DANDY-WALKER ALLIANCE

1 in 10,000

babies is born with

Dandy-Walker

www.dandy-walker.org

The Dandy-Walker Alliance was established in 2006 by a family in Maryland after their child was diagnosed in utero with the brain malformation at 19 weeks gestation.

At that time, there was little known about Dandy-Walker Syndrome and no organization advocating on their behalf, so the decision was made to create a non-profit solely focused on Dandy-Walker to provide families with reliable information and support for free. We believe 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 our founding, the Dandy-Walker Alliance has connected families with one another worldwide, worked with researchers to discover genes associated with Dandy-Walker, provided outreach and support to families, produced educational publications, hosted awareness events and programs, worked with legislators across the United States to dedicate 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 dandy-walker.org and follow us on Facebook, Twitter, Instagram and LinkedIn.


I AM LIVING WITH
DANDY-WALKER.
DADDY'S LITTLE
I AM A LIFE WORTH SAVING.
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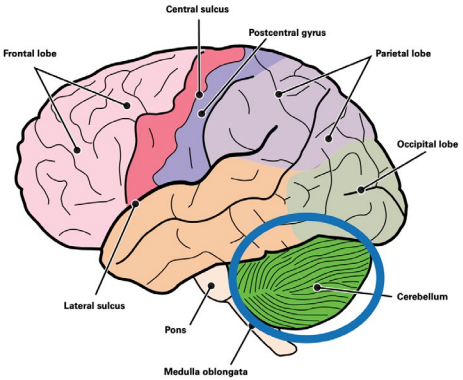
What is Dandy-Walker?

Dandy-Walker 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 Dandy-Walker 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).
- A cyst formation near the internal base of the skull.
- In some cases, an increase in the size of the fluid spaces surrounding the brain, as well as an increase in pressure.

What are the Symptoms?

Infants

- Slow motor development
- Progressive enlargement of the skull

Older Children

- Increase of brain pressure
- Irritability
- Vomiting
- Seizures
- Bulging at the back of the 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

Associated Conditions

Individuals with Dandy-Walker may have other conditions as well, the most common being hydrocephalus, which affects 70 to 80 percent of people with Dandy-Walker.

Hydrocephalus is a neurological condition caused by an accumulation of fluid within cavities of the brain called ventricles, resulting in pressure on the brain. With early detection and intervention, it is treatable with surgery.

Other common associated conditions include:

- Problems with the nerves that control the eyes, face and neck.
- Abnormal breathing patterns.
- Disorders of the other areas of the central nervous system including absence of the corpus callosum.

Prognosis

The effects of Dandy-Walker on intellectual development are variable. Some children have normal cognition while others experience intellectual differences. Longevity depends on the severity of other co-occurring associated malformations or conditions.

While many families are given a grim prognosis when the diagnosis is made in utero, the overwhelming majority of people with Dandy-Walker do very well.

Advances In Research

The Dandy-Walker Alliance funds research into the genetic causes of Dandy-Walker. Currently, a few genes are associated with Dandy-Walker, but those only account for a few outcomes.

We help researchers with patient recruitment of people living with Dandy-Walker and their parents who provide DNA samples. These samples, called trios, are then genetically sequenced to identify new genes linked to the diagnosis to get a more complete picture and find a more conclusive genetic cause of Dandy-Walker.

The Seattle Children's Research Institute, where research is conducted in search of the genetic causes of Dandy-Walker.

We are always looking to partner with more researchers and clinicians to increase the understanding of Dandy-Walker. Our goal is to evolve the body of knowledge about the causes of Dandy-Walker, detect its presence early enough in pregnancy, and intervene non-invasively to reverse or lessen the effects.

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Scientific & Medical Advisors

The Dandy-Walker Alliance Scientific and Medical Advisory Board clarifies clinical and research questions and advises the Alliance on new research possibilities.

Meet our Scientific and Medical Advisory Board:

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Awareness & Family Support

In addition to funding research to make new genetic discoveries, we provide individualized family support, crisis management, educational and awareness activities, and advocate for public policy changes that would benefit individuals living with Dandy-Walker and their families.

The Alliance provides a reliable support system for families around the globe who need information about Dandy-Walker, its causes and its treatments. Some examples include:

- Providing outreach and individualized support to families in more than 80 countries 24 hours a day at no cost
- Conducting patient recruitment for researchers and clinicians
- Funding genetic research activities
- Promoting awareness events and hosting fundraisers
- Working with the biomedical industry to improve treatment options
- Partnering with technology companies to utilize artificial intelligence machine learning to identify genetic variants
- Lobbying local, state and federal governments to pass legislation and issue proclamations that raise the profile of Dandy-Walker and the needs of our community to better understand the causes and true disease burden


Christian


Tiernan

Alison


Matthew

Frequently Asked Questions

Is there a cure for Dandy-Walker Syndrome?

Currently, there is no cure for Dandy-Walker. Treatment for individuals generally consists of treating the associated conditions, if needed. Many individuals benefit from early intervention with occupational, physical, speech, vision and education therapies depending on their needs.

When hydrocephalus is present, a special spinal tube called a shunt may be placed inside the skull to drain off excess cerebral spinal fluid, reduce pressure, and control swelling, or a surgery called an endoscopic third ventriculostomy may be performed.

Will my child with Dandy-Walker look different?

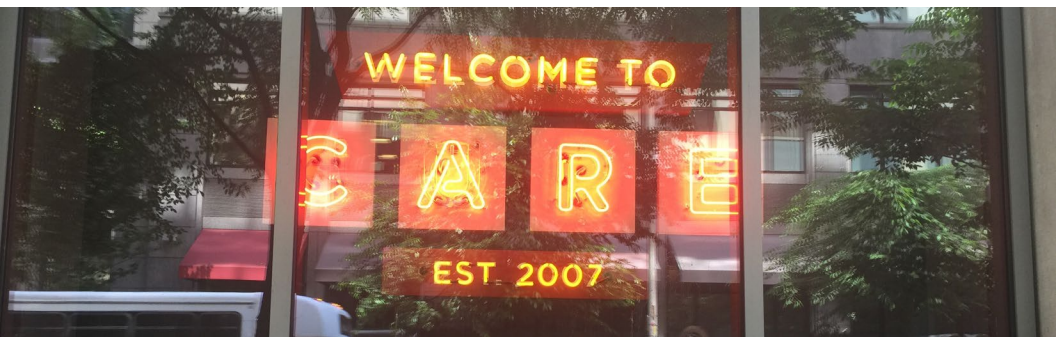
Individuals with Dandy-Walker look just like anyone else with the same variation seen in the general population. When other conditions are present (e.g., cleft lip), their physical expression may be different. It is important to distinguish Dandy-Walker from another diagnosis that someone may have to understand those observable features and characteristics.

Is Dandy-Walker progressive? Will it get worse over time?

Dandy-Walker is not progressive, so it will not get worse over time. Many people who are diagnosed with isolated Dandy-Walker have no changes in intellectual or physical capabilities.

An individual's lifespan may be affected depending on any other co-occurring conditions, many of which are treatable. It is important to see a clinical specialist for these conditions to discuss what interventions or treatments are possible.

If you have other questions not addressed in this brochure, please visit
www.dandy-walker.org/dw-FAQs

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www.dandy-walker.org

Help us support families, raise awareness and fund research!

Scan here to donate to the Dandy-Walker Alliance, or visit dandy-walker.org/donate.

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