



The Dandy-Walker Alliance Newsletter

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Welcome from Chris Rogers

Dandy-Walker Families and Supporters,

I am beyond excited to step in as the first-ever full-time Executive Director of the Dandy-Walker Alliance. I have followed this organization's great work from the outside for a couple years now, and I am thrilled to have the opportunity to help grow the operation to support even more families, broaden our network, and fund more important research into the genetic causes of Dandy-Walker Syndrome and any possible treatments.



I am working with Eric Cole, the rest of the board, and other staff members to build a robust operation that furthers our mission of spreading awareness, connecting families, and funding research. Currently, we are updating the resources, research and educational materials listed on our website so that it can be a one-stop-shop for anyone with questions about Dandy-Walker. I'm producing written and video feature stories about our Dandy-Walker families around the world as we work to raise awareness. We're helping families host fundraisers, both virtual and in-person, to help us fund even more genetic research.

As part of these expanded and renewed efforts, we're bringing back the Dandy-Walker Alliance newsletter! This newsletter, available by email, on our website, and on our social media channels, will keep Alliance members updated on our (and your) current efforts – from spreading awareness to fundraising, from personal stories to advances in research. Make sure you sign up for our email list using the QR code at the right, or by visiting www.dandy-walker.org/email.

I want to serve families and those affected by Dandy-Walker Syndrome, so your input is valuable so we can grow the ways in which we can serve you. Please feel free to get in touch with me if you have any questions or ideas for the Dandy-Walker Alliance. You can email me anytime at chris.rogers@dandy-walker.org.

All the best,

Chris Rogers

Executive Director

Dandy-Walker Alliance, Inc.

The Dandy-Walker Alliance Newsletter is back! 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!





May 2022: Dandy-Walker Awareness Month Recap

Numerous locales across America recognized Dandy-Walker Awareness Month this May.

During May, the Dandy-Walker Alliance worked diligently to raise awareness. In lieu of an in-person fundraiser, we held a Virtual 5K to raise money for research into the genetic causes of Dandy-Walker. Families all across the United States – from Wisconsin to Maryland, from Massachusetts to Missouri – took part, walking or running a 5K (3.1 miles). We thank everyone who participated, especially those who sent in photos from their walk/run and earned a Dandy-Walker 5K finisher certificate!

We want to give a big thank you to Krystal Lacey of Massachusetts, whose request for a May fundraiser spurred on the idea for a Virtual 5K. Lacey's son, Declan, has Dandy-Walker, and she was looking for a way to raise awareness and money in her hometown. She ultimately enlisted several family members and friends across the northeast to register for the 5K. In addition to helping organize the walk/run, she has worked diligently to sell greeting cards throughout May to raise money for the Dandy-Walker Alliance.

All month long, we encouraged families across the country to work with their elected officials to get May recognized as Dandy-Walker Awareness Month in their hometowns or states. Several states and locales across the country, including Alabama, Mississippi, and Maryland issued



Several of our Dandy-Walker 5K Finishers, from left to right: Kara Allnutt of Pennsylvania; Lisa and Austin Hulsey of Missouri; and Chris Rogers and Taylor Jaczko of Washington, D.C.

proclamations recognizing the month.

We want to give special recognition to Lisa Bullock, who successfully lobbied the mayor and city council in her hometown of Monrovia, California, to declare May as Dandy-Walker Awareness Month. She also set up a Dandy-Walker Alliance fundraiser at a Blaze Pizza in Monrovia, which brought in money for research as well as spread awareness throughout the local community, and allowed people to unite around a common cause.

In Millport, Alabama, Don and Edna Cole set up a booth at the town's spring pop-up sale to spread awareness and promote the Dandy-Walker Alliance's mission. Their display featured photos of local kids who have Dandy-Walker, and they passed out informational flyers to educate passers-by about the condition.

Thank you to everyone who participated in all of our Dandy-Walker Awareness Month activities. Your support made May 2022 a success for our organization and for families around the world!



Lisa Bullock successfully lobbied the mayor and city council in Monrovia, California, to declare May as Dandy-Walker Awareness Month. Numerous other states and locales across the United States also acknowledged Dandy-Walker Awareness Month in May.



Make an impact today!

Support the Dandy-Walker Alliance at www.dandy-walker.org/donate.



Muller Raises \$15,000 Through NYC Half Marathon

For most of her life, Paula Muller has been a runner. Growing up an avid mountain biker in Canada, she took up running in her early 20s during the winter when it was too cold and rainy to venture up into the British Columbian hills.

Decades later, she has 20 half marathons and six marathons under her belt. But this March, completing the New York City Half Marathon meant more to her than usual. She had decided to run the race for a cause, raising more than \$15,000 for the Dandy-Walker Alliance in honor of her son, Andrew.

Andrew was born in 2006. During Muller's pregnancy, doctors thought they found fluid in the back of his head and neck, but scans and tests returned no signs of malformation.

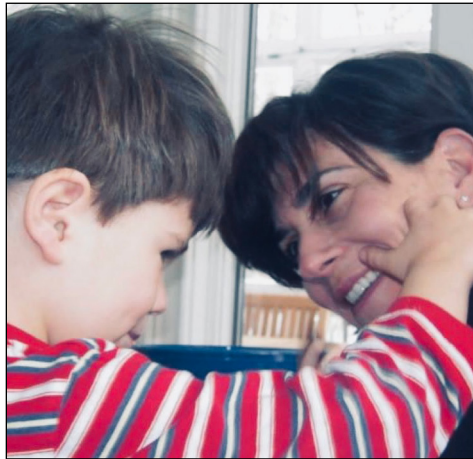
"Nothing conclusive was found, so we didn't really think much of that," Muller said. "But then we had him, and it was pretty clear right away that something was amiss. He had trouble physically: he didn't sit up when it was typical, he walked late, those types of things."

Ultimately, Andrew was diagnosed with autism and began 25 hours of in-home therapy per week – physical, occupational, speech, and floor time. According to Muller, Dandy-Walker wasn't even on their radar at all.

Then, at two and a half years old, Andrew had strabismus, a misalignment of the eyes causing them to turn inward toward each other. Before performing surgery, the eye doctor ordered an MRI to confirm it was a muscular issue rather than neurological.

The MRI came back with a surprising result: Andrew had Dandy-Walker Variant.

"It was kind of an incidental finding, but it explained so much to us," she said.



Above: Paula Muller and her son, Andrew, who was diagnosed with Dandy-Walker Variant at two-and-a-half years old.

Right: Paula Muller after finishing the New York City Half Marathon in March. She ran the race in honor of Andrew and raised more than \$15,000 for the Dandy-Walker Alliance in the process.



"Once we understood more about it, the physical delays, the social delays, that sort of came with the diagnosis."

By second grade, Andrew no longer qualified as autistic, "falling off the spectrum" as he grew socially and intellectually. In hindsight, Muller says, the doctors see autism as a misdiagnosis, with many of his early struggles instead caused by Dandy-Walker.

His Dandy-Walker diagnosis allowed him to continue with some physical and occupational therapies, and he now excels in school, far exceeding the expectations and concerns his parents had early on.

A few years ago, his neurologist suggested he take up rowing to help work out both sides of his body evenly. Now, Andrew, who will turn 16 in July, is an avid rower on his school's team.

While Andrew found his athletic calling on the water, his mother has made it an annual tradition to run the New York City half marathon. Though

now living in Connecticut, Muller is still a Canadian citizen, meaning she can gain admission to the race through a lottery that favors international entries.

A decade ago, when Andrew still appeared to be on the autism spectrum, Muller ran the New York City Marathon to raise money for Autism Speaks. Leading up to this year's race, she decided to run for charity again, putting her half marathon efforts toward a newer cause near and dear to her heart: Dandy-Walker.

"I've been running the New York Half Marathon for years, and it just occurred to me, what if [I ran for Dandy-Walker]?" she said. "I was already in the race so I didn't have to do the charity to get in, but I thought what if I reached out? Why not?"

She contacted Dandy-Walker Alliance Founder & President Eric Cole, who set up a fundraising page highlighting

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her efforts and Andrew's story. At first, she just shared the page on her personal Facebook, yielding moderate success. But fundraising really took off when she began emailing her friends, family, and colleagues, and got her husband, Tom, to share it at his company, Freepoint Commodities.

Her Dandy-Walker fundraiser was selected as the company's charity of the month, as Tom encouraged all his colleagues to donate. Freepoint ended up matching all the employee donations, totaling more than \$5,000.

Muller didn't have a fundraising goal in mind when she started her efforts – she just wanted to raise awareness and bring in any money for research that she could – but she was “blown away” with the response she got and how quickly things took off.

“Once you start raising money and it's coming in, you just keep going, and it kind of takes on a life of its own,” she said.

In all, Muller raised \$15,618 for Dandy-Walker research funding and awareness



Paula Muller (second to left) and her son Andrew (left) with the rest of their family. Paula has run nearly two dozen half marathons, and this year decided to turn her race into a Dandy-Walker Alliance fundraiser.

events and programs. But for her, the most rewarding part wasn't the money, but rather the feeling that with every step she took during the race, she was making an impact on families just like hers.

“Above the money and everything that we raised, so many people reached out and had so many supportive things

to say,” she said. “When I was running that race, I just felt different. Like I know it was hard, and there were times near the end that I wanted to stop, but there was something else that took over. At the end, I had tears in my eyes. It was just a beautiful thing to be able to have done for Andrew and all the other kids with Dandy-Walker.”

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!



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