



The Dandy-Walker Alliance Newsletter

Issue 9 | April 29, 2023 | dandy-walker.org

May is Dandy-Walker Awareness Month!

Help us raise awareness about Dandy-Walker and its associated conditions all month long. Check out all the ways to get involved below!

Join our Awareness 5K from anywhere!

We're excited to bring back our Dandy-Walker Awareness Virtual 5K this year. This walk/run is open to all and can be done at your own speed, wherever and whenever you want within the month of May. Take a Sunday stroll with your family around your neighborhood, go for a run at the gym, take a hike in a nearby park – whatever you prefer.

[Register here to make your impact today!](#) Your \$15 registration fee will go toward raising awareness worldwide and funding Dandy-Walker genetic research. If you want, you can make an additional donation toward this on top of your registration fee.

Our Northeast Coordinator, Krystal Lacey, is organizing an in-person component of this 5K on Sunday, May 21. For those in Connecticut who want to get involved, email her at krystal.lacey@dandy-walker.org.



Get your state or town on the map!

Our goal is for every state (plus cities and towns across the U.S.) to recognize May as Dandy-Walker Awareness Month annually. You can help the cause by sending letters to your governor and local officials requesting a proclamation.

[Download our template here](#), fill in your state's information, and mail it to your governor! Alternatively, email us at awareness@dandy-walker.org and we'll send you a pre-filled letter for you to send out!



Share your story!

Our Dandy-Walker community is full of so many wonderful individuals with unique experiences and stories. It is our goal to share as many of these stories with the public as possible. This helps those outside of our community better understand what it means to live with Dandy-Walker, and to reassure those in our community that they are not alone.

Over the last year, we've featured numerous families in our [newsletters](#) and on [our website](#) and [YouTube channel](#). If you are interested in sharing your story and being featured here, contact Chris Rogers at chris.rogers@dandy-walker.org to set up an interview!

Welcome to the Dandy-Walker Alliance Newsletter!
Each month we'll recap the big Dandy-Walker stories, highlight community members who are making a difference, and give updates on research, events, and more!

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Join our Contact List!

The Dandy-Walker Alliance Email and Contact List will keep you up to date on all organizational news and updates.

Plus, registering for the contact list allows us to connect you with other Dandy-Walker families so that you can create your own support network right in your home town or state! Register at www.dandy-walker.org/email or scan the code below!





Scientific & Medical Advisory Board Spotlight

Dr. Seth Norrholm, PhD

Behavioral Neuroscientist

U.S. Air Force Academy | Colorado Springs, CO



Each month, we are profiling one of our Dandy-Walker Alliance Scientific and Medical Advisory Board members. For April, our Executive Director Chris Rogers sat down with **Dr. Seth Norrholm, Ph.D.**, from the United States Air Force Academy. Dr. Norrholm is a behavioral neuroscientist focusing on anxiety, fear, and PTSD.

Part of the chat with Dr. Norrholm is printed here. To read the full interview, visit our website or scan the QR code in the section below.

Dr. Norrholm, thank you for joining me today. To start out, tell me a little bit about yourself. What does your work entail?

I am a neuroscientist by training, currently serving a one-year distinguished visiting professorship at the United States Air Force Academy in Colorado Springs where I'm teaching cadets about abnormal psychology and stress and health.

I'll be back in Detroit in May to return to my full-time position as the Director of the Neuroscience Center for Anxiety, Stress, and Trauma at Wayne State University in their school of medicine. There, I am an associate professor covering trauma and the brain, with an emphasis on PTSD and the other illnesses that tend to come along with it like depression, anxiety disorders, and substance use.

I've been at Wayne State since 2019; before that I was at Emory University in Atlanta for fifteen years and worked at the Atlanta VA. So, I've been working with individuals with PTSD and related disorders for over 20 years now.

What made you want to get involved with the Dandy-Walker Alliance?

I've had a long interest in early life, shall we say, adversity and challenges. That's anything from an upbringing where you're faced with maltreatment or abuse, but also biological and physiological illnesses and events that can happen to people.

When [Dandy-Walker Alliance Founder and President] Eric Cole approached me about serving on the Board, it was – pardon the pun – a no-brainer for me, because I had such a strong affinity for helping those with derived illnesses, and of course, my close relationship with Eric played an important role as well.

[Interview continued on our website.](#)

Full Interview with Dr. Norrholm

Due to space constraints, we couldn't fit the full conversation with Dr. Norrholm in this newsletter. Scan the QR code below or [click here to read the full story on our website.](#)



Dr. Seth Norrholm (back center) hikes with his wife and children. Dr. Norrholm, a behavioral neuroscientist with the U.S. Air Force Academy, has been on the Dandy-Walker Alliance Scientific and Medical Advisory Board since 2009.

Lacey, Dennis Named Regional Coordinators

The Dandy-Walker Alliance is excited to announce the addition of two new regional coordinators to our organization.

These volunteers will help the Dandy-Walker Alliance in their communities by serving as a resource for local families, organizing community events, promoting awareness on a local level, and much more.

Krystal Lacey, of Connecticut, will serve as our Northeast Coordinator. Krystal has a five-year-old son, Declan, with Dandy-Walker.

During the pandemic, she partnered with the Dandy-Walker Alliance to set up an annual Virtual 5K, which is coming up again in May. This year, she is also organizing an in-person component of the walk/run for those in Connecticut.

Anntonette Dennis, of Louisiana, will serve as our Southern Coordinator. Anntonette's daughter, Kerrington, was diagnosed with Dandy-Walker two years ago just before her 11th birthday, and is now thriving. Anntonette has worked to raise awareness in her community since Kerrington's diagnosis, and is planning awareness events for the Ark-La-Tex region this year.

If you live in Krystal or Anntonette's communities and want to get involved with their work, send them an email by clicking their names above.

You can become a Dandy-Walker Alliance volunteer and make an impact in your own community too! If you're interested, send an email to awareness@dandy-walker.org to get started.



Top: Anntonette Dennis with her family, including her daughter, Kerrington.



Bottom: Krystal Lacey with her family, including her son, Declan.

Host Your Own Dandy-Walker Fundraiser!

Want to support families around the world, spread awareness, and fund research into the genetic causes of Dandy-Walker?

Sign up to host a Dandy-Walker fundraiser today!

We'll help you figure out the best event for your style and resources – a walk/run, a bake sale, a restaurant fundraiser, a Facebook fundraiser, or whatever else floats your boat. Then, *we'll build you a personalized fundraising page* that you can send out to all of your friends and family!

Email chris.rogers@dandy-walker.org or call 301-775-5853 to brainstorm the possibilities and get started!



Thank You, Corporate Partners!



Medtronic



Your imaging can help train the Bionauts!

Over the past few months, the Dandy-Walker Alliance has collaborated with Bionaut Labs as they investigate a novel treatment for obstructive hydrocephalus associated with Dandy-Walker Syndrome.

In this new treatment, a micro-scale robot known as a Bionaut would be delivered into the CSF space at the base of the skull and guided by an external computerized magnetic propulsion system to pierce the Dandy-Walker cyst, relieving obstruction and normalizing flow of cerebrospinal fluid.

While the Bionaut technology is still in its early stages, the goal is to introduce it as a new, less-invasive standard of care for hydrocephalus treatment.

In order to develop the Bionaut system to the point where clinical trials can be conducted, Bionaut Labs needs images of classical cranial cysts in Dandy-Walker patients who have developed hydrocephalus. These images will help the Bionaut engineering team better understand the cyst anatomy and in turn properly train the devices and optimize their performance.

All images are shared and used confidentially. Those who participate will be helping develop a treatment that could help people around the world facing complications of Dandy-Walker and hydrocephalus, along with numerous other types of conditions and diseases.

Get Involved Today!

Confidentially share your head imaging (MRI or CT) with Bionaut Labs to help them train the Bionauts and advance a potential new standard of care for hydrocephalus.

Express your interest at the [link here](#) or use the QR code on the right.



Learn More About the Bionauts



Hear from Dr. Bill Loudon, VP of Neuroscience at Bionaut Labs, about the device's development and how it can make an impact in our community.



BIONAUT
LABS



**Collaboration Between
the Dandy-Walker Alliance
and Bionaut Labs**

Learn about the Bionaut devices and our collaboration with Bionaut Labs.



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