

The PAGC  
Newsletter is  
brought to you by  
the Membership  
Committee

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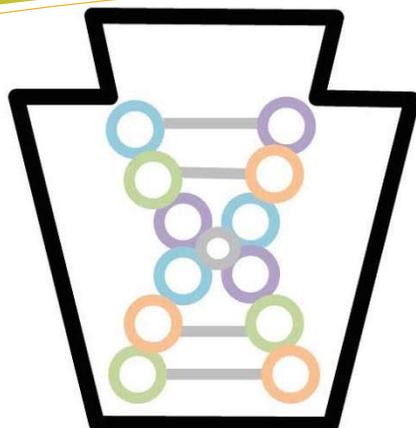
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If you have anything that  
you would like to share  
including upcoming events,  
seminars, an exciting new  
career role, etc, please  
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## 2020 Annual PAGC Spring Meeting Online

In lieu of the 2020 Annual PAGC Spring meeting, the PAGC Education Committee is happy to offer an **online course** featuring most of the material that was planned for the 2020 Spring Meeting!

This course will include approximately 6.2 Category 1 contact hours (0.6 CEUs) and will encompass the Sessions and Accepted Abstracts that were slated to be presented at the in-person meeting.

### Purchase Information

If you paid for registration and the CEU fee for the Spring Meeting, any funds that were paid toward the meeting will cover the cost of the recorded version. A \$25 CEU fee is still due to claim CEUs if you had not previously paid them online. If you instead desire a refund, please reach out to us at [pagcmembership@gmail.com](mailto:pagcmembership@gmail.com) so that can be coordinated.

If you were not planning to attend the Spring Meeting but are interested in watching the series for CEUs, the information to purchase this course can be found below.

### Purchase Type Price

- PAGC Member: \$50 (includes CEU fee)
- Non-member: \$100 (includes CEU fee)
- Student: \$25

### Course Format

The course will consist of pre-recorded presentations by the speakers. The presentations will include the presenter's lecture, fully synchronized to the slide presentation. Participants can listen to presentations on their own schedule.

### Accessing the Course

The course recordings will be available sometime after June 1st and an email with a link to the recordings and quizzes for CEU credit will be distributed to participants as soon as they are available.

### Continuing Education

The Education Committee is working on NSGC CEU approval now and further information will be disseminated by email and through the PAGC website as soon as possible. Those interested in obtaining CEUs will need to do the following:

- Complete viewing the course recordings by 10/15/2020
- Take all quizzes and receive a score of at least 80% by 10/15/2020
- Complete the course evaluation forms

### Additional Remote Learning Opportunities

In addition to this online series, the Education Committee is planning a **quarterly webinar series**.

## PAGC EXECUTIVE BOARD MEMBERS

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This webinar series will include the two panels that were planned for the 2020 Meeting, as well as other content. CEUs will be available for this webinar series as well, and more information will be available soon. Stay tuned and watch your email inboxes!

*Cont. from p. 1 PAGC Annual Meeting*

If you have any additional questions, please do not hesitate to contact the Education Committee at [pennsylvaniagc@gmail.com](mailto:pennsylvaniagc@gmail.com).

### PAGC Education Committee

Natalie Carter  
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Wendy Glatfelter  
Tara Schmidlen  
Donna McDonald-McGinn  
Maegan Smith  
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## The Gene: An Intimate History

(<https://www.pbs.org/kenburns/the-gene/watch>)

Part 1: Dawn of the Modern Age of Genetics

Part 2: Revolution in the Treatment of Disease

Review by Susan Walther, MS, CGC



For more than three decades, Ken Burns and his colleagues have produced some of the most critically acclaimed documentaries on public television. “The Gene: An Intimate History” is the latest production from his team. This two-part series aired on April 7 and April 14, 2020 and can be viewed through the PBS website. The series is based on the book by Siddhartha Mukherjee, author of “The Emperor of All Maladies: A Biography of Cancer”. Part 1 features a family with a daughter diagnosed with a KIF1A mutation. Susannah Rosen is experiencing neurodegenerative decline accompanied by seizures, and her charm and determination fill her story with hope. Susannah’s mother poignantly expresses her dismay at being told by the physician

who diagnosed her daughter, “Enjoy every day you have with her.” Susannah’s mother wasn’t looking for condolences; she was looking for answers. Many of those answers begin to emerge through the clinical care provided by Dr. Wendy Chung at Columbia University. The family is empowered to form an advocacy organization for research, and they galvanized KIF1A families into action with a “We Need a Mouse!” social media campaign to develop a mouse model of the disease.

The human-interest aspect of Part 1 is interspersed with genetic discoveries from Mendelian traits to chromosomes to genes and linkage to DNA. When a coworker told me she saw this series, she commented,

*Continued on page 4*

## Perspectives: How a Pandemic Can Impact Clinical and Laboratory Practice

### From the Prenatal Clinical Counseling Perspective

*-By Julia Stone, MS, CGC  
UPMC Magee-Womens  
Hospital*

There is no denying that the COVID-19 pandemic has had a significant impact on all of us here in Pennsylvania. Between social distancing and stay-at-home orders, business closures and panicked grocery shopping, this has been a novel experience for us all. From a clinical genetics perspective, these last few weeks have been a practice in flexibility and problem solving. As our state and hospital policies have rapidly changed, so too have our clinic workflows. Many things seem to change on a week-by-week basis, and we are all trying our best to go with the flow.

We are incredibly fortunate in that many of us have been able to transition to primarily working from home, but with that transition has come new and unexpected challenges. Those of us who live with spouses, partners and children have had to figure out how to establish private workplaces at home and how to navigate our work effectively in the presence of these new 'coworkers.' We had to discover how to make and receive patient calls without surrendering our personal phone numbers. We miss each other...

Many of our appointments have transitioned to video or phone consults. Video appointments are not new in my institution—our prenatal and cancer teams each do regular telemedicine consults with satellite locations. However, working with clients in their homes (rather than through an office at a separate, fully-staffed hospital) means we've had to determine new ways of coordinating testing and documenting patient consents.

My hospital has three primary clinical genetics departments: prenatal, cancer, and adult genetics. Each clinic has had to consider their specific patient population in determining whether or not to see patients in person while stay-at-home orders are in place. Our prenatal team, for example, decided that we would meet with patients in person if they were already going to be in the hospital for another reason (such as an ultrasound). That has allowed us to continue to see prenatal patients on an urgent basis as needed. The lesser number of in-person appointments has also allowed the team to spend more time working from home. As it stands now, most counselors are only coming into the office 1-2 days a week.

I could write a novel explaining all of the changes that our clinics have embraced (or tolerated) through COVID-19. One thing that has not changed, though, is our commitment to quality patient care. We are adopting alternate delivery models and truly trying our hardest to ensure that our clients are getting the care they need. One positive aspect of the at-

home video visit is that we have been able to connect with patients who have barriers to care and may not have otherwise been able to come to an appointment.

Now that we are hearing rumblings about plans to lift the strict stay-at-home orders, we are starting to think about transitioning back to the office. Just as we have done so far, we are continuing to take things week-by-week (who knows what our workflow will look like by the time you are reading this!). I am thankful to work with an fantastic team of counselors, and I know that with our continued support of each other and flexibility we will make it through to the other side of this round of COVID-19.

### From the Genetics Lab Perspective

*-By Marianne McGuire, MS, CGC  
UPMC Magee-Womens  
Hospital*

Working in a young hospital-based laboratory where product development is at the core, working remotely has its own set of challenges. So much of what we do during the development stages are not routine and requires continual collaboration. Team communication can feel fragmented even in the era where video conferencing is available. Many processes were in place so that lab personnel could evaluate cases off-site but trouble shooting seems to go a bit smoother when someone is within arm's distance. I think in all work environments one feels more emotionally connected to their colleagues



## 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 and committee volunteers are always welcome!

when you share the same space. All that being said, as a whole I believe our team has transitioned into this space quite well.

### *"The Gene" cont. from p. 2*

"There's some good patient stories, but then it gets bogged down in the science history." The history is the most fascinating part of the series, for the genetic counseling profession would not exist without the discoveries of early pioneers in genetics. As scientists reported on the complexity of genetic inheritance, medical professionals recognized the need to explain this complexity to patients and to provide guidance for decisions that could be made based on the knowledge at the given time. In the ever-evolving and growing field of genetics, any genetic counselor who has been in the field for a length of time can appropriately lament, "If we only knew then what we know now" when reflecting on their years of patient care.

Part 2 focuses on the Human Genome Project and treatment modalities that have been developed due to our sequence knowledge of the genome, including gene editing and gene therapy. There are 135 years of genetic scientific discoveries between Mendel's pea plants and the announcement of the completion of the Human Genome Project. Some of those genetic discoveries were made by people directly affected by the disease on which they work. This series profiles two patient pioneers – Nancy Wexler for Huntington's disease and Audrey Winkelsas with SMA.

DNA can tell us about our ancestral past, and precision medicine can optimize prevention and treatment of disease. I was struck by the irony that Ken Burn's "Baseball" series is 18 hours of information, yet the history of discovering who we are at the DNA-level was covered in only four hours. Maybe my colleague was right. Getting bogged down in the science history is interesting to far fewer people. As a genetic counselor, this series was my American pastime.



# PAGC

## Business Meeting

Mark your calendar for the annual  
PAGC virtual business meeting.

**May 22nd at 11:00 am**

A meeting invite will be sent via email shortly.

## 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.

## Professional Development and Continuing Education

### Upcoming Events

- **American Society of Human Genetics 2020 Annual Meeting**
  - October 27-31, 2020
  - San Diego, CA
- **National Society of Genetic counselors 39<sup>th</sup> Annual Conference**
  - November 18-22, 2020
  - Nashville, TN
    - Earlybird registration will be mid-May-August 13th

## A Note From Our PAGC President

Hi Friends,

The last time our newsletter went out we were preparing to come together in Pittsburgh for a much-anticipated educational and networking event. We were finalizing our posters for ACMG and planning reunions with classmates. Many were looking forward to spring break plans and holidays with family. Since that time our world has shifted and we are all trying to maintain stable footing in an everchanging landscape. Our plans may have changed but the PAGC remains committed to serving the genetic counselors in our community.

We recognize that the pandemic has changed the circumstances of many professionals in our state. The board of directors and our committee leads have been working to identify innovative solutions to help address some of these challenges. I am looking forward to hearing all our valued speakers give their PAGC AEC presentations by webinar in the coming months. Our genetic services committee is working to examine the results from the PAGC PSS to learn more about our community and how we can best be of service. If you have thoughts or ideas on how PAGC can better serve our community during this time please email us directly a [pennsylvaniagc@gmail.com](mailto:pennsylvaniagc@gmail.com). As always, we would love to hear your thoughts.

During this time of isolation I encourage you to reach out to your genetic counseling colleagues. We so often rely on our co-workers and classmates for emotional support and it is important to continue to support each other even if we are not seeing them every day. Let's remember to celebrate each other's milestones and achievements and share in each other's pains and losses. It is easy to look around right now and say, "*look how much we have lost*". I feel it too, and I feel it deeply, but at the same time I am amazed at how much we are gaining.

Genetic counselors across our state and country are diving head first into the world of telemedicine. We are testing our psychosocial skills like never before to make human connections through phone lines and video calls. New billing methods are being explored and alternative work arrangements are being implemented. Laboratories are validating their existing testing on alternative sample types to facilitate at-home sample collection. Our students are able to have friends and extended family witness their thesis presentations who would have missed out on an in-person event. The parameters of clinical rotations are being examined and re-defined and the concept of online genetic counseling training is being put to the test.

None of these things have come easily, or without cost, and the challenges and solutions will continue to evolve. When we come out of this, and we will come out of this, we will have new skills, new ideas, and a new sense of what can be accomplished. I look forward to that day.

Warmest regards,  
Margaret Harr

2020 PAGC President

