

# HYDROCEPHALUS

March of Dimes • University of South Florida • Florida Department of Health

## Welcoming your new baby into your family.

Your baby was born with a special condition. This condition is known as congenital hydrocephalus. We know this is not easy for you and you may not know how to feel. That's okay. Parents of children with hydrocephalus feel shock, denial, grief, and even anger. It is all right to feel like this and no one will blame you. It will get better. You are not alone. Soon you will find lots of people and programs to help you. You may want to join a support group. Get to know your baby. Enjoy your baby.

## What is congenital hydrocephalus?

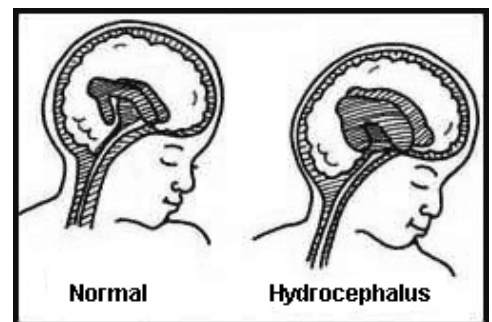
- Congenital (present at birth) hydrocephalus (say: hi-dro **seh**-fuh-lus) means that a baby is born with too much fluid inside the brain.
- The fluid that builds up (collects) is cerebrospinal fluid (CSF), a clear, water-like fluid that normally surrounds the brain and spinal cord.
- Hydrocephalus is sometimes called hydrocephaly or "water on the brain".

## Why are some babies born with hydrocephalus?

- Most of the time we do not know.
- Sometimes babies born with spina bifida (a birth defect of the spine) or encephalocele ([say: en-seh-fa-loe-seel] when a baby is born with a gap in the skull) also have hydrocephalus. See fact sheet on spina bifida.
- Some babies who are born early (premature) have hydrocephalus.
- Sometimes it is caused by an infection the mother had when she was pregnant.
- In some rare cases it runs in families. This means that a baby with hydrocephalus may have someone in the family with hydrocephalus.

## How will this affect my baby?

- Some common signs and symptoms include:
  - Head is larger than normal
  - A bulging "soft spot" on the top of the head
  - Vomiting
  - Sleepy all the time
  - High pitched cry
  - Baby is cranky
  - Seizures (see-zhurs)--baby is shaking all over
  - Baby cannot look up
  - Baby may take longer to learn things (learning problems).
- Not all babies will have these signs or symptoms.
- The extra fluid is often under a lot of pressure which can compress (squeeze) and damage the baby's brain.



Graphic courtesy of:  
Cincinnati Children's Hospital Medical Center.

## How is hydrocephalus treated?

- There is no cure for hydrocephalus but it can be treated with surgery. The doctor puts a thin tube called “shunt” in the brain. The shunt helps drain the fluid.
- As your baby grows, the shunt may need to be replaced.
- Shunts are usually kept for life but sometimes there may be some complications:
  - It may not work properly
  - It may get blocked or clogged
  - It may become infected. If there is an infection you will see redness and the area of the shunt will be tender. The baby will have a fever.
- After surgery, your doctor will tell you how to care for your baby at home and when you will need to

## If we have more children, will they have hydrocephalus?

Once you have one baby with hydrocephalus, the chance for it to happen again in another child may be go up. If you plan to have another baby, it would be important to talk to your doctor before you become pregnant.

## What about my baby’s future?

With the help of a shunt, many people with hydrocephalus enjoy normal activities and live a full and active life.

## Where can I go for help?

- Ask the hospital’s social worker for information about support groups in your area.
- Call the Early Steps Program in your county right away.
- Early Steps services can help your child get a good start during his first three years.
- They offer free services to help your child grow and learn. They help you care for your child.

## Other Resources

- All Children’s Hospital: 727-898-7451
- Children’s Medical Services (CMS): call your local county health department for a CMS clinic in your area or visit: [www.cms-kids.com](http://www.cms-kids.com)
- Florida Directory of Early Childhood Services: 1-800-654-4440.  
They will refer you to your local Early Steps Program and other programs.
- For resources, support and education contact:  
BRAIN: 1-800-352-9424 or [www.ninds.nih.gov](http://www.ninds.nih.gov)  
Hydrocephalus Association: 1-888-598-3789 or visit: [www.hydroassoc.org](http://www.hydroassoc.org)  
Hydrocephalus Foundation, Inc: 1-617-942-1161 [www.hydrocephalus.org](http://www.hydrocephalus.org)
- March of Dimes: visit [marchofdimes.com](http://marchofdimes.com)
- National Hydrocephalus Foundation: 1-888-857-3434 or visit: [www.nhfonline.org](http://www.nhfonline.org)
- Shriner’s Hospital for Children: 813- 972-2250

Funded by a community grant from the March of Dimes.

