

**Office for Genetics
and
Children with Special Health Care Needs**

SPINA BIFIDA FACT SHEET

What is Spina Bifida?

- Spina Bifida is the incomplete development of the spinal cord or its coverings

There are two forms of Spina Bifida:

- A. Meningocele- The membranes which cover and protect the spinal cord are exposed at birth. Usually the spinal cord is not affected
- B. Myleomeningocele- This type is characterized by the meninges and the spinal cord pushing through a hole in the back. In addition, hydrocephalus is associated with this type. An infant born with Myleomeningocele will usually have effects on their neurological and/or motor functioning. The severity of the effect depends on the location of the opening

What is the cause of Spina Bifida?

- The cause of Spina Bifida is unknown. However, scientists suspect that genetic, environmental and nutrition factors may play a role in the cause of Spina Bifida
- Research studies indicate that women who get 0.4mg of folic acid per day before they become pregnant and early in pregnancy have a lower risk of having a baby with Spina Bifida

Signs and Symptoms (depending on location of the opening)

- Motor effects – in very low openings, there may be little effect, but in higher lesions children have weakness or paralysis in their legs
- Bowel and bladder function are often affected
- In openings in the upper back or neck there may be weakness of the arms. This type is rare
- **Learning disabilities and seizures are more common in children with spina bifida**

Is there any treatment for Spina Bifida?

- Surgery is done in infancy to close the opening
- There is no cure for Spina Bifida but there is available treatment to help manage Spina Bifida and prevent further complications. Treatment depends on the type and severity of the opening
- Treatment may include: surgery, medications, physical and behavioral therapy. Your baby's doctor will evaluate and decide what is the best type of treatment for your baby
- If learning disabilities are present, educational services will also be needed

Support Groups/Resources

- Kennedy Krieger Institute
<http://www.kennedykrieger.org>
443-923-9200
- March of Dimes
www.marchofdimes.com
1-410-546-2241
- Office for Genetics and Children with Special Health Care Needs
<http://fha.maryland.gov/genetics/bdris.cfm>
1-800-638-8864
- Spina Bifida Association
www.sbaa.org
1-866-938-3407
- The Parents' Place Of Maryland
www.ppmmd.org
410- 768-9100