



The Dandy-Walker Alliance Newsletter

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Register for our webinar with Dr. John Myseros

On Friday, July 7, the Dandy-Walker Alliance is hosting a live Q&A session with Dr. John Myseros, M.D., a practicing neurosurgeon Children's National Hospital in Washington, D.C.

Dr. Myseros is the Vice Chief of Neurosurgery at Children's National, where he takes a particular interest in surgical treatment of tumors, chiari malformations, and other hind-brain malformations such as Dandy-Walker.

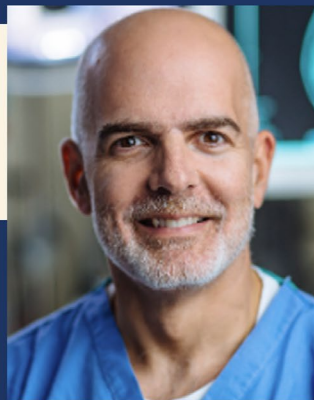
This free Q&A webinar is a perfect opportunity to ask Dr. Myseros questions about what a Dandy-Walker diagnosis means, what to expect from various associated conditions, what treatment options are best for different scenarios, and much more. This event will take a more clinical approach in contrast to our webinar earlier this spring with Dr. Kimberly Aldinger, Ph.D., which was focused more on Dandy-Walker research.

The live webinar will take place on Friday, July 7, 2023 at 7 p.m. ET. [Registration is open now for this free event.](#)

For those unable to attend, you may submit questions ahead of time at the registration link, and a recording will be available on our YouTube channel the week after the event.

A Neurosurgeon's View of Dandy-Walker

A LIVE Q&A WITH
Dr. John Myseros, MD
CHILDREN'S NATIONAL HOSPITAL



Friday, July 7 | 7 p.m. ET

Register at www.dandy-walker.org/webinar



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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. Kathleen Millen, PhD

Professor of Pediatrics | University of Washington | Seattle, WA
Associate Director, Center for Integrative Brain Research | Seattle Children's Research Institute | Seattle, WA



In each newsletter, we are profiling one of our Dandy-Walker Alliance Scientific and Medical Advisory Board members. For June, our Executive Director Chris Rogers sat down with **Dr. Kathleen Millen, Ph.D.**, from the University of Washington and Seattle Children's Research Institute.

Dr. Millen is a professor and researcher focusing on brain development, including the cerebellum. Together with Dr. Bill Dobyns, Dr. Kimberly Aldinger, and others, she has led the charge in Dandy-Walker research over the last decade-plus.

Part of the chat with Dr. Millen is printed here. To read the full interview, visit our website or scan the QR code at the bottom of this page.

Dr. Millen, thank you for joining me. What made you interested in brain development, and the cerebellum specifically?

I have been interested in studying development since I was an undergraduate, at the end of my first year of university. I was visiting a research lab and watched in real time a worm embryo divide from one cell to two cells to four cells. It was entrancing! How can one fertilized cell form into an entire being? That was the question that hooked me from the very beginning.

In graduate school, I had the choice to study multiple aspects of development, but I was really interested in the brain, because it's so complicated and amazing. I wanted to learn out how it all comes together and how it works.

I was in graduate school at the very beginning of genome engineering revolution in mice –technology that enables us to very specifically make any mutation we can imagine in the DNA of mice to determine how development is perturbed. The gene that we were working on was expressed in the mouse brain.

When we made the first mutant mouse missing that gene, the cerebellum was malformed. I became very interested the cerebellum and its development. The cerebellum has a really unique structure. It's folded and layered, and very distinct from other parts of the brain. Therefore, it is easier than other brain regions to identify when the structure is malformed.

And cerebellar malformation often translates into cerebellar dysfunction.

From that beginning, I was really interested in how genes build the beautiful cerebellar structure. I have studied cerebellar developmental genetics for many years in mice. When I became junior faculty at the University of Chicago, I realized that there were human disorders with malformations of the cerebellum. The literature on those malformations was confusing, incomplete, and not informed at all by what we knew about cerebellar development in mice.

I saw an opportunity to impact how people thought about human brain development and how some of these human cerebellar birth defects arise.

Full Interview with Dr. Millen

Due to space constraints, we couldn't fit the full conversation with Dr. Millen in this newsletter. To read the full interview, scan the QR code below OR visit dandy-walker.org/dr-kathleen-millen.



New Dandy-Walker T-Shirts Are Available Now!



Represent the Dandy-Walker Alliance with one of our new t-shirts! We have two great designs covering four different color schemes, each available for just \$20!

Free shipping is included for all orders within the U.S., and all proceeds go toward raising Dandy-Walker awareness.

Place your orders now at www.dandy-walker.org/merchandise!



Share Your Story with the Dandy-Walker Community!

We have restarted the [Dandy-Walker Alliance YouTube channel](#) and are dedicated to sharing your stories on there. Executive Director Chris Rogers is working on a series of video interviews with Dandy-Walker families across the country and beyond, highlighting both the struggles and successes that come with Dandy-Walker.

Over the past few months, we've highlighted numerous families across the country: [Paula Muller](#), a Dandy-Walker mom in Connecticut who ran the New York Half to raise money for the Alliance; [Nick Nguyen](#), an Arizona man raising awareness through soccer; [Anntonette Dennis](#), a Dandy-Walker mom raising awareness in Louisiana; [Krystal Lacey](#), a Dandy-Walker mom and our new Northeast Coordinator; and [Emily Jones](#), a Maryland woman whose own struggles inspired her career in nursing and occupational therapy.

We are looking for other individuals and families who are willing to share their stories and serve as an inspiration to our community. If you're interested in participating or learning more, please email chris.rogers@dandy-walker.org to set up a preliminary call.

Thank You, Corporate Partners!





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.

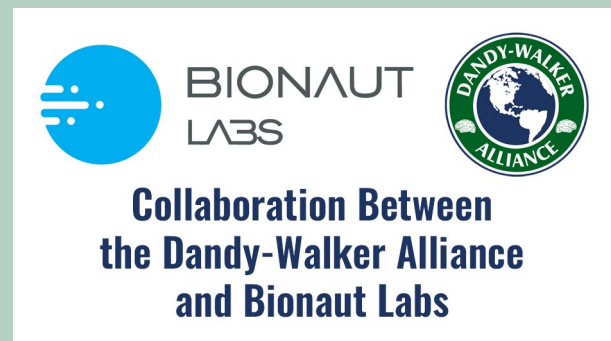
Express your interest at the [link here](#) or use the QR code on the right.



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.



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



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