ISSUE
11
SEPTEMBER
2022

Official Newsletter
of the Pennsylvania
Association of
Genetic Counselors

PAGC News

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

Susan Walther, MS, CGC

Kelsey Bohnert, MS, CGC

Emily Lancaster, MS, CGC

Amy Kunz, MS, CGC

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

PAGC ANNUAL CONFERENCE
SAVE THE DATE
SEE PAGE 6

WELCOME TO OUR NEW PAGC TREASURER: ALYSON EVANS

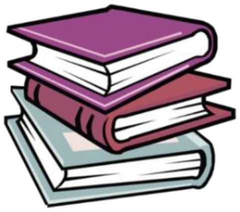
We are pleased to announce that Alyson Evans has been elected as the new PAGC Treasurer for the two-year term of January 1, 2023 to December 31, 2024. She will work with our current, and outgoing, Treasurer Jessica Goehringer to transition into her position on the Executive Board. Thank you to our members who voted in this election. We are excited to have Alyson join our organization in this valuable role, and we sincerely thank Jessica for her financial acumen!

Every Vote Counts!

The General Election in Pennsylvania will be on Tuesday, November 8. This year there are two important state-wide positions on the ballot – PA Governor and U.S. Senator. Please take the time to make sure you are registered (deadline is Oct. 24) and to review the political agendas of each candidate. This year in particular, there are many policy stances that are important to understand, as several stances could significantly affect how genetic counselors are able to practice in Pennsylvania when providing information to guide our patients' decision-making. Please don't underestimate the power of your vote at all levels of government. The last day to request a mail-in or absentee ballot is Nov. 1.

Prism: Shedding Light on Life with Duchenne

By David K.



Book Review by Emily Lancaster, MS, CGC

David K. provides a first-hand account of his lived experiences having a diagnosis of Duchenne muscular dystrophy. This memoir does not set out to educate about his condition, which genetic counselors are already quite familiar with, so it's refreshing to have David share candidly about what it's like for him to navigate his life and independence instead of focusing on the details of his diagnosis. While the book does describe his childhood and teenage years, the main focus is his time away at college. While attending a muscular dystrophy camp, David learned about the Roberts program, at what he dubs 'Generic Midwest University', which is a residential hall that has adaptive dorms and personal assistants that help allow someone with a physical disability to live on campus. While at school, David goes on to have many of the typical college experiences - attending class, having his first kiss, and partying with friends - all while learning to independently manage his care and medical needs. In his memoir, David shares his personal experiences and allows us a chance to see the whole picture and not just one side of living with a disability.

Biohacked: Family Secrets

Podcast Review by Amy Biery Kunz, MS, CGC

BioHacked is a podcast series that shares the stories of people whose lives have been transformed by the intersection of medicine and technology, and the ethical, scientific, and political issues surrounding those intersections. The first season explored the industry of assisted reproduction and fertility clinics, with some stories directly relating to the field of genetic counseling.

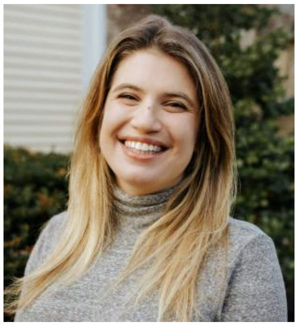
Episode 6 described the story of a donor-conceived child who was initially born healthy, but in childhood she was diagnosed with autosomal dominant polycystic kidney disease (PKD). When the parents contacted California Cryobank to ask about their daughter's donor, the sperm bank declined to share any information citing the agreement with the donor for guaranteed anonymity, including name, contact information, AND health information.

The family sued the cryobank, arguing that the right to medical information superseded the donor's right to privacy. The court initially sided with California Cryobank, but the judgement was overturned years later. The records were unsealed, and it was discovered that the sperm bank *did* know about the donor's personal and family history of PKD, but did not disclose the diagnosis to their customers. They actually went so far as to provide families with falsified medical records to hide the truth, possibly because he was a popular donor with selling more than 300 of his sperm samples to families. However, because there were no laws regulating this industry at the time, there were no criminal consequences for the sperm bank. Issues surrounding medical malpractice, negligence, and wrongful life complicated the outcomes for this family.

Episode 9 took a dive into the world of donor-conceived activism. These individuals are pushing for changes to the baby business that entitle them to the identity and health information of their donor parents. This is a controversial position given that personal health information is protected, even in situations that could pose risk to family members (as we genetic counselors are aware). As a genetic counselor working in the area of hereditary cancer, I have witnessed firsthand the barriers that family members face when it comes to accessing the health information of their relatives, leading to complicated grey areas created by these health protections.

The emergence of direct-to-consumer testing resulted in substantial unintended consequences in the fertility industry as well, and several episodes of the podcast are dedicated to this revolution in scientific technology. In all, this series allows the listener to hear new perspectives from the donor-conceived, and the evolving business of making babies.

Featured Genetic Counselor: **Lily Hoffman-Andrews**



Genetic Counseling Program: Stanford University
Year of graduation: 2018

Current Employer: Penn Center for Inherited Cardiovascular Disease

What attracted you to pursue a career in genetic counseling?
I was a biology major in college and loved the intellectual aspects of it, but still didn't know quite what I wanted to do when I graduated. I spent my twenties working a few different jobs, but during that time was also dealing with a serious illness in my family. A few of the health care providers we met through that process made such a difference in our lives during some very dark times, and it crystallized for me that I wanted to be able to do the same. When I learned about genetic counseling, I was especially drawn to the role we play in tough conversations and difficult decisions.

What are your responsibilities in your current position?
I work as a clinical genetic counselor as part of a multidisciplinary team that cares for patients with a personal or family history of inherited cardiac disorders, or who have lost a family member to sudden cardiac death. I see patients both as part of joint visits with our MDs and NPs and independently for genetic counseling-only visits. I also contribute to research projects and participate in the Penn Genetic Counseling graduate program as a clinical supervisor, lecturer, and thesis committee member.

How has COVID-19 affected your job responsibilities?
Our patient volume dropped briefly at the start of the pandemic when our in-person visits were put on hold, but has rebounded with a vengeance! The biggest change has been that we are now able to see a lot more patients via telehealth, which has definitely increased access and uptake of genetic counseling.

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?
I haven't been practicing for that long, but even just in that time, it's been fascinating to watch colleagues start to work in settings and specialties that I did not even know existed when I was a student. For example, one of my graduate school classmates now works for a sperm bank – fascinating! A pivotal event for me was having a cardiogenetics rotation as my final clinical placement in graduate school. I hadn't even considered working in the specialty previously, but I'm so glad I kept an open mind! The passion for cardiogenetics I developed in that placement, and the connections I made there, led to my current job.

What "I wish I knew then what I know now" advice would you give to recent GC grads?
Good colleagues and a healthy work-life balance are the difference between burning out and staying happy in your work. (I lucked out in this respect!) And, if you can, take some time off and do some traveling or relaxing before you start your first job – vacation is a scarce resource once you're employed!

HOT TOPIC: Developing video education materials for the return of genomic test results to parents and adolescents

Publication Summary by Michaela Idleburg, MS, CGC

Given the increase in genomic research participation, time for face-to-face return of results is becoming less available, and researchers are turning to other methods of education about results. The goal of this study was to describe the development of an audiovisual tool made to provide information about genomic testing and the return of genomic results to adolescents and parents.

The data collection phase of this study ranges over five years, using focus groups and interviews with adolescents and young adults ages 13-25, and parents or legal guardians. The audiovisual tool went through various phases, including development, implementation, and revision phases. Participant input for each phase on items such as timing and topics of interest resulted in changes to the video before it was presented in the next phase.

Audiovisual tools are an effective means to provide information to adolescents and parents in genomic research-based settings and should be created with input from the intended audience of use. This study suggests that genomic education videos should be brief (<4 mins) to improve the odds that participants will view the entirety of any required video. It should be noted that uncertainty and anxiety around participant decisions was ongoing despite information viewed in the optional videos confirming participant choices. This uncertainty may be an underlying factor in divided views on content of the required video and should be further studied along with potential relationships to comprehension of information provided, trust in research information, and comfort with decisions made.

Citation
John A. Lynch, Michaela J. Idleburg, Melinda Butsch Kovaciccde, Kristin E. Childers-Buschle, Kevin R. Dufendachc, Ellen A. Lipstein, Michelle L. McGowan, Melanie F. Myers, Cynthia A. Prows. Developing video education materials for the return of genomic test results to parents and adolescents. PEC Innovation, Volume 1, 2022, 100051, ISSN 2772-6282, https://doi.org/10.1016/j.pecinn.2022.100051

Bev's Gift: Scholarship Opportunity

For the second year, PAGC is privileged to offer the Beverly Tenenholz Memorial Scholarship (Bev's Gift). Scholarships are intended for individuals who require financial assistance with costs related to professional development activities. For additional information, please visit the PAGC website at: https://www.pennsylvaniagc.org/ and click the link under "News and Announcements" labeled "Bev's Gift". Funds are provided for conference/CEU fees, travel for conferences, certification fees, textbooks for students, and other professional development expenses.

<<< GC Licensure Renewal Due December 31, 2022 >>>

The licensure bill for genetic counselors in Pennsylvania was signed into law on December 22, 2011 by Governor Tom Corbett. The law requires individuals practicing as genetic counselors in Pennsylvania to renew their license every two years. Renewal applications typically open 30-60 days prior to the expiration date.

Everything you need to know about applying for a first-time license and the renewal requirements can be found on the PAGC website at https://www.pennsylvaniagc.org/licensure

Key Requirements to Remember for Renewal:

- 30 hours of Continuing Education Needed (no distinction between Category 1 and Category 2); CEUs earned between Jan. 1, 2021 and Dec. 31, 2022.
- Complete 2-hour course on recognizing and reporting child abuse (enter your name in the course to exactly match how it is listed on your license)
- Carry liability insurance

Initial license application fee is $50 / Renewal fee is $75

Key Provisions of Licensure Bill:

- Provide oversight of genetic counselors in Pennsylvania by the State Board of Medicine
- Define the title, Genetic Counselor
- Describe persons who may provide genetic counseling as part of their scope of practice or training without holding a genetic counseling license
- Define qualifications needed to apply for a license to practice as a Genetic Counselor in Pennsylvania
- Define the parameters under which an applicant may qualify for a provisional license (e.g. active candidate for the American Board of Genetic Counseling certification exam)
- Describe the requirements for continuing education to maintain a license

PAGC
Pennsylvania Association of Genetic Counselors

MEMBERSHIP STATS

PAGC has grown our membership to 99 Full Members, 5 Associate Members, and 30 Student Members. Thank you for your ongoing support in growing our organization!

Please note: PAGC operates under the umbrella of NSGC for our non-profit status. Due to NSGC bylaws, PAGC memberships must renew each calendar year and be in effect from January to December.

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

Check out the "Find A Genetic Counselor" feature on the PennsylvaniaGC.org website! The feature now includes a Google map of genetic service locations. Let the Membership Committee know if a clinical site needs to be added or information updated.

PAGC Committees

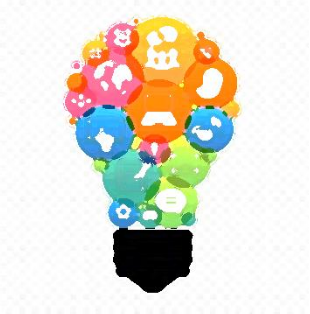
Volunteers are always welcome!

Contact committee chair if you are interested in being involved

Education

Chairs:
Amanda Back (backa@chop.edu))
Shannon Terek (terks1@chop.edu)

SAVE THE DATES: Annual Conference on March 2-3, 2023 at Geisinger Health Center (Danville) with Virtual Option



Professional Issues

Chair: Becky Sullenberger (becpitt30@gmail.com)

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

Genetic Services

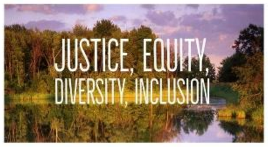
Chair: Kallyn Stumm (kallyn.stumm@gmail.com)

- Working on 2022 Pennsylvania Professional Status Survey for mid-Fall
- Evaluate GC services in PA

Membership

Chair: Susan Walther (susanwalther1203@gmail.com)

- Implement website design and maintain content
- Manage e-blast communications
- Develop content for PAGC newsletter



Justice, Equity, Diversity and Inclusion

Chairs: Kelsey Bohnert (kelsey.bohnert@chp.edu) and
Aaron Baldwin (aaron.baldwin@pennmedicine.upenn.edu)

For the remainder of 2022, this committee will be working on creating a recorded webinar series that will be available for CEU credit, as well as partnering with high school and genetic counseling programs to increase high school students' exposure to the field of genetic counseling. We will be hosting an online information session in September; stay tuned for details. Please contact the committee chairs for more information or to express your interest in joining the committee.