



The Dandy-Walker Alliance Newsletter

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Join us on the golf course for the 2024 Dandy-Walker Open!

The Dandy-Walker Alliance is excited to announce the inaugural Dandy-Walker Open golf tournament will take place on June 3, 2024 in Pasadena, Maryland.

This tournament is a charity event to raise money for the Dandy-Walker Alliance and raise awareness about Dandy-Walker malformation. All proceeds raised will go toward Dandy-Walker awareness, education, and research initiatives and family support programs.

Event details and registration and sponsorship information are below. Plus, learn more about the family behind the event on the next page!

Monday, June 3, 2024

Compass Pointe Golf Course | 9010 Fort Smallwood Rd, Pasadena, MD 21122

www.dandy-walker.org/golf

Register to Play

Sponsor the Open



Dandy-Walker Open

SUPPORT FAMILIES | RAISE AWARENESS | FUND RESEARCH



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www.dandy-walker.org



Welcome to the Dandy-Walker Alliance Newsletter! In each edition, 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!





Jones Family Kickstarts Dandy-Walker Open

In March, the Dandy-Walker Alliance held an awareness dinner at a local Rockville, Maryland, restaurant, near our organization's D.C. area home base. Emily and Ian Jones were among the attendees, making the hour-long trek from the Baltimore area to connect with others in the Dandy-Walker community.

Emily was born with Dandy-Walker malformation. After a relatively "normal" childhood, she began dealing with hydrocephalus symptoms as a teenager. More than a decade later, she has had more than 20 brain surgeries. Despite her obstacles, she is thriving, with multiple degrees and a desire to support and give hope to others facing the same challenges. *[\(You can learn more about Emily's journey in our video interview with her from earlier this year.\)](#)*

When she and her husband, Ian, connected with the Dandy-Walker Alliance at the March dinner, they immediately wanted to get involved further. Ian is an avid golfer, and from there, the idea for Dandy-Walker Open golf tournament was born. Now, planning for the tournament is in full force.



Emily Jones with her husband Ian. The couple is working to put on the Dandy-Walker Open golf tournament next June in Maryland.

The Dandy-Walker Open will take place on Monday, June 3, 2024 at Compass Pointe Golf Course in Pasadena, Maryland. We are currently looking for both players and tournament sponsors. Players can [register](#) as a team of four (\$600), or can sign up individually (\$150) and be placed on a team.

Tournament day includes breakfast, lunch, and drinks for all golfers, plus post-tournament awards. Plus, register before the end of January and you'll get a free Dandy-Walker Open t-shirt on tournament day.

Take it a step further and put your name on the Dandy-Walker Open as one of our [tournament sponsors](#)! Top-level sponsors can attach their name to the breakfast, lunch, and beverage carts. All sponsors can enter players into the tournament as well for no additional charge.

For more information on registration and sponsorship, click the buttons to the right or email golf@dandy-walker.org.

Dandy-Walker Open REGISTRATION

Dandy-Walker Open SPONSORSHIP

Contact Us About the Dandy-Walker Open

Learn More About the Jones Family

Thank You, Corporate Partners!



Medtronic

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!

Place an order before January 1, 2024 and you'll receive a free Dandy-Walker Alliance wristband pack with your order!

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!



Help Advance a Potential New Treatment!

Confidentially share your head imaging (MRI or CT) with Bionaut Labs to help them train their Bionaut devices and advance a potential new standard of care for hydrocephalus associated with Dandy-Walker.

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.