



The Dandy-Walker Alliance Newsletter

Issue 6 | January 16, 2023 | dandy-walker.org

Kicking Off the New Year

As we move into the new year, we want to take time and reflect on all the blessings we experienced in 2022. We are incredibly grateful to our board members, scientific partners, sponsors, donors, and all those who have donated countless, hours, energy and support to ensure that we continue our mission of serving families worldwide affected by Dandy-Walker Syndrome.

Here are a few of our favorite moments from 2022:

- In March, [*Paula Muller ran the New York Half Marathon*](#) in honor of her 16-year-old son, Andrew, who has Dandy-Walker. Not only did she spread awareness in the process, but she raised more than \$15,000 to go toward supporting families like hers and collaborating on research and treatment initiatives.
- In April, we hired [*Chris Rogers*](#) as our first-ever full-time Executive Director. Chris has helped solidify our day-to-day operations, serve as a support for families who reach out, increase our outreach across multiple platforms, boost our relations with private industry companies, and more.
- In June, we launched our [*Dandy-Walker Alliance newsletter*](#), a regular release that chronicles what's going on in the Dandy-Walker spheres and highlights a few of the many amazing people that make our community so wonderful.
- In October, we began [*partnering with Bionaut Labs*](#), a biotech company that is developing a novel, minimally invasive treatment for hydrocephalus. The Dandy-Walker Alliance is supporting them as they work to train and develop their Bionaut technology with the goal of beginning clinical trials and eventually making it a new standard of care for Dandy-Walker/hydrocephalus patients everywhere.

These are just a few of our favorite moments from 2022. We are so appreciative of everyone who made the whole year a success!. Now, as we set our goals for 2023, we want to hear from you!

How can we best support you and your family? What kind of resources and tools would you like to see us provide? What kind of events, if any, would you want to get involved in?

Fill out our 2023 [*survey here*](#) with any feedback of how we can improve this year, and help us continue to grow and serve families like yours around the world!



Share Your Ideas!



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

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!

In This Issue

Kicking Off 2023 – Let's Hear from You!	1
A Daily Dose of DJ: A Mother and Son's Journey	2
Your Imaging Can Help Train the Bionauts!	4

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!



Daily Dose of DJ: A mother and son's journey

The gentle reach of his hand asking to hold hers, resting his foot on her leg, a smile as he looks her way – Kelly Satter has grown to appreciate the little signs of gratitude and love from her son, DJ.

The now-five-year-old was born in 2017 with Dandy-Walker and numerous other co-occurring conditions. Since his birth, Kelly has transformed her life to become not only DJ's full-time caretaker, but a fierce advocate dedicated to raising Dandy-Walker awareness in her community and on social media.

Her Facebook page, *Rocks-N-Rainbows*, gives more than 4,000 followers a "Daily Dose of DJ," chronicling his ups and downs as he navigates seizures, mobility limitations, feeding tubes, and more. But through it all, Kelly and DJ are usually wearing smiles in their pictures.

Kelly and her husband, David, learned of DJ's Dandy-Walker diagnosis in utero. At 28 weeks they were sent to a high-risk doctor who listed six abnormalities found on the latest ultrasound, including Dandy-Walker.

The Satters had previously suffered a stillbirth, so despite knowing the challenges ahead, they were excited for DJ's arrival.

"We were going to ride this journey out with him and bring him into this world," Kelly said.

Throughout her pregnancy, they worked with the same doctor who guided them through the stillbirth process, so they had a level of comfort and familiarity. Kelly took time off work early and went on bed rest, knowing that DJ was a high-risk pregnancy and there was a chance of an emergency c-section.

Ultimately, she gave birth naturally, and was able to hold DJ for a few seconds.



LEFT: DJ Satter with his parents, David and Kelly. Since DJ's birth in 2017, Kelly has transformed into a full-time caretaker and advocate for her son. ABOVE: DJ celebrates his fifth birthday in November. Photos courtesy of Kelly Satter.

Then, doctors whisked him away to the NICU, where he stayed for 42 days. He needed six surgeries in that month and a half, including fixing a recessed chin that made him unable to breathe on his own and a double cleft palate. Throughout this time, Kelly stayed in the Rainbow House near the Omaha Children's Hospital, visiting him daily.

Finally, DJ came home in December 2017, six weeks after birth and just a few days before Christmas – a perfect present for two parents who were beyond excited to have him.

"We'd had so much loss before he came, and he's actually here now."

In the five years since, the Satters have experienced wild variability in his day-to-day outlook -- what Kelly calls the "revolving door of DJ." Sometimes he'll have a stretch of a good few days or weeks. Then, he might have a seizure that requires a hospital trip or wake up in the middle of the night needing more oxygen.

In 2020, he had a serious bout with (respiratory syncytial virus) that led to double pneumonia. He flatlined twelve times in front of his mother, and ever since then it's been a different journey, she said.

DJ still has not yet gained back all the skills he had developed in the first three years of his life. He's slowly gained new skills in place of the ones he lost, and his parents are hopeful that as time goes on, he'll continue to hit milestones and regain many of the old ones. But, more importantly? He's still here.

To this day, he still sees his fair share of specialists and therapists. He regularly goes to occupational and physical therapy, as well as intermittently going to speech therapy. But many of his other appointments – his pulmonologist, neurologist, plastic surgeon, and ENT, among others – have transitioned to annual check-ups.

He needs to be fed through a gastrostomy button in his stomach. For a

while, his dietician would give Kelly recipes that she could make at home – she would cook from scratch using fresh ingredients and then blend up to a point where he could consume it through his button.

As DJ has grown, Kelly has grown as a parent and caregiver as well. Along the way, she decided to start sharing their family’s journey on her Facebook page.

Not only has this provided a space for her to share her thoughts and feelings as she and DJ navigate each day together, but it’s built a community where she and other families in similar situations can share stories, experiences, and ideas with each other.

Perhaps most importantly, it’s created an avenue for her to show the beauty and value that a child with Dandy-Walker can give the world.

Kelly often thinks of what DJ’s original geneticist told her just weeks after he was born: there’s nothing wrong with him, he’s just unique. She’s carried that forward, making it her mission to help those around her understand that DJ is human in all the same ways that a neurotypical child is.

“They are people too. Whether they can talk or sit or walk or respond, they can feel it all,” she said. “You can see it in his eyes, there’s more going on up there than a lot of people give him credit for. The biggest thing is to slow down so you can see it and appreciate it.”

Through all the ups and downs, the spark in his eyes and the subtle demonstrations of affection reaffirm Kelly’s unconditional love for DJ and drive her to keep finding solutions to help him grow and thrive.



Faced with a number of challenges, DJ and Kelly still often wear smiles on their faces. Photo courtesy of Kelly Satter.

“I just want to keep him around,” she said. “I just want to give him everything I can give him.”

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!



Medtronic



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.

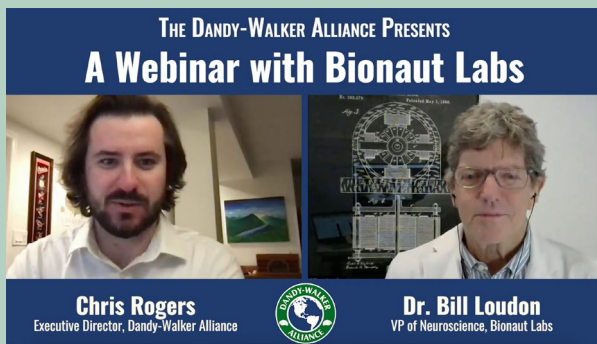
Get Involved Today!

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.

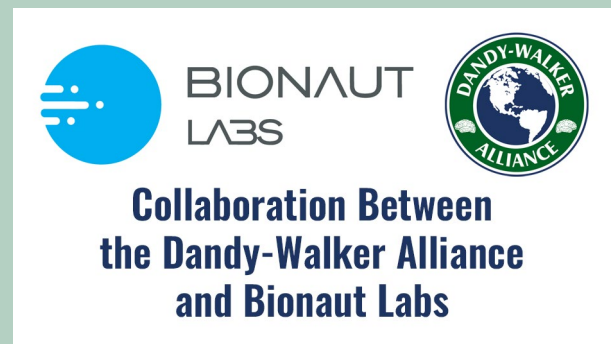
Express your interest at the [link here](#) or use the QR code on the right.



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.



/dandywalker



/company/
dandywalkeralliance



@DandyWalkerAll



@dandywalkeralliance

