ISSUE

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Official Newsletter of the Pennsylvania Association of Genetic Counselors

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The PAGC Newsletter is brought to you by the Membership Committee

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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:

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### Featured Genetic Counselor

Janet Ober Berman, MS, CGC is a 2003 graduate of the Arcadia University (now University of Pennsylvania) Genetic Counseling Program. Like many genetic counselors, she states that her interest in genetics started in high school biology when she started solving classic Punnett squares. "It was the perfect combination of two of the most interesting subjects: genetics and statistics." She recalls reading a paragraph in an issue of Time magazine that described the emerging field of genetic counseling. Given this career incorporated what she was learning in school, she spoke with her biology teacher who offered encouragement that she should explore pursuing this field. This lead to shadowing a genetic counselor at a local academic hospital where she witnessed the complicated medical and psychosocial components that often emerge in a genetic counseling session. "In one session the genetic counselor identified medical information that the patient was withholding from her partner. I remember her asking the partner to exit the session and pick up the car for her to

further discuss this with the patient." Janet recognized that the mutual respect between patient and provider was unlike any doctor's appointment she experienced. She knew she found her career path and applied to college and then went directly to graduate school afterwards.

Janet has worked at Lewis Katz School of Medicine at Temple University since graduating from Arcadia. As Assistant Director of Perinatal Genetics, she splits her role between clinical and administrative responsibilities. She shared that she sees approximately 15-20 new clinical prenatal or preconceptional appointments weekly, along with two result follow-up sessions. When not wearing her clinical hat, she focuses on managerial and departmental tasks. "Many of the projects that I work on help to improve services within the genetics department, prenatal ultrasound unit and the Department of OB/GYN....assessing available genetic tests and laboratory offerings to ensure equal access to care, representing the department for improvements and changes in the Epic electronic medical record, training

### PAGC EXECUTIVE BOARD MEMBERS

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The PARDAC was created through legislation (House Bill 239) and signed into law as Act 14 on July 7, 2017, by Governor Tom Wolf. The council consists of the secretaries of Health, Human Services, and Education (or their designees), the Insurance Commissioner (or his/her designee), and members of the public, including various health practitioners, health insurers, researchers, parents of children with rare diseases, self-advocates and others with expertise in providing care to individuals with rare diseases.

@PARareDiseaseAdvisoryCouncil is working to better understand the challenges faced by rare disease patients and their families throughout Pennsylvania. If you are a rare patient or a caregiver for a rare patient in Pennsylvania, please take a few minutes to take an anonymous survey at <a href="PARDAC.ORG">PARDAC.ORG</a> The Council needs your input to provide direction on how best to advocate for the PA rare disease community to state elected officials.

Please feel free to reach out to Jodie Vento, MGC at <a href="mailto:ventojm@pitt.edu">ventojm@pitt.edu</a> with any questions.

### WELCOME TO THE PAGC BOARD!

We would like to welcome Jessica Goehringer, MS, CGC to the PAGC Executive Board as incoming Treasurer for a two-year term (January 2021 – December 2022). Jessica has served as Chair of the Membership Committee since 2018 and we look forward to having her as part of our Board!



Announcement

### The Art of Happiness: A Handbook for Living

By His Holiness the Dalai Lama and Howard C. Cutler, MD

Review by Susan Walther, MS, CGC

I thought I would end 2020 with reviewing a book that provides guidance for living with a sense of fulfillment and serenity, which has been a difficult approach to life during the COVID-19 pandemic. I will admit I had to push through this book because, in my struggle to focus on positivity, I kept thinking that of course the Dalai Lama can focus on attaining happiness when he doesn't have to worry about daily stressors like meeting work deadlines or managing childcare.

The purpose of the guidance in this book is to confirm we all have the right to



happiness and to find fulfillment, and we achieve happiness by minimizing the effects of suffering. No one lives a life free from suffering and loss, but the key to enjoying a happy and fulfilled life is shifting our state of mind. The ability for us to shift our perspectives is the most powerful tool we have to cope with problems and stress. Through the spirit of compassion and through deepening our connections to others, we can carry the belief that life is mostly fair and that we are all good people to whom good things deserve to happen.

#### Featured GC cont. from p. 1

interpreters in genetic counseling terminology, performing audits to ensure genetic counseling testing and services are routinely performed at all Temple locations, serving as a liaison with referring satellite clinics, and coordinating multidisciplinary meetings within the institution for prenatal to postnatal care transitions." Janet acknowledged that switching from clinical care to an administrative role within the same day can be a challenge, but that challenge and diversity of responsibilities and opportunities brings her the most satisfaction within the position. Professional activities like coordinating professional conferences and creating prental education courses have also been important to Janet.

For any genetic counselor right now, but especially those in clinical positions, we can't ignore the current times and challenges that have arose with COVID-19. Janet mentioned that, like many clinical sites, when medical practices were beginning to shut down, prenatal genetic counseling services through the Department of OB/GYN at Temple University transitioned to offering telemedicine visits. "This was a significant change in our practice as we were previously an in-person service and did not offer any virtual appointments. The positive impact for patients was unanticipated and will most certainly alter our care model for the future." It's noteworthy that their "no show" rate for a genetic counseling appointment dropped from approximately 20% to almost zero! She thinks that "individuals who had been at home for an extended period of time were excited to have an appointment for more human interaction." Janet shared that the percentage of each session that was spent on psychosocial counseling increased dramatically. Prior to COVID-19 patients listed several reasons why they couldn't keep appointments including: access to transportation, childcare, and limited daytime appointment hours. As many

genetic counselors have seen, telemedicine offers flexibility and for Janet, this meant the ability to expand clinical counseling sessions into the evening. "With these barriers reduced or eliminated, patients gained access to services and were able to have many additional family members participate in appointments." Due to seeing more patients, she has found that it was necessary to decrease the amount of time she could dedicate to administrative tasks.

When asked what "I wish I knew then what I know now" advice she would give to recent genetic counseling graduates, it is to focus on more than the clinical responsibilities. "During my clinical rotations in graduate school the emphasis was always specifically on patient care and cases." She acknowledges that it is obvious that one of the most important aspects of a rotation is actively participating in the patient appointment and gaining counseling experience. However, she recalls being told not to worry about certain typlical administrative tasks, like insurance, since it was possible that insurance rules would differ depending on the state she would practice in. Janet emphasized that she feels it is just as important to learn all of the additional responsibilities of supervising genetic counselor. "Even if the details of insurance or other aspects of the position will change with your first job, the foundational knowledge will give you a head start." She would like to encourage students to struve ti be active participants in all areas of training. Additionally, she offered, it is prudent for new graduates to seak out and speak with staff members who have other areas of expertise at their institution to help them to form into well-rounded genetic cousenlors, "prepared for all of the non-genetic issues that will come their way!"



#### **EYE ON IT**

#### PAGC Membership

As you start to think about renewing your annual NSGC membership, consider renewing your PAGC membership for 2021, or perhaps joining for the first time! Being a current member of NSGC is required to be eligible to hold a full PAGC membership.

Upon completing your PAGC membership registration, the form has a spot for you to specify any committees you may be interested in becoming a part of. Currently, all our our committees are in need of volunteers. Information about each of our committees is available on the website. Please email us with any questions about committee membership at: pagcmembership@gmail.com

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!

### **PAGC 2021 Spring Conference**

Mark you calendar for the *virtual* Annual PAGC Spring Conference on <u>April 22<sup>nd</sup> and 23<sup>rd</sup></u>. Please watch your email and the PAGC website for additional details, coming soon!

### **Call for Abstracts!**

We are currently accepting abstract proposals for oral presentation at the 2021 PAGC Annual Meeting. Completed abstract submission forms must be submitted via email to <a href="mailto:pennsylvaniaGC@gmail.com">pennsylvaniaGC@gmail.com</a> with the word "ABSTRACT" in the subject line. Visit the <a href="PAGC 2021">PAGC 2021</a> Meeting webpage for more information and to download the abstract submission form.

Abstract submission deadline: Friday, February 19th, 2021.

#### **Abstract Submission Requirements:**

- -Abstract text: limit 400 words
- -Preferred submission type
- -Topic category
- -Two learning objectives
- -A brief biography of the presenting author
- -Completed abstract submission form



### License Renewal Time

Pennsylvania Genetic Counseling Licenses expire on Dec. 31, 2020 (biennially on even numbered years). An email notification will be sent from the State Board to the email on file when the renewal period opens. Be sure that your email address is correct; you can verify your address or change it by visiting:

#### https://www.pals.pa.gov/#/page/default

The Members section of the PAGC website is updated with the links to the PA Board of Medicine and other licensure-related details. You will need to login to access this section.

#### LICENSE RENEWAL REQUIREMENTS:

☑ 30 hours of NSGC/ABGC approved continuing education (3.0 CEUs) ☑ 2 hours of Child Abuse Recognition and Reporting training. Child abuse clearance must be submitted within 60 days of license renewal. A list of approved training resources can be found at:

https://www.dos.pa.gov/professionallicensing/boardscommissions/pages/act-31.aspx

## **Attention Program Directors** and Researchers

Are you or your genetic counseling graduate students looking to recruit participants for a research project being conducted in Pennsylvania? If so, please email <a href="mailto:PAGCmembership@gmail.com">PAGCmembership@gmail.com</a> to advertise the project in an upcoming edition.

### **Research Participant Request**

From: Michaela Mundt, second year genetic counseling graduate student at the University of Pennsylvania

We want to hear about your experience working with genetic counseling graduate programs and supervising students. Participation involves a single 10-minute online survey with the option to participate in an additional 30-minute interview, scheduled at your convenience by phone or teleconference. All certified genetic counselors are invited to participate. This mixed methods study is being performed as part of a research protocol entitled *Genetic Counseling Supervisors' Perceptions on Working with Multiple Training Programs* which is a genetic counseling thesis project through the University of Pennsylvania.

If you are interested, please click the following link <a href="https://redcap.link/gcsuppercep">https://redcap.link/gcsuppercep</a> to provide your consent and please forward this email to other genetic counselors.

From: Brooke Meader, second year genetic counseling graduate student at Thomas Jefferson University

You are invited to participate in a study (Prenatal Genetic Counselors' Response to Recommendations on Fetal Exome Sequencing by the ACMG) from Thomas Jefferson University's Department of Human Genetics and Genetic Counseling about fetal whole exome sequencing following the Points to Consider document released by the American College of Medical Genetics (ACMG) on January 8, 2020. Currently practicing prenatal genetic counselors are eligible and encouraged to take this survey. All participants who complete the survey will have the opportunity to be entered in a drawing for a \$25 Amazon gift card. Our study consists of an online survey that will take approximately 10 minutes to complete. Your participation in this study will contribute to advancing our understanding of the clinical use of whole exome sequencing in the prenatal setting. Survey link: https://jefferson.co1.qualtrics.com/jfe/form/SV daobf8LUGfdr8C9