

Fact Sheet

Division of Child and Adolescent Health
Pediatric Screening and Genetic Services
Virginia Genetics Program
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Hydrocephalus

What is hydrocephalus?

Hydrocephalus (or hydrocephaly) is a buildup of cerebrospinal fluid inside the brain. Sometimes it is called “water on the brain.” The brain normally makes cerebrospinal fluid to cushion the brain inside the skull. Then the fluid drains away down the spine. Hydrocephalus occurs when excess fluid is made or an obstruction prevents the fluid from draining properly.

What types of problems occur with hydrocephalus?

Hydrocephalus can cause the size of the head to increase. It can also place pressure on the brain. This pressure can damage brain tissue and cause developmental delay, learning disabilities, or mental retardation. Children may have restricted or slow movement, lethargy (appearing tired), or other physical disabilities. Children with hydrocephalus may have slow growth and difficulty feeding. Unfortunately, some children with hydrocephalus will die from these complications.

How common is hydrocephalus?

Hydrocephalus occurs in about 4,000 births each year in the United States. In Virginia, about 80 children are born yearly with hydrocephalus.

What causes hydrocephalus?

Hydrocephalus can occur as the only birth defect a child has. It can also occur in combination with other birth defects (especially spina bifida) or as part of a syndrome (combination of findings). The way in which a syndrome is passed through the family is specific to the given syndrome. A genetic counselor or geneticist can help you determine the risks for your family and situation. It is believed that most hydrocephalus occurs due to a combination of environmental and genetic factors. Environmental factors may include infections or bleeding at or before birth. The chance for parents of one child with hydrocephalus to have another child with hydrocephalus is increased. If no syndrome is present, the chance is about 4%.

How is hydrocephalus treated?

Hydrocephalus may be monitored over time with measurements of the head, ultrasounds of the head, X-rays, CT scans or MRI scans. It may also require surgery to remove the drainage obstruction or to insert a shunt (a thin, flexible tube). A shunt can drain the fluid from the brain to the inside of the abdomen or heart. Some children will do well after surgery, while others will have long-term learning problems.

Where can I go for more information about hydrocephalus?

Hydrocephalus Association
www.hydroassoc.org 1-888-598-3789

March of Dimes Birth Defects Foundation
www.modimes.org 1-888-MODIMES (1-888-663-4637)

Infant and Toddler Connection of Virginia (Early Intervention Services)
www.infantva.org 1-800-234-1448

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