

March 2022

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President's Update

McNesby Act



I can't believe another month has passed. Mr. Gibbs and Dr. Smith again came calling for comments from me to lead off this month's DAM Newsletter. Are we on the other side of COVID? Time will tell.

We, particularly my wife, have been providing continued advocacy on behalf of our son, Andrew, an adult with severe autism, and his friends. As often is the case, advocacy demands funding.

The legislature has been working on the budget and we had an opportunity with A-Team DE, a non-partisan, grass roots group of people with intellectual and developmental disabilities, their families, friends and caregivers, to meet with local

legislators. One of our major concerns was the incomplete funding of the McNesby Act. This was passed in 2018 and was a first in the nation act requiring the state to fully fund providers of IDD services for 100% of a benchmarked rate to allow for increases in salaries, training, and supervision of Direct Support Professionals (DSP). It is named for Michael McNesby, a man with Downs Syndrome who died in 2018 and whose parents and siblings were life-long advocates of their son and brother and this population. His sister, Teesie Bonk, was one of the founders of A-Team DE and cared for her brother following their parent's deaths for 12 years. The shortage of DSP's to provide care is one of the greatest concerns of persons and families in the IDD community.

Many of the A-Team members were able to testify at the Joint Financial Committee. My wife has done this in the past and has included Andrew at her testimony. This year we chose to submit a letter and I include it here to express our concerns.

"As we were preparing advocacy efforts with other families of adult children with Intellectual and Developmental Disabilities on the full funding of the McNesby Act, all conversations led back to the need for our children's stories. Each person represented in that group has a story that describes a compelling need for services to live their best lives. It seems impossible not to be touched. Yet, year after year of testifying or writing letters it appears the stories are not heard as the decision on funding for services falls far below the need. As we thought about why this continues to happen, we remembered another story. Our son Andrew was probably no more than four when we signed him up for his first extracurricular program in Montgomery County, Maryland. Still new to the world of special education and services, Pat was quite nervous, and her closest friend came with her to drop him off. Not only was she a masters prepared special education teacher, but she also had an older brother with severe autism. She had a lifetime of personal experience teaching and also watching her parents advocate. As we approached the building where Andrew's program was held, Pat was struck by how run down it was and remarked that it seemed odd the program would be held there. Her friend stopped and held out her hand. "Welcome to the world of special needs," she said. "People think they

don't get it."

People with intellectual and developmental disabilities are currently in a fierce battle to have their civil rights recognized. In a time of increased awareness of the needs of special interest groups in the US, Andrew and his peers struggle for recognition. Adding to the struggle is the fact that many in this group are non-verbal or unable to articulate their needs and rely on parents or loved ones to speak for them. Those in the disabilities community who can self-advocate dismiss anything but self-advocacy as legitimate and dismiss us as we try to articulate or give voice to our son and his needs. As Pat remembered her friend's comment many years ago, it occurred to us that there is another barrier. Is our son facing discrimination because society feels he really doesn't get it anyway? Are he and his peers overlooked because people feel they lack the capacity to understand?

We have other stories to tell you about our son. Hundreds of stories that would prove to you he gets it. The most poignant story happened at our daughter's wedding. Andrew and his sister, a special education teacher, have been extremely close since they were very young. On her wedding day, he saw her in her wedding dress and he started to sob. "Everything is changing", he said. He got it. Everything was changing for our other children as they grew up and left home. Andrew, dependent on supportive services for this to happen, remained at home with his parents. Everything was changing for everyone but him.

One thing that hasn't changed is Andrew's dependence on essential services provided to him by direct support professionals for him to lead his best, independent life. The COVID pandemic exposed the shortage of such providers and kept many of our adult children isolated. Post-pandemic, the workforce shortage has reached a crisis as activity returns to normal often leaving Andrew and others in his group without the services they require. Last month, Andrew missed two of his days at work due to lack of a support person. He is currently at risk to lose this support person altogether as his and other service providers are losing workers to the better wages at McDonalds and Amazon. You have the power to help change that. We ask that you fully fund the McNesby Act. We can assure that Andrew will get it. And what's more, he appreciates it.

Thanks for your attention. Back with you in a few months.

S. John Swanson, MD, FACS
President
Delaware Academy of Medicine/Delaware Public Health Association

TIMTalk

Transformation

2022 is proving to be a transformative year for the Academy/DPHA and I wanted to share just a bit about everything that is going on.

First, in partnership with the Public Health Management Corporation, we are activity supporting Community Health Workers in Delaware working specifically in the area of COVID-19 vaccine hesitancy, and with the pediatric population for whom vaccines are now approved. Community Health Workers (sometimes also called health navigators, health coaches, community health advisors, outreach workers, peer counselors, health interpreters, and



public health aides) have been around for decades in various capacities. For the past ten years or so, our colleagues in the Division of Public Health have been working to elevate

Community Health Workers with baseline training standards and supporting policy and procedural changes. We celebrate and support their efforts. As always, I extend special thanks to Dr. Kate Smith and the work of the Immunization Coalition of Delaware, a program of the Academy/DPHA, and to Stephanie Shell, our wonderful colleague at PHMC.

Second, our Collections Manager, Sharon Hess, applied for and obtained her first funding for our archives and history collection. This funding from the Humanities Forum will support digitization of our collection to be made accessible on our website. This is an important evolution, making the collection available to so many more students and researchers, and we thank Sharon for her hard work that has paid off.

Third, we are close to finalizing our Delaware Health Force program with details forthcoming in the next newsletter. This has been a long time in coming: the project was started before COVID-19 was even a blip on the world's radar. Through the pandemic the importance of this work to research, inform resource allocation and decision-making, and effect real change and improvement in key areas has only increased. We thank the Delaware Health Care Commission for their partnership, along with our colleagues in the Delaware Division of Professional Regulation, Secretary of Finance Rich Geisenberger, Secretary of Human Resources Claire DeMatteis, Secretary of Labor Karryl Hubbard, and Highmark Delaware President Nicholas Moriello. We, and the Delaware Health Sciences Alliance led by Dr. Omar Khan, look forward to kicking this program into high gear with the investment coming from the State of Delaware.

On other fronts, the Medical/Dental Lecture Series at Osher Lifelong Learning Institute is off and running, as is Delaware Mini Medical School in partnership with ChristianaCare. This year's Mini Med registration is historically high, and we are delighted. Working with the team at ChristianaCare (new colleagues Cindy Cavett and Teresa Rougeaux, and longtime associate Hiran Ratnayake) is always a pleasure!

Gratitude is everything in our line of work – and this barely scratches the surface of all those who work with us on a daily basis. You know who you are, and the board and I thank you.

Please see below for the dates of upcoming events including the Academy/DPHA's 2022 Annual Meeting.

Tim Gibbs, MPH
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Academy Updates

Mini Medical School

This free program is offered to all adults from high school students to adult learners. Attendees learn about important trends in diagnosing and treating illness, as well as general health topics. Faculty provide in-depth lectures, and a question and answer session enhances each presentation.

Although the series has already begun, you can still sign up!

These virtual classes will be held from **7:00 - 9:00 pm** on Thursdays until **March 31**.

3/17: The Growth of Telehealth and the Virtual Experience

3/24: Anesthesiology – the Silent Force Behind the Scenes

3/31: Childhood Development

Click here for registration and more information





APRIL 4-10, 2022 —

PUBLIC HEALTH IS WHERE YOU ARE

Call for Abstracts

All undergraduate, graduate students, and medical residents in Delaware completing research projects or internships are invited to present a poster on the status of their projects in the first Student Poster Presentation for National Public Health Week. Posters may be research or practice based, and will be presented online during National Public Health Week.

The deadline for abstracts has been extended. Abstracts must be submitted by 11:59 pm on **Sunday, March 20**.

<u>Learn More</u> Submit an Abstract

Hoopes Dental Lecture

The 2022 Frank M. and Robert R. Hoopes Medical Dental Lecture will be held on Monday, March 21, 2022 from 6:30 - 8:00 pm.

Dentistry in Special Needs Populations

Our speaker will be Dr. Andrew Swiatowicz, a general family dentist known for his work with special needs patients, including patients with intellectual disabilities, the medically compromised, and the severely dental phobic.



Learn More

Public Health Grand Rounds

Thursday, March 24, 2022 8:00 - 9:00 am

Alex Keuroghlian, MD, MPH is an Associate Professor of Psychiatry at Harvard Medical School (HMS) and Director of the Division of Education and Training at The Fenway Institute. He directs the National LGBTQIA+ Health Education Center at The Fenway Institute, a HRSA BPHC-funded cooperative agreement to improve care for LGBTQIA+ people across the U.S., as well as the HRSA HAB-funded 2iS Coordinating Center for Technical Assistance. He established the Massachusetts General Hospital



Psychiatry Gender Identity Program and is clerkship director for two senior electives in sexual and gender minority health at HMS, where he also co-directs the HMS Sexual and Gender Minority Health Equity Initiative, which leads longitudinal medical curriculum and faculty development in sexual and gender minority health.

Join on your computer or mobile app Click here to join the meeting

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Four times a year ChristianaCare partners with the Delaware Academy of Medicine / Delaware Public Health Association to bring a distinctly public health optic to our traditional medical grand rounds. While grand rounds are decidedly clinical in nature, we encourage all disciplines including public health, social work, epidemiology, and researchers of all types, as well as students and residents to attend.

Save the Date

2022 Annual Meeting of the Delaware Academy of Medicine/Delaware Public Health Association

When

Thursday, May 26, 2022 6:00 pm

Where

Dupont Country Club 1001 Rockland Road Wilmington, DE 19803

Keynote Speaker
Senator Sarah McBride

National Updates

APHA 2022 Annual Meeting: Call for Abstracts

The American Public Health Association is now accepting abstracts for oral and poster presentations for the 150th Annual Meeting and Expo in Boston, Nov. 6-9, 2022. Authors are encouraged to submit abstracts on the



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meeting theme — "150 Years of Creating the Healthiest Nation: Leading the Path Toward Equity" — and current and emerging public health issues.

See Submission Guidelines

Additional Resources

Delaware Division of Public Health - <u>The DPH Bulletin</u>
Trust for America's Health: Wellness and Prevention Digest - <u>Subscribe</u>
Johns Hopkins Infectious Diseases COVID-19 Grand Rounds - <u>View Schedule</u>

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