

**Office for Genetics
and
People 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 may be 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 indicates 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 – weakness or paralysis in areas below the defect.
- Bowel and bladder function may be affected depending on the level of the defect.
- Learning disabilities and seizures are more common in children with spina bifida than in those without 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 care includes management of symptoms and prevention of further complications.
- Treatment may include: surgery, medication, physical therapy and occupational 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. For therapy and educational services you can contact the Maryland Infants and Toddlers program listed on the next page

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
- Maryland Infants and Toddlers Program
http://www.marylandpublicschools.org/MSDE/divisions/earlyinterv/infant_toddlers/
410-767-0261 or 1-800-535-0182
- NIH Health information:
<http://health.nih.gov/topic/BirthDefects>
- CDC National Center for Birth Defects and Developmental Disabilities
<http://www.cdc.gov/ncbddd/birthdefects/index.html>
- National Organization of Rare Disorders (NORD)
<http://www.rarediseases.org/>
- Birth Defects Research for Children, Inc
<http://www.birthdefects.org/>