

Welcome to the PAGC Newsletter!

We will be bringing you news on upcoming events, genetics entertainment, featured colleagues and more in our new quarterly newsletter. If you have any information that you would like to share including upcoming events, seminars, an exciting new career role, etc, please contact us at : pennsylvaniaGC@gmail.com

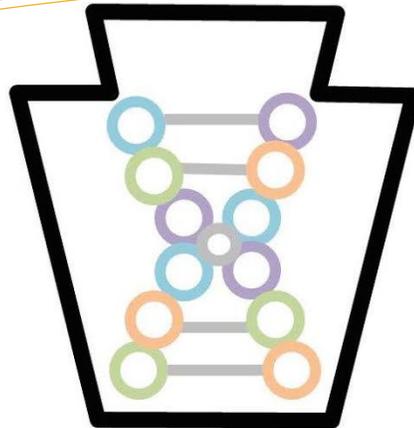
Brought to you by the Membership Committee

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This issue:

Featured Genetic Counselor **P.1**

Genetics Entertainment **P.2**

Meet the Board **P.3**

NSGC Conference Review **P.3**

Upcoming Events **P.4**

Featured Genetic Counselor: Jennifer Farmer

For those of you who have never met Jennifer Farmer or heard about her extraordinary role as the Executive Director at Friedreich's Ataxia Research Alliance, now is your chance!

As a 1997 graduate of the Arcadia University Genetic Counseling Program, Jen was immediately attracted to the non-traditional or evolving role for genetic counselors. Jen shared that, "This is one of the important traits that really attracted me to this profession. It was easy to see even at early and naïve stages of career exploration that the training, skills and knowledge that I would acquire could be applied in different ways and more recently with the explosion of genetic technologies and treatments for inherited diseases growing exponentially one is only limited by his/her imagination and vision."

When asked if there was a pivotal occurrence that opened a career opportunity for her, she indicated that a few key individuals and opportunities were instrumental to finding a career that is both challenging and fulfilling. Back in 1998 ("that makes me really old," Jen jokes), soon after the gene for Friedreich Ataxia (FA) was identified Jen had the chance to begin working with FA patient families to provide genetic testing and counseling of their prior clinical diagnoses. She also facilitated their

participation in research studies that lead to a better understanding of the pathophysiology and clinical progression of the disease, with the end goal of potential drug discovery. "I was captivated by the strength, courage and optimism of the people in this community," Jen said.

As a genetic counselor new in the field, Jen felt it was important to seize the opportunity of becoming active in NSGC and served on the Board of Directors. It was through this experience that she learned about non-profit organizational management (special shout out to Bea Leopold from Jen for the mentorship).

In 2005 the Friedreich's Ataxia Research Alliance contacted Jen and invited her to join their growing organization. She recognized this as, "a unique opportunity to stretch my genetic counseling skills and experience in new ways and leverage my growing interest in non-profit organizational management."

In her current role as the Executive Director of a non-profit rare disease research advocacy organization, Jen is responsible for carrying out the mission of the organization (to treat and cure Friedreich's Ataxia) by leading strategic initiatives and programs, overseeing the finances and operation, and reporting to the Board of Directors.

continued on page 2

PAGC EXECUTIVE BOARD MEMBERS

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LCGC*

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West Regional

Representative and

Board Liason to

Membership Committee:

*Juliann McConnell, MS,
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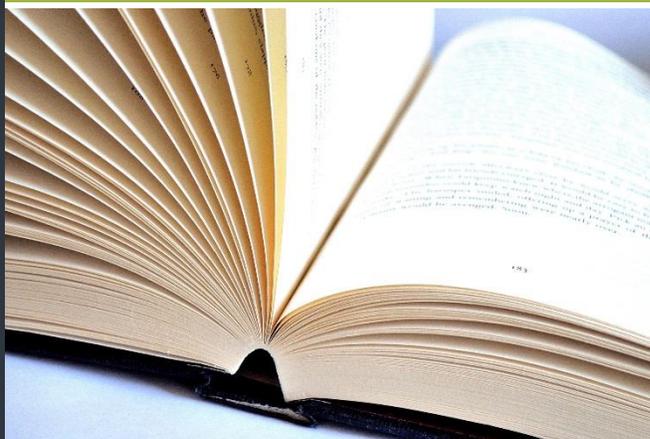
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Patient H.M.: A Story of Memory, Madness, and Family Secrets

By Luke Dittrich

Henry Molaison developed intractable epilepsy as a child after a bike accident. In 1953, at age 27, Henry was treated with lobotomy to relieve his seizures. The seizures remained; however, Henry was left profoundly amnesic, unable to create long-term memories. Henry became known as Patient H.M., and over the next sixty years, was the most studied individual in the history of neuroscience.

The author, Luke Dittrich, is the grandson of the neurosurgeon who developed one of the most widely used techniques for lobotomy and who operated on Molaison. Dittrich weaves his family's personal story

of lobotomies and mental illness into a fascinating history of brain surgeries and the bitter battle over the academic ownership of data collected from studies of Henry's memory, and ultimately, Henry's brain.

If, as a genetic counselor, you have ever worried about providing appropriate informed consent, this book will relieve those concerns. The story of Patient H.M. will leave you in awe of how far we've come in the ethical treatment of vulnerable patient populations.

-Submitted by Susan Walther

(Cont,d from page 1: Jennifer Farmer)

Jen explains that, in a nutshell, this boils down to:

Research - Active role in leading and building research programs – including a worldwide patient registry, longitudinal natural history study, and managing a scientific research grant program that funds more than 30 research grants per year.

Operations – We are a small business with 8 full time employees and several part-time employees. I am responsible for payroll, human resources, financial reporting, company insurance, and other administrative functions.

Fundraising – I am fortunate to work with a dedicated group of individuals and patient families who lead our fundraising efforts. In the last 10 years, FARA has gone from an organization raising about \$1 Million a year for research to >\$8 Million in 2018. My key contribution is connecting with our families and donors to develop trusting relationships and helping them understand how their contributions make a difference in accelerating research. I am also responsible for ensuring that the funds raised go to our mission and keeping our overhead costs as low as possible.

Patient Engagement and Education – Ensuring that we have an engaged and educated patient community that can participate in clinical trials. Taking calls from families who are newly diagnosed and providing good old-fashioned genetic counseling.”

Who's Who Behind the PAGC



Each quarter we will feature one of the PAGC's board members so you can get to know who is behind the organization. This quarter the Secretary & Treasurer, Dr. Andrea Durst, MS, DrPH, LCGC is in the spotlight.

Dr. Andrea Durst is a certified and licensed genetic counselor with eight years of experience in cancer genetic counseling. She is currently an Assistant Professor in the Department of Human Genetics at the

University of Pittsburgh. As the Associate Director of the Genetic Counseling Program and the Co-Director of the MPH Program in Public Health Genetics at the University of Pittsburgh, she teaches courses in both genetic counseling and public health genetics, mentors students, and serves as a committee member/reader for student thesis and essay projects. She received her Master of Science in Genetic Counseling from the University of North Carolina at Greensboro and her Doctor of Public Health in Health Management and Policy from the University of Kentucky where she investigated the potential for identification of individuals appropriate for genetic referral via bidirectional cancer registry reporting.

Dr. Durst is currently working with a number of organizations

to advance public health genetics and genetic counseling projects. In addition to serving as the Secretary & Treasurer of PAGC, she also serves as Chair of the Steering Committee for the New York Mid-Atlantic Regional Genetics Network (NYMAC), Co-Chair of the National Society of Genetic Counselors (NSGC) Public Health Special Interest Group, Co-Leader of the Pennsylvania Cancer Coalition Screening and Early Detection Workgroup, and a member of the Genetics/Genomics Committee of the Pennsylvania Cancer Control, Prevention and Research Advisory Board. She has previously provided her public health genetics management expertise to the Midwest (Region 4) Genetics Network and The Genetic Alliance.

EYE ON IT



PAGC Membership

It's time to renew your PAGC membership!

Renew to enjoy the benefits of being a member of AGC. Membership officially expires on December 31, 2018.

Scroll to the bottom of the website page

<http://www.pennsylvaniagc.org/membership.html> to renew today!

E-Blasts

Keep your eye out for occasional e-blasts from the PAGC!

The Annual Spring Meeting CALL FOR ABSTRACTS was recently distributed to GCs in our state. For more information, visit

<http://www.pennsylvaniagc.org/>

NSGC Annual Conference Review

Last month, genetic counselors and colleagues from across the country and beyond convened in Atlanta for the largest National Society of Genetic Counselors (NSGC) Annual Education Conference (AEC) to date! The conference appropriately took place in the Georgia World Congress Center, which is one of the largest convention centers many of us have ever navigated. There was certainly no problem getting our steps in that week. This year's conference was as wonderful as always, with inspiring speeches, informative presentations, unique discussions, and plenty of networking (read: social) opportunities.

"Adapting • Evolving • Thriving," this year's conference theme, seemed particularly relevant in the fast-paced, ever changing world of genetics that we live in. The education presentations touched on a variety of relevant (and often complicated) topics, including polygenic risk scores, counseling patients who identify as LGBTQ, transfer of mosaic embryos during in vitro fertilization, gene therapy, and biobanking. There were also riveting discussions regarding ethical and social considerations within our own field, including conflicts of interest, alternative delivery models, and diversity concerns. One of the absolute highlights this

year were the patient presentations. Chantae Cann, an artist who had presymptomatic testing for Huntington's disease and tested positive, shared with us her positive, upbeat, inspirational music and demeanor, and Eva Moon left us in tears after performing her hilarious but poignant one-woman comedy show about her experiences as a carrier of a BRCA1 pathogenic variant (The Mutant Diaries: Unzipping My Genes).

PA Posters

As always, there were a plethora of exciting posters and platform presentations. Per our count, there were approximately 20 posters from institutions or genetic counselors currently located in the state of Pennsylvania. That makes up about 8% of the total posters presented! Poster topics included prenatal, pediatric, cancer, and adult/specialty genetics, as well as professional issues related to a broader audience. We are thrilled to see that Pennsylvania research is contributing to the field in such a large way. Congratulations to everyone who presented a poster or led a presentation at the conference.

-Submitted by Julia Stone

Upcoming Events

• **PAGC Webinar: Chutes and (Career) Ladders-- Developing a Division of Genetics at Your Institution**

January 28, 2019 at 12:00 noon EST

Moderator: Becky Milewski, MS, CGC (Education Committee, PAGC)
GeneDx, Inc.

Speakers: Donna McDonald-McGinn, MS, CGC
Chief of the Section of Genetic Counseling
Associate Director of Clinical Genetics Center
Children's Hospital of Philadelphia

Christine Spaeth, MS, LGC
Clinical Manager, Division of Human Genetics
Cincinnati Children's Hospital

• **PAGC 3rd Annual Spring Meeting**

May 9-10, 2019

UPMC Pinnacle Harrisburg, Brady Hall Auditorium
205 S Front Street, Harrisburg, PA 17104

Hotel room blocks:

Hilton Harrisburg: (Room block available thru 4/18/19)

Standard room rate: \$144.00 +tax (Parking is \$10/night)

Reservations: 717-233-6000 copy and paste the entire booking URL

https://secure3.hilton.com/en_US/hi/reservation/book.htm?inputModule=HOTEL&ctyhocn=MDTHHHF&spec_plan=PAGC&arrival=20190509&departure=20190510&cid=OM,WW,HI LTONLINK,EN,DirectLink&fromId=HILTONLINKDIRECT

Group code: LINK COMING

Group Name: PA ASSOCIATION GENETICS

Quality Inn Riverfront: (Room block available thru 4/25/2019)

Standard room rate: \$79.00 +tax including parking

Reservations: 717-233-1611

Group code: Pennsylvania Association of Genetic Counselors

Professional
Development
and Continuing
Education