

FACES:

The National Craniofacial Association 1-800-332-2373

What is Hydrocephalus?

Hydrocephalus is caused by the excessive accumulation of cerebrospinal fluid. Characteristics include:

- Increased intracranial pressure
- Dilation of the ventricles (the cavities of the brain)
- Rapidly increasing head circumference
- Downward deviation of the eyes
- Full or bulging fontanel (the soft spot on an infant's head)
- Prominent scalp veins

Why did this happen?

Hydrocephalus is the result of an imbalance in production and absorption of cerebrospinal fluid. It can be the result of development anomalies, infection, injury, or brain tumors.

Will this happen to children I have in the future?

The chances of having another child with Hydrocephalus are very small.

What kinds of problems could my child have?

In addition to the physical characteristics common to Hydrocephalus, your child may have the following problems:

- Severe nausea and vomiting
- Severe headaches
- Excessive tiredness
- Difficulty waking up or staying awake
- Seizures

- Sudden decline in behavior and/ or school performance
- Visual impairment
- Irritability

Will my child need surgery?

At this time, a long flexible tube called a shunt is passed through the brain to the abdomen. This allows the excess fluid to drain away from the brain. Either enough tubing is placed to allow for a child's growth or additional length will be added two or three times during periods of rapid growth.

New advances in procedures to treat Hydrocephalus are continually being studied. Be an advocate for your child!

How do I get help for my child?

Your child should be treated by a qualified craniofacial medical team at a craniofacial center. Currently, FACES has information on many of these teams. This is by no means a comprehensive list of all the craniofacial teams. Please contact FACES for details.

Am I alone?

No! There are many families and organizations who will be glad to talk with you and help you with information and support. Don't forget books, videos, and web sites. The listing on the back of this page will get you started.

FACES: The National Craniofacial Association
Post Office Box 11082
Chattanooga, TN 37401
(800) 332-2373
e-mail: faces@faces-cranio.org
website: www.faces-cranio.org

We provide financial support for nonmedical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.

National Hydrocephalus Foundation
112413 Centralia Road
Lakewood, CA 90715-1623
(888) 857-3434 or (562) 402-3523
Website: www.nhfonline.org
Email: nhf@earthlink.net

Quarterly newsletters for individuals affected by hydrocephalus, their families, and professionals. They also have videos and cassettes available.

Hydrocephalus Association
870 Market Street, Suite 705
San Francisco, CA 94102
(415) 732-7040
(888) 598-3789
Website: www.hydroassoc.org
Email: info@hydroassoc.org

Excellent resource that provides fact sheets, newsletters, support groups, resource guides, physician guides, and internet discussion groups.

Pediatric Hydrocephalus Foundation, Inc.
10 Main Street Suite 335
Woodbridge, NJ 07095
732-634-1283
Website: www.hydrocephaluskids.org
Email: President Kim Illions
kim@hydrocephaluskids.org

This organization is dedicated to providing support, educational resources, and networking opportunities to patients and families.

Pike Institute on Law & Disability
Boston University School of Law
765 Commonwealth Avenue
Boston, MA 02215
(617) 353-2904

This institute gives legal information on issues related to a handicap or disability at no charge.

Children with Facial Difference: A Parent's Guide.

Written by Hope Charkins, MSW.

Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges present by facial differences of their children. Look for this book at your larger bookstore chains.

Available at: www.Amazon.com