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Neurodevelopmental/Birth Defects

206-987-2184

www.seattlechildrens.org
• Spina Bifida Advocates of Washington State
  888-289-3702, sbaws.org
• Spina Bifida Association of America (SBAA), Washington, DC
  800-621-3141, spinabifidaassociation.org
• Parent Help 1-2-3
  800-322-2588, parenthelp123.org
• National Center for Birth Defects and Developmental Disabilities — Center for Disease Control and Prevention (CDC)
  800-232-4636, cdc.gov/ncbddd/spinabifida

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## Spina Bifida

### What is Spina Bifida?

Spina Bifida is also called a neural tube defect. It happens when the neural tube, which includes the brain and spine of the embryo, does not close. This happens during the first month of pregnancy, often before the mother knows she is pregnant. There are many forms of neural tube defects.

### Spina Bifida Occulta (oh-cull-tuh)

In this form, there is an opening in one or more of the bones (vertebrae) that make up the spine. These openings can be seen by X-ray only. The spinal cord, nerves and skin covering are normal. In fact, up to 10% of all Americans may have this most mild form of the spina bifida. In most cases Spina Bifida Occulta causes no problems.

### Spina Bifida Aperta (ay-per-tuh)

In these forms, the neural tube does not close, and parts of the bones (vertebrae) that make up the spine are missing. A cyst or lump pokes out from the opening in the spine. There are 2 types of spina bifida aperta:

**Meningocele (muh-ninge-oh-seal)**

The cyst is covered with skin and most of the time there is minimal, if any, paralysis. Most children with meningocele grow normally. Your child with meningocele should be checked for fluid on the brain (hydrocephalus) and bowel and bladder problems so they can be treated promptly.

**Meningomyelocele (muh-ninge-oh-my-uh-low-seal)**

This is the most severe form of neural tube defect. The open defect contains nerve roots of the spinal cord and the cord itself. There may or may not be a cyst that can be seen. Most often there is damage to the nerves, which cannot be reversed. Your child will most likely have some degree of limb paralysis, sensory, bladder and bowel problems. Prompt surgery helps prevent further nerve damage from infection or trauma. A child with meningomyelocele also often has:

- Fluid on the brain (hydrocephalus). A child may need a tube (shunt) to help the flow of cerebrospinal fluid back into the child’s body. About 90% of children with meningomyelocele have hydrocephalus.
- Some degree of leg paralysis. This varies by child and the level of their defect on the spinal cord.
- Bowel and bladder problems, which can be managed well.
- Compression of the brain at the base of the skull (this is called Chiari II (key-are-ee) Malformation).
- A brain difference and learning disabilities. At least 70% of children with spina bifida have normal intelligence, although most children have learning problems. Some intellectual delays can be more severe.

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### To Learn More

- Neurodevelopmental 206-987-2210
- Ask your child’s healthcare provider
- seattlechildrens.org

### Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.
Can neural tube defects be prevented?

Studies have found that the B-vitamin, folic acid, may help to prevent spina bifida in some cases. Women who have a family history of these defects and could become pregnant should take a vitamin with 4000 micrograms of folic acid daily. Use this vitamin only if recommend by your healthcare provider. They should also eat foods rich in folic acid such as green vegetables and whole grains. The key is having enough folic acid in the system before and during the early weeks of pregnancy, before the neural structures close.

How is spina bifida detected?

Blood tests of the mother and an ultrasound of the baby in the uterus may find the defect. Most health care providers offer pregnant women a blood test called the maternal serum alpha-fetoprotein (MSAFP) screening test. It is part of the “triple screen” test. When a neural tube defect is diagnosed before birth, health care providers can provide you with information and support. They can plan for the best method of delivery, often by cesarean section, to prevent infection and damage to the affected nerves.

Resources

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