



DID YOU KNOW

1 in 2,500

babies

ARE BORN WITH

Dandy-Walker

The Dandy-Walker Alliance was established in 2006 by a family in Maryland after their child was diagnosed with the congenital brain malformation in utero at 19 weeks gestation. At that time there was little known about Dandy-Walker Syndrome and the decision was made to create an organization where families could access reliable information and support. With the belief that by promoting awareness, providing a support network for the Dandy-Walker community, helping to set and support research activities and by making information available, we can offer encouragement, services and support to families while also moving results from the laboratory to clinical practice.

Since inception, the Dandy-Walker Alliance has connected families with one another worldwide, worked with researchers to discover genes linked to Dandy-Walker, created a worldwide Dandy-Walker Patient Registry, provided outreach and support to families, produced educational publications, hosted awareness events and programs, worked with Governors across the United States to observe the month of May as Dandy-Walker Syndrome Awareness Month and passed national Dandy-Walker legislation in the United States Congress.

Finding out you or your child has Dandy-Walker can be a stressful time. We are here to support you. To connect with the Dandy-Walker Alliance, please visit us at www.dandy-walker.org and follow us on Facebook and Twitter.



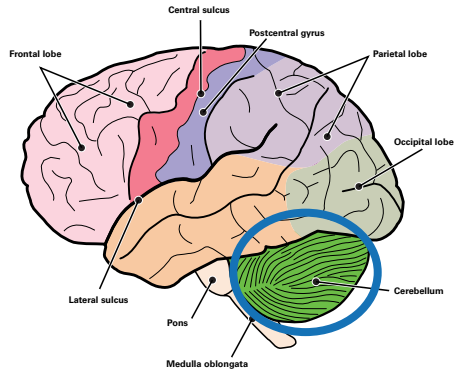
**I AM LIVING WITH
DANDY-WALKER.**

I AM A LIFE WORTH SAVING.

Madison

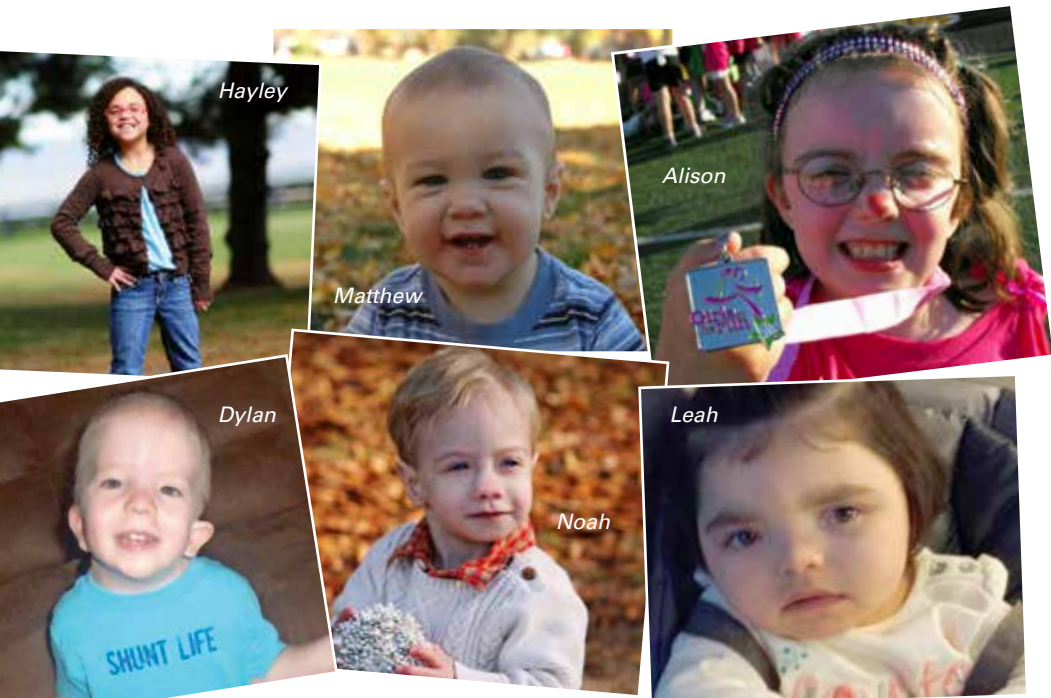
What is Dandy-Walker?

Dandy-Walker Syndrome is a congenital brain malformation involving the cerebellum (an area at the back of the brain that controls movement) and the fluid filled spaces around it.



The key features of this syndrome are an enlargement of the fourth ventricle (a small channel that allows fluid to flow freely between the upper and lower areas of the brain and spinal cord), a partial or complete absence of the cerebellar vermis (the area between the two cerebellar hemispheres), and cyst formation near the internal base of the skull. An increase in the size of the fluid spaces surrounding the brain as well as an increase in pressure may also be present.

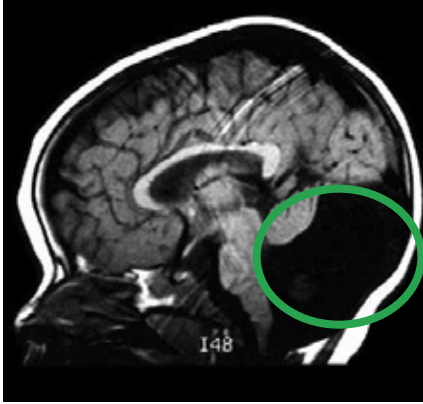
The syndrome can appear dramatically or develop unnoticed.



What are the Symptoms?

Infants

- Slow motor development
- Progressive enlargement of the skull



Above: MRI of Dandy-Walker Malformation

Older Children

- Increase of brain pressure
- Irritability
- Vomiting
- Convulsions
- Bulging at back of skull
- Cerebellar dysfunction: problems with portion of brain controlling movement of voluntary muscles
- Unsteadiness
- Lack of muscle coordination
- Jerky movement of the eyes
- Central nervous system dysfunction: Lack of control of the eyes, face or neck
- Malformations of the heart, face, limbs and fingers or toes



Ana



Josh



Madison

Treatment, but No Cure

Treatment for individuals with Dandy-Walker Syndrome generally consists of treating the associated problems, if needed. A special tube to drain off excess cerebral spinal fluid may be placed inside the skull reducing intracranial pressure and controlling swelling for a condition called hydrocephalus. Parents of children with Dandy-Walker may benefit from genetic counseling if they intend to have more children.



At 16 weeks gestation, we were given the option to terminate due to Dandy-Walker Syndrome. This little girl has every chance to live a happy, fulfilling life. More education is greatly needed for parents & physicians, so every Dandy-Walker kiddo has a chance. Please learn & share to help more children, like Abby, light the lives of so many as she does today!

-Rick, Leigh, & Grace

Prognosis of Dandy-Walker Patients

The effect of Dandy-Walker Syndrome on intellectual development is variable, with some children having normal cognition and others never achieving normal intellectual development. Longevity depends on the severity of the syndrome and any other associated malformations. The presence of multiple congenital defects may shorten life span. While many families are given a grim prognosis when the diagnosis is made in utero the overwhelming majority of people with Dandy-Walker Syndrome do very well.

Advances in Research

While a few genes are linked to Dandy-Walker Syndrome those only account for a few outcomes. The Alliance funds research to discover the remaining genes. Our goal is to one day be able to detect Dandy-Walker Syndrome early enough and intervene non-invasively to reverse or lessen the affects.



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Carter

The Dandy-Walker Alliance Scientific and Medical Advisory Board helps set research priorities, clarify clinical questions, conduct patient recruitments and identify areas for new research possibilities.



Five years ago Tess was born with both Dandy-Walker & hydrocephalus. It was scary for our family & we had no idea what to expect. Today she is a happy, healthy, five year old getting ready to start kindergarten! She's overcome some challenges and amazes us everyday with all she accomplishes. There is no doubt she can do anything she sets her mind to! Don't let anyone tell you what your child can't or won't do, many children with Dandy-Walker defy their prognosis everyday!

-Terri

Meet our Advisory Board.

Kimberly A. Aldinger, PhD

Seattle Children's Research Institute,
Seattle, WA

David J. Clark, PhD

National Institutes of Health,
Bethesda, MD

Robert Cornfeld, MD

Walter Reed Army Medical Center,
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William B. Dobyns, MD, PhD

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Eric R. Trumble, MD

Neurosurgeons for Kids,
Orlando, FL

Marcie Oser Wertlieb, MD

Medical and Surgical Ophthalmology,
Laurel, MD

Dandy-Walker Patient Registry

The registry allows individuals diagnosed with Dandy-Walker, their family members and researchers to gather and share information and health history in a safe, confidential, online database. The registry is helping us better understand the major health issues among individuals with Dandy-Walker, improve the natural history for the diagnosis and help us recruit for genetic, pre-clinical research studies and future therapeutic clinical trials all while educating the community and raising awareness regarding diagnosis, study of the causes and treatments for Dandy-Walker.

Dandy-Walker Awareness & Family Support

In addition to the Dandy-Walker Patient Registry, genetic discoveries made by our Scientific and Medical Advisory Board and on-going patient recruitment we continue to provide individualized family support, crisis management, educational, public policy and awareness activities every single day of the year.



LaKaya

Joshua

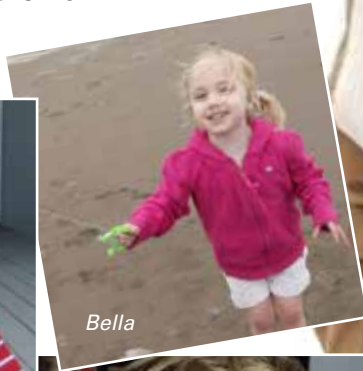
Sean

The Alliance's goal is to be a steady support system for families around the globe who need information about Dandy-Walker, its causes and its treatments. We provide this support by:

- Providing information to over 80 countries
- Providing outreach and individualized support to families 24 hours a day worldwide at no cost
- Conducting patient recruitment
- Supporting research activities
- Lobbying the United States Congress, State Legislators and Governors to pass legislation and issue proclamations to raise awareness and increase our knowledge and understanding into the epidemiology, diagnosis, pathophysiology, disease burden, and improved treatment of Dandy-Walker Syndrome



Tiernan



Bella



Louise



Gabriel

Christian



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Tommy



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www.dandy-walker.org

Donate to the Dandy-Walker Alliance at
www.networkforgood.org



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The Dandy-Walker Alliance, Inc. is a 501(c)(3) tax-exempt public charity registered in the State of Maryland. In giving to the Dandy-Walker Alliance, you help us continue our commitment to providing educational and informational activities, programs and publications and supporting non-partisan research and events to increase public awareness. We support all efforts to determine the cause(s) of, find the cure for and ameliorate the effects of Dandy-Walker Syndrome. All contributions are tax-deductible to the extent permitted by law. Please consult your tax advisor for more information concerning the tax treatment of donations to the Dandy-Walker Alliance.