

**www.dandy-walker.org**

The Dandy-Walker Alliance is an all-inclusive organization comprised of individuals directly and indirectly affected by Dandy-Walker sharing a collective interest in educational, informational activities and supporting non-partisan research to increase public awareness of the congenital birth defect Dandy-Walker. We support all efforts to determine the cause(s), find the cure and to ameliorate the effects of Dandy-Walker. We believe that by making findings available to families affected in an organized and accessible way and by disseminating the direct and indirect outcomes of translational research we can more swiftly move the results from the bench to the bedside in an expeditious manner.



**www.dandy-walker.org**

The Dandy-Walker Alliance, Inc. is a not-for-profit organization recognized as tax-exempt under Internal Revenue Code section 501(c)(3). 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 for Dandy-Walker Syndrome. We support all efforts to determine the cause(s) of, find the cure for and to ameliorate the effects of Dandy-Walker Syndrome. Donations directly to the Dandy-Walker Alliance 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.



**www.dandy-walker.org**



4422 Clearbrook Lane  
Kensington, MD 20895  
Phone MD: 301-919-2653  
Phone FL: 321-446-0349  
[cureDW@dandy-walker.org](mailto:cureDW@dandy-walker.org)

## Dandy-Walker Alliance

### 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. Dandy-Walker Syndrome is frequently associated with disorders of other areas of the central nervous system including absence of the *corpus callosum* (the connecting area between the two cerebral hemispheres) and malformations of the heart, face, limbs, fingers and toes.

### Is there any treatment?

Treatment for individuals with Dandy-Walker Syndrome generally consists of treating the associated problems, if needed. A special tube to drain off excess fluid may be placed inside the skull. This will reduce intracranial pressure and help control swelling. Parents of children with Dandy Walker Syndrome may benefit from genetic counseling if they intend to have more children.

### What is the prognosis?

The effect of Dandy-Walker Syndrome on intellectual development is variable, with some children having normal cognition and others never achieving normal intellectual development even when the hydrocephalus is treated early and correctly. Longevity depends on the severity of the syndrome and associated malformations. The presence of multiple congenital defects may shorten life span.

### What research is being done?

The National Institute of Neurological Disorders and Stroke (NINDS) conducts and supports a wide range of studies that explore the complex mechanisms of normal brain development. The knowledge gained from these fundamental studies provides the foundation for understanding abnormal brain development and offers hope for new ways to treat and prevent developmental brain disorders such as Dandy-Walker Syndrome.

*Source: National Institute of Neurological Disorders and Stroke, 2008.*

### On-line support groups

<http://health.groups.yahoo.com/group/dw-adults/>

<http://health.groups.yahoo.com/group/Dandy-Walker/>

[http://health.groups.yahoo.com/group/Dandy-Walker\\_Syndrome/](http://health.groups.yahoo.com/group/Dandy-Walker_Syndrome/)