SEPTEMBER 2021

Official Newsletter of the Pennsylvania
Association of Genetic Counselors

PAGC News

The PAGC
Newsletter is brought
to you by members of
the PAGC Membership

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If you have anything that you would like to share including upcoming events, seminars, an exciting new career role, etc, please contact us at:
PAGCmembership@gmail.com

PAGC Mailing Address: 2021 Arch Street Philadelphia, PA 19103

PAGC Website: www.pennsylvaniagc.org

NEW LOGO!

Thank you to Scott Goehringer for designing our new PAGC logo

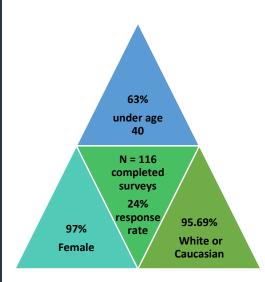


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PAGC-Initiated Professional Status Survey

The PAGC Genetic Services Committee collected data from genetic counselors practicing within the state of Pennsylvania. The following summary is only a highlight of the data, and not an extensive representation of the PA-PSS report. For further details and information not highlighted, the complete report can be found HERE on the PAGC website.

Demographic Highlights:



Data Highlights:

Category	Criteria	% of Respondents
Experience	12 or fewer years' experience	62%
Certification and Licensure	CGC credentialed	78%
Certification and Licensure	Licensed in Pennsylvania	74%
Professional Activities	Lecturing	86%
Professional Activities	Supervise GC students	62%
Professional Activities	Role in Research	50%
Salary	\$70,000-\$89,999 annually	50%
Raises	Most recent raise occurred 2019	90%
Assistance	Genetic Counseling Assistants (GCA)	50%
Work Environment	Clinical GC in Academic/Private Hospital	62%
Areas of Practice	Cancer genetics	38%
Areas of Practice	Pediatric genetics	32%
Service Delivery	Video conferencing	77%
Service Delivery	Phone calls	48%
Billing and Reimbursement	Counselors billing for services	45%
Billing and Reimbursement	Telemedicine counselors billing for services	52%
Licensure	Positive impact on service reimbursement	17%

PAGC EXECUTIVE BOARD MEMBERS

President & Chair:

Margaret Harr, MS, CGC

Vice President:

Juliann McConnell, MS, CGC

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Megan Marshall, MS, CGC

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Jess Goehringer, MS, CGC

East Regional Rep: Tanya Bardakjian, MS, CGC

West Regional Rep: Amy Kunz, MS, CGC

She Has Her Mother's Laugh: The Powers, Perversions, and Potential of Heredity

By Carl Zimmer

Review by Emily Lancaster, MS, CGC



Carl Zimmer, award winning author and writer for the New York Times, starts off his book describing the time he and his then pregnant wife met with a genetic counselor in 2001 to discuss their risk of having a child with a genetic condition. Initially the couple didn't see the value in talking with a genetic counselor, especially as Mr. Zimmer had written about genes for his work and considered himself well versed in the field, and by the end of the visit realized how much more there is to consider about our genetic makeup. From there, Mr. Zimmer weaves a long but easy to understand and engaging story about the history of human heredity and what it means to pass on our genes, starting from the very beginning when life was a single celled organism, to the near future when technologies including CRISPR and gene therapy have the potential to bring great progress but also great ethical dilemmas. While some of the content will be familiar for a genetic counselor, this book offers an interesting perspective on where the study of genetics has come from and where we might go moving forward.

Featured Genetic Counselor: Hannah Campbell

Genetic Counseling Program: JHU/NIH

Year of graduation: 2020

Current Employer: Fox Chase Cancer Center



What attracted you to pursue a career in genetic counseling?

When I was in high school, I received a significant medical diagnosis and unfortunately did not feel like my providers took time to understand how I was coping. When I heard about genetic counseling, I was drawn to the idea that I could be involved in supporting someone through a new diagnosis. I feel that my personal experience helps me take a more empathetic approach to my practice. It has been very empowering to feel like I can advocate for people managing a medical diagnosis. As a genetic counselor I feel that I have unique training to be able to engage clients in conversations about mental health and coping strategies.

What are your responsibilities in your current position?

As a cancer genetic counselor, the majority of my time is spent speaking to individuals and families at risk for hereditary cancer. I assess their risk based on personal and family history, and guide clients through the genetic testing process. I work at an academic center, so I'm also encouraged to be involved in research and other side projects. At the moment, I am involved in two projects. I am part of a group of genetic counselors who identify as having a disability or chronic health condition. We are advocating for increased awareness and equitable treatment in the genetic counseling profession. I am also, along with a few Fox Chase clinicians, working to establish better resources for our trans clients who are navigating both gender-affirming care and a genetic risk for cancer.

How has COVID-19 affected your job responsibilities (e.g. increasing/decreasing number of patients being seen; scheduling procedures or evaluations; facilitating genetic testing)?

I began my job right after stay at home orders were placed. This meant my first few months of work were entirely virtual and it took me longer to get settled in my new job. The most challenging aspect of working during COVID has been the constant changes to safety recommendations and workflow. It has required our office to be extremely flexible when switching back and forth between virtual and in person work.

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Featured Genetic Counselor: Hannah Campbell

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How have you seen opportunities for genetic counselors evolve during the course of your career? Is there a pivotal occurrence that opened a career opportunity for you?

My career has just begun, but I do believe that the move towards virtual options for both genetic counseling appointments and professional meetings has been a positive result of the pandemic. Not only does telemedicine allow clients to more easily attend their appointments, it also allows genetic counselors to have more flexibility in their work. For example, I have several colleagues with disabilities who described being able to attend the NSGC conference for the first time in years since it was broadcasted virtually.

What "I wish I knew then what I know now" advice would you give to recent GC grads?

One of the hardest parts of starting my career as a new GC was feeling like I needed to do my job perfectly right away. There is always a learning curve at a new job, and even experienced counselors make mistakes. Letting go some of this perfectionism actually allowed me to be a better counselor since I was able to free up mental space to be present with my clients. If you don't know the answer to a client's question, it's okay to say, "I don't know, I'll look into that for you". Most clients care more about someone listening to their concerns and making a genuine effort to help.

PAGC Membership

PAGC was formed to promote genetics education, foster professional development, encourage communication and facilitate access to services in the state of Pennsylvania. Professional membership, participation in conferences and webinars, and volunteer support are crucial to our success!

If you purchased a membership through the new PAGC website, your membership for PAGC will automatically renew for 2022. Remember to renew your NSGC membership. Being a current member of NSGC is required to be eligible to hold a full PAGC membership. You can check your account and subscriptions in the Membership tab on the PAGC website: https://www.pennsylvaniagc.org

Enjoy the benefits of being a member of PAGC, including discounted registration fees for the annual Spring conference, access to the newsletter, and committee opportunities for professional development.

Questions regarding membership and account set-up can be sent to PAGCmembership@gmail.com



PAGC JEDI Working Group – Information and Updates

In January of 2021 PAGC leadership called for the establishment of an ad-hoc committee to create an action plan for improving justice, equity, diversity, and inclusion (JEDI) in the genetic counseling field in the state of Pennsylvania. The PAGC JEDI Working Group was formed with the goal of using 2021 to create this action plan, which will include a framework for a permanent JEDI committee in PAGC. The main arms of the working group were created; Outreach and Mentorship led by Aaron Baldwin MS, LCGC and Education and Research led by Kelsey Bohnert MS, LCGC and Natasha Berman MS, LCGC. In addition, we will be looking to identify resources so that initiatives have the financial backing they may require. At the end of 2021 our working group will submit the comprehensive PAGC JEDI action plan to the Executive Board with the hope of laying a pathway for systemic change. -Anna Raper MS, LCGC and Amanda Back MS, LCGC; Co-Chairs for the PAGC JEDI Working Group

The Education and Research Committee (ERC)

focuses on JEDI efforts within academia. From the interview process through student and professional research, the ERC will be collaborating with genetic counseling programs across Pennsylvania to support more inclusive interview practices, create resources for programs to implement in their curriculum, and incentivize research of JEDI topics at the graduate and professional level. Our first step has been to speak directly with program leadership in each of the PA GC training programs to gain an understanding of their current best practices in integrating JEDI tenets into their interviewing process and curriculum and determine what supports and resources would be most helpful for curriculum enhancement. Following this needs assessment, we plan to create tangible resources for students, current genetic counselors, and site supervisors to assist in JEDI efforts. – Kelsey Bohnert MS, LCGC and Natasha Berman MS, LCGC; Directors of JEDI Education and Research

The Mentorship and Outreach arm of the PAGC JEDI group aims to connect with current and prospective genetic counselors from underserved and ethnic minority backgrounds while exemplifying a model for success for outside states and regions. The group has discussed outreach concepts, including creation of a universal resource for prospective genetic counselors, containing information on admissions requirements and experience opportunities for graduate application. We are also looking forward to getting our "boots on the ground" by scheduling lunchtime and genetic counseling awareness events to connect with middle school, high school and college aged students from underserved and minority communities. -Aaron Baldwin MS, LCGC; Director of JEDI Outreach and Mentorship

Interested in getting involved? Please send an email to Amanda (amanda.back@Jefferson.edu)





As of August 24, 2021, the decision was made to hold the **annual NSGC conference as a fully virtual format**. The initial decision was based on surging cases of COVID-19 and a decrease in the number of registrations due to infection risk and travel restrictions from employers. This decision was fortuitous with the recent damage caused by Hurricane Ida to New Orleans and surrounding areas. The dates of the conference remain the same – September 22-26 – with access to all conference sessions, and opportunities to network with colleagues and to view product demos with industry exhibitors.

Featured Genetic Counseling Student: Frank Swann IV University of Pittsburgh Genetic Counseling Program





What was your major as an undergraduate? Psychology

What attracted you to pursue a career in genetic counseling? I have a background in counseling and psychological research, and I have always taken a humanist approach to learning about and engaging with those around me. However, I wondered if there was a career that would allow me to combine this commitment to patient-centered practice with a latent passion for genetics. Genetic counseling was that answer and, after several shadowing experiences, I was more determined than ever to make a career change towards the field. This was a career in which I could work to elevate and empower patients to direct their own clinical care through education (another of my joys - teaching) in the field of genetics, a fast-growing and exciting medical specialty. I only wish that I had known about genetic counseling sooner, because I hadn't learned about it until my mid-20s. One of my future goals is to help educate and inform high school students and teens about careers in genetic counseling, particularly those living in Black and Latinx communities.

What field of genetic counseling are you most interested in post-graduation? Currently, I am most interested in prenatal genetic counseling because I really consider it an honor to work with expecting patients. I find it especially rewarding to confront the great psychosocial demands that parents often face in an atypical perinatal experience. I value the trust that patients put in genetic counselors to guide them through such a vulnerable time.

What has been the most valuable aspect of your training so far? I cannot underscore enough the importance of mentorship that is patient, thought-provoking, and reassuring because those qualities have given me the confidence to both take on more clinical responsibilities and try new styles of counseling. Clinical supervision is vital to student growth, and gains are much more efficient when it is clear that supervisors are invested in your development.

Please provide a brief description of your thesis project. I am part of a research team that has been working with communities in both the Independent Nation of Samoa and American Samoa, and we are conduct a survey to identify gaps in genetic literacy, attitudes regarding return of results, and perceived benefits and risks of participating in genetic research. The goal is to determine if there are differences among Samoan adults who have been engaged with the research team long term, the general Samoan public, and Samoan adults living in the United States. We will be working very closely with local stakeholders, village leaders, and the Samoan Ministry of Health to help guide the use of this information. One of the big concerns that I have is equitable access to genetic services. I strongly believe that part of bringing all communities to the table means having some discussion about how communities feel about genetics, what they expect experiences with genetic services to look like, and how experts in the field can listen to those voices and appropriately accommodate them.



PAGC Committees

Volunteers are always welcome!

Contact committee chair if you are interested in being involved

Education

Chairs:

Natalie Carter (ncarter@guardanthealth.com)

Dana Farengo Clark (dana.farengoclark@pennmedicine.upenn.edu)

- Plan annual Spring meeting
- Plan CEU-eligible webinars throughout the year





Professional Issues

Interim Chair:

Tanya Bardakjian (tanya.bardakjian@pennmedicine.upenn.edu)

- Updating GC licensure in PA
- Examine barriers to credentialing of GCs in PA
- Develop education on process & benefits of credentialing

Genetic Services

Chair: Kallyn Stumm (kallyn.stumm@gmail.com)



- Implemented Professional Status Survey for PA GCs and analyzed results (see PAGC website)
- Continue to evaluate GC services in PA



Membership

Chair: Susan Walther (susanwalther1203@gmail.com)

- Implemented new website design and maintain content
- Manage e-blast communications
- Create PAGC newsletter

Diversity, Equity & Inclusion Working Group (currently, an ad hoc committee)

Chairs: Anna Raper and Amanda Back (Amanda.back@jefferson.edu)

- Develop framework for initiatives to improve DEI in the PA GC community
- Diversify "best practices" for GCs as they relate to minority patient populations
- Develop education on DEI issues

