cancer, prenatal and pediatrics. A few “rogue” individuals worked in labs/industry. “Now,” Tara said, “there are so many diverse ways that GCs are applying their unique skill set in many more clinical settings (cardio, neuro, ophthalmology), in research, in labs, in technology companies, working in insurance, public policy, patient advocacy, education, etc. I tell all my student mentees that this is the best field because you can change careers without needing to go back to school!”

Tara had some “what I wish I knew then” advice for our recent genetic counseling graduates. Mainly, she wishes that she would have gotten involved with extracurriculars like NSGC and PAGC earlier in her career as she feels these experiences help keep you grounded and connected to the “big picture” of why we became GCs and where we are trying to go and grow.

Tara pointed out that she has learned so much through volunteering on various committees. Undoubtedly, it affords an individual the opportunity to meet many amazing and talented genetic counseling colleagues. Tara said that it also allowed her to view the genetic counseling profession from a broader perspective. For example, she shared that it’s important to understand, “why what we do (and don’t do) matters, and what we need to do moving forward to help better illustrate our impact and value to our healthcare colleagues and payors.” Tara feels strongly that the exposure she has received through volunteering with different societies has helped clarify her research goals and solidify her commitment to mentoring aspiring GCs to carry the torch.

Mentoring is another important aspect of a professional’s growth and Tara expressed that she regrets not signing up for the NSGC mentoring program sooner. “Everyone can benefit from having a mentor—not just at transition points like deciding to go to graduate school, changing careers, etc.,” shared Tara. You can meet mentors through a professional society and volunteerism, or through your work place. It’s a good reminder, as we continue to grow the amount of genetic counseling graduates entering the field each year, that experienced genetic counselors can play an important and impactful role by providing mentorship and opportunities for professional development.

*Student Essay Contest Winner cont. p.3*



Brooke Meader  
Class of 2021 at  
Thomas Jefferson  
University

mistakes can be made tracing suspects with common last names. While law enforcement tries their best to find valid potential suspects, using these DTC company genealogy databases runs the risk of leading them astray. Data sharing of genetic information to aid in police work is a benefit to law enforcement but regulations need to be in place so that patient data is not being abused.

Educating patients on the use of their genetic data is a critical aspect of being a genetic counselor. It cannot be assumed or expected that patients have a working knowledge of the complications, consequences, or outcomes of adding their genetic data to a large consortium like a DTC company. It is important to discuss all of the possibilities with patients regarding data sharing and their privacy, especially when it has the potential to cause them harm like with law enforcement. From an ethics view it should also be stressed to the patient the affect this testing may have on their family members. Moving forward it will be important to educate ourselves on the practices of large DTC companies to be better able to inform our patients.

There are many groups who can possibly be affected by data sharing or selling from DTC genetic testing companies. Genetic testing costs have decreased significantly over the years and made genetic testing more accessible to consumers. This increase in genetic testing and data tracking has benefits and limitations for everyone involved. It is important to continue learning and updating the best practices for DTC companies and genetic counselors in order to observe maximum benefits for the patients.

References:

- 1.Hendricks-Sturup RM, Lu CY. 2019. Direct-to-Consumer Genetic Testing Data Privacy: Key Concerns and Recommendations Based on Consumer Perspectives. J Pers Med. doi:10.3390/jpm9020025
- 2.Kennett D. 2019. Using genetic genealogy databases in missing persons cases and to develop suspect leads in violent crimes. Forensic Sci Int. 301: 107-117. doi:10.1016/j.forsciint.2019.05.016.

## Upcoming Events

- **PAGC 2020 Annual Meeting**
  - March 12-13, 2020 at Allegheny General Hospital, Magovern Conference Center in Pittsburgh PA
    - [Register here](#) until 2/21/20
- **Familial Hypersholesterolemia Community Day**
  - April 25, 2020 at Geisinger Medical Center Henry Hood Center for Health Research in Danville PA
  - Genetic counselors, physicians, pharmacists and patients/families welcome. *CEU application has been submitted to NSGC for 0.5 CEUs*
    - [Register here](#)
- **2020 ACMG Annual Clinical Genetics Meeting**
  - March 17-21, 2020 at Henry B. Gonzalez Convention Center in San Antonio TX
    - [Register here](#)

## Professional Development and Continuing Education

## Presidential Address by Margaret Harr

Happy New Year and welcome to a new decade! As we turned over a new year and welcomed new faces to our executive board we took the opportunity to reflect on the mission statement and strategic initiatives set forth by our founding members.

As I look back on the establishment and early years of the PAGC I am reminded of the phases of an organization's life cycle. First came **Ideating**, an idea of an organization to promote professionals within our state was conceived largely driven by a desire to revise and amend the scope of practice as defined by our licensure bill. Next came **Concepting**, the mission of the PAGC was born, to promote genetics education, foster professional development, encourage communication and alliances, and facilitate access to genetic services. And to complete the phases of establishment came **Committing**; the early executive board and committee leads have demonstrated unwavering commitment to our mission. The PAGC annual education conference embodies this commitment and highlights the many hardworking individuals in our state who live this mission every day. With these establishment phases now under our belt I am thrilled to be part of our transition into the next phases of development, **Validating and Scaling**. We have proven our commitment to ourselves and our membership, it is now time to validate that commitment by extending beyond our internal membership and bringing the mission of the PAGC to our patients, students, interdisciplinary colleagues, third-party payers, and legislatures. In order to accomplish this work we will need to continue growing by nourishing our membership, building new leaders, promoting our profession, and extending our reach. It is an exciting time to be part of the PAGC!

Throughout this process of reflection I was struck by the accomplishments of a relatively small number of hardworking individuals and inspired by my fellow genetic counselors! At our January 2020 executive board meeting we embraced the spirit of the new year and each member formulated thoughtful goals for themselves, for our PAGC executive board, and for the future of our organization. During the coming weeks we will be using these goals and the data gathered from the PAGC professional status survey to develop the 2020-2021 strategic plan. Therefore, I urge to you to please take 15 minutes out of your day to complete the survey and share it with your PA friends, colleagues, classmates, and alumni.



" I look forward to seeing the results of the status survey and sharing updates from our strategic planning with you at the annual meeting. See you in Pittsburgh!"

-Margaret Harr

Continue to p. 6 to learn about the PAGC Professional Status Survey.

## Attention Program Directors and Researchers

Are you or do you know a genetic counseling graduate student or researcher from Pennsylvania looking to recruit participants for a research project being conducted in Pennsylvania? The PAGC is now accepting research postings to be included in our quarterly newsletters. Please email [PAGCmembership@gmail.com](mailto:PAGCmembership@gmail.com) if you have a project to advertise in an upcoming edition.

## Research Recruitment

Student contact: Carlee Grubbs – [cmg033@jefferson.edu](mailto:cmg033@jefferson.edu)

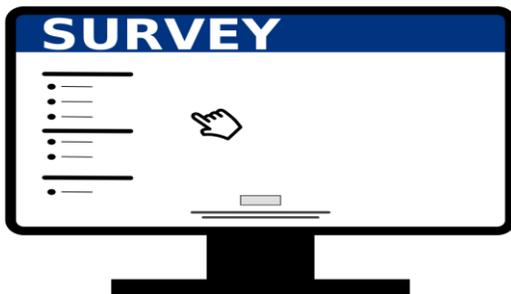
GC Program: Thomas Jefferson University

Advisors: Zohra Ali-Khan Catts, Rachael Brandt, Barbara Bernhardt

Project title: Referrals to Mental Health Professional by Genetic Counselors

Project summary: You are invited to participate in a research study regarding genetic counselors' referrals to mental health professionals. The overall purpose of this study is to determine the current practices and opinions of genetic counselors surrounding the referral process including indications, barriers, and overall readiness. This study has been approved by the IRB of Jefferson University. All board eligible/certified genetic counselors with current or past experience in the clinical setting are eligible to participate. Specifically, individuals who have previously referred patient(s) to a secondary mental health resource are encouraged to complete the survey. The survey takes approximately 10 minutes to complete with the option to enter to win an Amazon Fire Stick.

Survey link: <https://forms.gle/Z7WRy2EGsP8JPWcS9>



## The 2020 PAGC Professional Status Survey (PSS) is now live!

We are asking all constituents of Pennsylvania, regardless of PAGC membership, to take the time to complete the survey. Your input is valuable to future PAGC endeavors! Please visit the link below to access the survey.

<https://www.surveymonkey.com/r/PAGC2020PSS>

We also encourage you to share the survey with your PA friends, colleagues, classmates and alumni!

Thank you for your contribution!

*The PAGC Genetic Services Committee and Executive Board*