



The Dandy-Walker Alliance Newsletter

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Fine and Dandy Documentary Production Beginning Soon

Darla Rae, a Colorado-based filmmaker, is familiar with Dandy-Walker on a personal level. Her nephew, Hunter Schultz, was born with Dandy-Walker Variant.

In 2008, she set out to tell her nephew's Dandy-Walker story. Her company, Film It Productions, produced *Dandy Kids*, a documentary about the rarity of Dandy-Walker and the challenges that families who are affected face when trying to find answers about the condition.

Now, nearly a decade and a half later, Film It Productions is working to produce *Fine and Dandy*, a sequel highlighting teens and adults with Dandy-Walker, like Hunter, and how they are now thriving after the initially grim prognosis.

Rae hopes that *Fine and Dandy* can help grow Dandy-Walker awareness, increase education, and encourage new research so that those affected by Dandy-Walker can be further supported.

"*Fine and Dandy* will carry the torch forward and fan the flame to grow brighter for those living with Dandy-Walker, regardless of how they entered this world," Rae said.

"It will motivate, uplift, inspire, encourage and educate audiences into action. I hope you will join us on this journey."

Film It Productions has released a 10-minute teaser which can be [viewed here](#). Now, with the help of the Dandy-Walker Alliance, they are raising money



to create a full-length feature film illustrating the success stories of adults around the country thriving with Dandy-Walker.

You can support this project today by [donating here](#). Ten percent will go to the Dandy-Walker Alliance to fund educational resources and family outreach programs, while the rest goes to fund the production of *Fine and Dandy*.

Contributions are tax-deductible, and all contributors will get a digital copy of the film upon its completion.

For any questions about the documentary, please contact Film It Productions CEO Darla Rae at filmitproductions7@gmail.com.

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!





Dandy-Walker Alliance Launches Southern Chapter

The Dandy-Walker Alliance is excited to announce the launch of a new Southern Chapter. With this new chapter, we aim to connect and grow a network of individuals and families affected by Dandy-Walker across the Southern United States. This will be a community for people to share their stories, discuss their diagnoses, recommend doctors, and organize in-person events.

Other parts of the country, such as California, New York, and the D.C. Metro Area, have successfully launched Dandy-Walker Alliance chapters to connect families and organize meet-ups. After her daughter's recent Dandy-Walker diagnosis, Anntonette Dennis of Shreveport, Louisiana, decided that she wanted to do the same in her region.

In May 2010, Anntonette gave birth to her daughter Kerrington. For nearly a decade, Kerrington struggled with developmental delays with no known cause. Finally, in April 2021, a new pediatrician diagnosed her with Dandy-Walker, giving Anntonette the answer she had been looking for over the course of a decade. With a new understanding of her daughter's diagnosis, she has set out to meet and support other families in the South.

"My desire is to connect with families in this region so that we can support and encourage each other through this journey," she said.



Above: Kerrington Dennis. Right: Kerrington and her mother, Anntonette.

After Kerrington was diagnosed with Dandy-Walker at age 11, Anntonette decided to start a Southern Chapter of the Dandy-Walker Alliance to connect with other families in their position.

Ultimately, it is our goal for the Dandy-Walker Alliance Southern Chapter to host awareness events and fundraisers to help fund research and important educational materials for families and medical professionals, as well as organize dinners and outings for families to get to know each other and form a tight-knit community.

"We've seen chapters like this in other parts of the country be really successful and helpful for many families during



their journeys," Dandy-Walker Alliance Executive Director Chris Rogers said. "I think there are a lot of families in the South that will really value a network like this."

Southern Chapter membership is free and is open to anyone in the Dandy-Walker community who lives in the Southern United States. For more information about getting involved, please contact Executive Director Chris Rogers at chris.rogers@dandy-walker.org.

Thank You, Corporate Partners!



After Adult Diagnosis, Bullock Becomes Advocate

Lisa Bullock likes to read. When she finds a topic that interests her, she plunges into it fully, researching and learning as much as she can.

For most of her life, Bullock has struggled with headaches. They first started to come on when she was about six years old, and as she grew, the headaches stayed with her. She had scores of brain scans done from the 1970s onward, but it wasn't until 2009 that a doctor finally pinpointed the cause: Dandy-Walker.

Initially, the diagnosis shocked her. She had never even heard of Dandy-Walker before. So, she decided to read up on her newfound condition and become more knowledgeable about it.

Thirteen years later, Bullock, armed with a decade of research on the topic, has become a fierce Dandy-Walker advocate, both in her hometown of Monrovia, California and on social media.

"I think it's important to bring an

awareness," she said. "There are so many diseases out there that nobody knows what they are. I just want to help people to learn about Dandy-Walker."

Her journey isn't free of obstacles. Dandy-Walker has caused some co-occurring conditions that make it hard for her to walk, so most days she has to use a walker or a wheelchair to get around.

But that doesn't keep her from raising awareness and spreading the word in her community. If anything, it motivates her more.

"I'm not going to stop talking about it until there is a cure or a treatment for [Dandy-Walker]," she said.

Each year, Bullock sets up a fundraiser at a restaurant in Monrovia to raise money for Dandy-Walker awareness and research. This year, she held it at Blaze Pizza and encouraged her network to come out and support the cause she is so passionate about.

But in addition to that, she had another

idea: get a local big wig involved.

She set up a meeting with Monrovia mayor Tom Adams, asking him to declare May as Dandy-Walker Awareness Month in the city. He immediately jumped at the opportunity, and at a city council meeting in April with Bullock in attendance, [Adams issued the proclamation](#).

"If I had known how easy it would be, I would've asked for his help years ago. I was starstruck, I even asked for his autograph," Bullock chuckled about meeting the mayor and getting him involved.

Now, between the annual fundraisers, the city council proclamation, and Bullock's tireless work advocating for herself and others in her network, the Dandy-Walker community has a strong voice in Monrovia.

"It pays in the long run, and it makes me feel good to raise awareness [for Dandy-Walker]," she said. "I've worked so hard and to actually get a proclamation, it gives me such a warm feeling that I'm doing something right."

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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