



The Dandy-Walker Alliance Newsletter

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Nguyen Uses Soccer to Raise Dandy-Walker Awareness

Nick Nguyen was born with Dandy-Walker and hydrocephalus, but by his account, had a fairly normal childhood. He had a shunt revision at age seven, but went on to play collegiate soccer and graduate with a business degree.

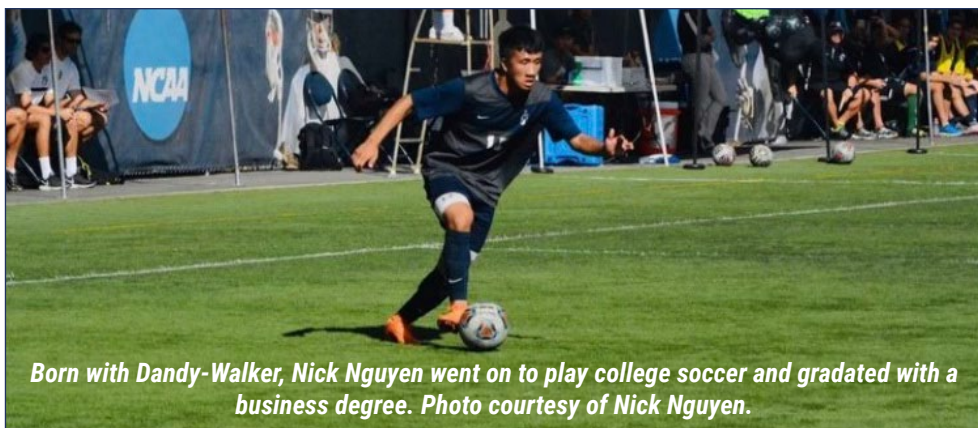
During college, he needed a second shunt revision, and has had two more since graduating in 2018. Now armed with a better understanding of Dandy-Walker malformation and the experience of several recent surgeries, Nguyen wants to do his part to raise awareness in his community and beyond.

An avid soccer fan, he has played the sport since elementary school, even going to play in Spain for a short stint after his graduating college. He decided to pair his love for this game with his drive to educate those around him about Dandy-Walker and its associated conditions.

Last week, Nguyen launched an online store called "Footy Love" where he will sell a handful of soccer jerseys each month and donate a portion of the proceeds back to the Dandy-Walker Alliance. The website also features some information about Dandy-Walker in an effort to spread awareness among his fellow soccer enthusiasts.

Nguyen thinks of soccer as a great unifier, and hopes that he can use his story and experiences to inspire other athletes to give back and consider their peers who are unable to play competitive sports. He sees this store and awareness campaign as just the start.

Visit Nick's [online store here](#), and watch our [interview with him on YouTube](#).



Born with Dandy-Walker, Nick Nguyen went on to play college soccer and graduated with a business degree. Photo courtesy of Nick Nguyen.

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!



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Restaurant Fundraiser Unites Marylanders

On Wednesday, the Dandy-Walker Alliance held a fundraiser and meet-and-greet with the organization's leadership team at Honeygrow in Rockville, Maryland.

Dandy-Walker Alliance families and supporters from across the D.C.-Baltimore region joined Executive Director Chris Rogers and Founder and President Eric Cole at the restaurant to chat about the organization's initiatives and raise money for research and awareness programs.

Are you interested in hosting your own Dandy-Walker Alliance fundraiser in your hometown? Learn more below about how to get involved and work with us to set up an event!



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!



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We Want Your Feedback

Share your ideas and let us know how we can support **your** family this year at dandy-walker.org/2023survey.



Fine and Dandy Documentary Update

Darla Rae and her team at Film It Productions are still working on *Fine and Dandy*, a sequel to her 2008 documentary *Dandy Kids*.

A generous \$15,000 donation from a private, family-owned business has brought Film It Productions closer to their goal, needing just \$12,712 more to complete the documentary. If you are interested in making a contribution to the film's production, you may do so at the [donation page here](#).

All donations are made through the Dandy-Walker Alliance and are tax-deductible. Ten percent of the donation will go toward the Dandy-Walker Alliance's awareness and research programs, while the remaining 90 percent goes to Film It Productions for the documentary.

In the name of raising awareness, the completed film will be free to view online for community members, medical professionals, and anyone else interested in learning.

For more information about the documentary, please contact Darla Rae at filmitproductions7@gmail.com.



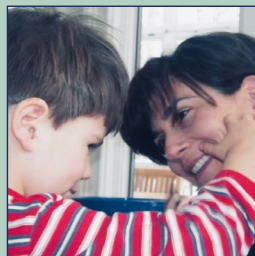
Maddie Sower, Hunter Shultz, and Christian Tuft star in *Fine and Dandy*, a new documentary highlighting the successes that many young adults have after an initially grim Dandy-Walker diagnosis. Filmmaker Darla Rae is in the process of raising money to complete the documentary's production. Photo courtesy Film It Productions.

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.

Our video interview with Nick Nguyen, featured on the front page and [linked here](#), was our second in this series. Previously, we highlighted [Paula Muller](#), a Dandy-Walker mom who recently raised more than \$17,000 for research and awareness by running the New York City Half Marathon. We are looking for other individuals and families who are willing to share their stories and serve as an inspiration to our community. This is a great opportunity to support, connect with, and give back to other families facing similar struggles and journeys.

If you're interested in participating or learning more, please email chris.rogers@dandy-walker.org to set up a preliminary call.





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.

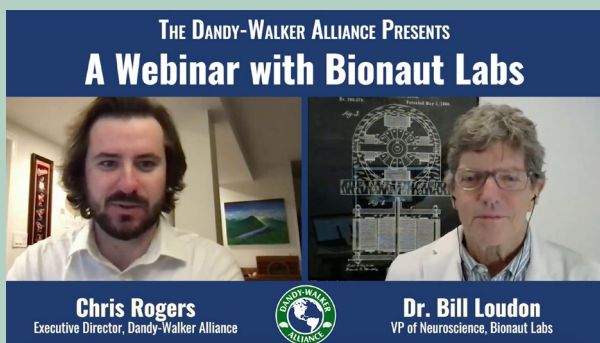
Get Involved Today!

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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