



The Dandy-Walker Alliance Newsletter

Issue 5 | December 3, 2022 | dandy-walker.org

What Are You Thankful For?

The Dandy-Walker community chimes in on what they appreciate most this year

"I am thankful for my miracle grandchildren."

—Barbara S.

"I'm most thankful that my little boy was able to walk despite the doctors telling us that he might not walk. Little by little he's uttering words. All in all he's one happy kid."

—Genalyn D.

"My son is more lovely than anything. I am thankful to have him."

—Lor Jane B.

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

What Are You Thankful For? **1**

Jeffrey Smart Thrives After 80 Surgeries **2**

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!



Thank You, Corporate Partners!



Medtronic

Follow Us!



/dandywalker



/company/
dandywalkeralliance



@DandyWalkerAll



@dandywalkeralliance



Eighty surgeries later, Smart is thriving

To many in Ocean Springs, Mississippi, Jeffrey Smart is just another neighbor: a father of four, an employee at the local Wal-Mart, a homeowner, a regular churchgoer.

To the Dandy-Walker community, he is a beacon of hope, a symbol of perseverance. He's had more than 80 brain surgeries and shunt revisions, including more than 60 before he turned 18 years old. But now, at 40 years old, he lives what many would call a normal American life.

Smart was born in Biloxi, Mississippi, in 1982, the son of an air traffic controller and a stay-at-home mom later turned schoolteacher. A few weeks after birth, he was diagnosed with Dandy-Walker.

He had a large cyst on his fourth ventricle which caused hydrocephalus. Doctors put in a shunt, relieving the

pressure and keeping him symptom-free for the next four years.

"I was your regular kid, I did everything else that kids do," he said. "Then, when I was four years old, I had to have a shunt revision. From age four to eight years old, I had 23 more of them."

It became an all-too-familiar cycle: Smart would have a headache that just wouldn't go away. He'd go to the hospital and the doctors would do a scan and find a clogged shunt. They would do a revision to fix it. Then his head would start hurting again and he'd be back to square one.

At age eight, the shunt finally held. He didn't need any revisions or operations for the next six years. He thrived in school, earning Honor Roll marks and straight A's, winning school spelling bees and even coming second in the regional

contest one year.

Through elementary and middle school, Smart attended the small private school where his mom taught. He thrived in the small classes and tight-knit community. But the K-8 school didn't offer a high school curriculum, so he headed off to public school for ninth grade.

It was a bit of a culture shock, he said. After a couple months, he started to find his groove and feel more comfortable. But then, on December 2, he went in for his first shunt revision in six years. That revision failed, and he went in for another one a week later. A month later, the shunt got infected, and he spent a month in the ICU.

He missed out on seeing his friends and his church youth group in what he

Continued on Page 3



Jeffrey Smart and his wife Christine with their kids Morgan, Hyett, TJ, and Noah. Photo courtesy of Jeffrey Smart.



called a formative time in his life, but it wasn't all bad. He laughs remembering how nurses brought snacks and a TV up to his hospital room for a mini Superbowl watch party. The Green Bay Packers – his favorite team – won.

But after his hospital stay and another failed shunt, his doctor didn't know what to do anymore.

"My head kept hurting constantly, even after the operations. And she just gave up," Smart said.

But he didn't want to give up. Neither did his parents, who drove him four and a half hours to Birmingham, Alabama, to get a new opinion.

The doctor in Birmingham took one look and found multiple shunts that weren't connected to anything, meaning they weren't draining or relieving the pressure in his head. They sent him into surgery to revise them, giving him "immediate relief"

Of course, this wasn't the end of the process for Smart. All in all, he had nearly 40 surgeries between age 14 and 19. His hospital visits forced him to miss too much time in school, and he dropped out and got his GED.

While he sometimes felt isolated, he had unconditional love and support

from his parents to keep him going.

"My parents always encouraged me," he said. "They always told me you're going to do this; you're going to have a wife, you're going to have a family. That's what pushed me. That's what kept me going."

Fast forward to 2004, and Smart, then 22, connected with a girl named Christine in an online Christian chatroom. They quickly began talking every day, often for several hours.

"I've got a family. I've got a house. I've got everything a guy can want. Especially for someone who has had 80 surgeries."

After a few months of talking, Smart flew to Long Island to meet Christine in person. He felt an instant spark when he saw her for the first time.

They married in 2007 and took a honeymoon cruise to the Caribbean – Smart's first time out of the country. Then, they returned to Biloxi and got an apartment near the mall where they both worked.

Their daughter, Morgan, was born a year later. Then came Noah, their first son, two years after that. When Christine became pregnant again, they needed more space than their Biloxi apartment had to offer.

After moving up to New York for a short while to be with Christine's parents, they returned to Mississippi and found a four-bedroom house for sale in Ocean Springs, just outside of Biloxi.

It was in a great school district, close to a new Wal-Mart where Smart could work, and most importantly, in their price range.

Now, their family of six is complete, with Morgan, Noah, and two younger boys, Hyett and TJ, all living in the home they own.

Smart still has seizures every few months, but his medication makes them much more manageable than they used to be. With everything that he has overcome, now he wants to be an inspiration for the other children and families out there affected by Dandy-Walker, hydrocephalus, and epilepsy.

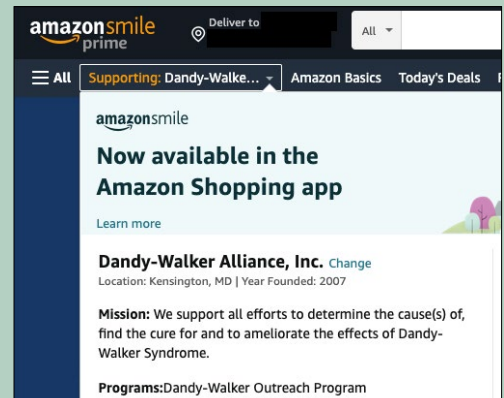
"I've got a family. I've got a house. I've got everything a guy can want," Smart says. "Especially for someone who has had 80 surgeries."

Support the Dandy-Walker Alliance While You Shop!

Holiday season is here, and many people are starting to think about gifts for their loved ones. As you make your list and start shopping, make sure you sign up to support the Dandy-Walker Alliance through Amazon Smile!

It's easy. Go to smile.amazon.com and sign into your Amazon account. Then, select "Dandy-Walker Alliance, Inc." as your charity of choice. Then, start shopping!

A percentage of each purchase made through smile.amazon.com accounts linked to the Dandy-Walker Alliance will go directly to us as we support families around the world, raise awareness, and fund research into the genetic causes of Dandy-Walker.



Bionaut Labs develops groundbreaking new treatment for obstructive hydrocephalus

Over the last five years, Bionaut Labs has developed a potentially life-saving micro-robotic technology for which the U.S. Food and Drug Administration (FDA) has granted a Humanitarian Use Device approval to treat *Obstructive Hydrocephalus associated with Dandy-Walker Syndrome*.

This remote-controlled micro-scale robot, called a Bionaut™, can deliver therapies to regions of the brain that are otherwise difficult or impossible to access with current interventions.

To treat obstructive hydrocephalus, the Bionaut is introduced at the base of the skull using a standard injection technique, much like that used for epidural anesthesia. It is then precisely guided by a computerized external magnetic propulsion system to pierce the cyst, relieving the obstruction and normalizing flow of cerebrospinal fluid.

The magnetic energy required for Bionaut guidance does not involve radiation and is less than 10 percent of that used in magnetic resonance imaging (MRI). The procedure is designed to be minimally invasive and is expected to take about an hour in a standard neuro-interventional suite.

Bionaut Labs' mission is to improve the lives of individuals



A Bionaut next to a penny for size comparison. Photo courtesy of Bionaut Labs.

with central nervous system conditions such as obstructive hydrocephalus associated with Dandy-Walker Syndrome. Their goal is to reduce the need for highly invasive and complication-prone procedures such as ventriculoperitoneal shunts and third ventriculostomies to bypass cyst-related CSF obstructions. Planning is already underway to conduct clinical trials in leading neurosurgical centers across the United States.

[Learn more about the Bionauts! Check out our webinar with Bionaut Labs VP of Neuroscience Dr. Bill Loudon.](#)

Your MRI Can Help Train the Bionauts!

In order to develop the Bionaut system, Bionaut Labs needs images of cranial cysts associated with Dandy-Walker Syndrome where obstructive hydrocephalus is present. These can either be MRIs or CT scans for their engineering team to better understand the cyst anatomy that occurs in patients who meet the criteria.

If you or your loved one meet these criteria and are willing to share any head MRI or CT image sets, you will be supporting the development of a promising groundbreaking therapeutic platform that could significantly improve the lives of patients with obstructive hydrocephalus associated with Dandy-Walker Syndrome and those with other serious central nervous system conditions.

Images will be securely maintained in a highly confidential manner, and only shared with the U.S. FDA regulators and the scientific community in an anonymized fashion. Should you be interested in helping, Bionaut Labs will send a simple consent form for your review and signature.

Get involved today! [Fill out the Bionaut Labs interest form here.](#)



**Bionaut Labs
VP of Neuroscience
Dr. William Loudon**