

My baby has...

Spina Bifida

You and your baby are not alone. Each year, about 17 babies in Kentucky and about 1,460 babies in the United States are born with spina bifida.

What is spina bifida?

Spina bifida is a type of neural tube defect that forms during the first 1-4 weeks of pregnancy. Early in your pregnancy, a hole formed on your baby's spine. Sometimes, all of nerves stay inside and the hole is covered by a layer of skin. In more complicated cases, the spinal nerves bulge out through the opening and form a small sac.

How did this happen?

Mothers without enough folic acid in their diets are at a higher risk of having a baby with spina bifida. However, your baby's birth defect is ***not*** your fault. There is no guaranteed way to prevent spina bifida. Mothers who have already had one baby with a neural tube defect should take 4,000 mg of folic acid every day during their next pregnancies, starting one month before they become pregnant. For the best chance of a healthy pregnancy and baby, doctors also recommend having a healthy weight, eating well, taking prenatal vitamins, and not smoking or drinking.

What's next for my baby?

Your baby will need surgery to repair the hole in his or her spine. This surgery will usually be scheduled within the first couple of days after your baby is born. Also the doctor may find it necessary to place a shunt (a type of valve) to drain fluid from your baby's brain, which may be done at a later time. Ask your doctor for more details about their care plan for your baby.

How can I help my baby?

Be prepared for potential complications. Your baby's legs may be paralyzed, and your baby may lack bladder or bowel control, or be prone to obesity, skin breakdown, seizures, eye disorders, or learning disabilities. However, with love and support from their families, many children born with spina bifida live long and happy lives.



Zachary's Story – Written by his mom, Amanda

I had two very active boys, two years and eight months old, when I found out I was four months pregnant, and that I was having another boy. It took me a long time to be happy about the pregnancy. I was 32 weeks along when we found out that our baby would be born with spina bifida. We were told that it was a very serious condition, that he would not walk, that he would have many other problems, and that he would have a "poor quality of life." We left feeling unsure and afraid, yet we also felt hope and knew that somehow, everything would be okay. Zachary was delivered at 37 weeks, as soon as his lungs were ready. Within 24 hours, he had surgery to close the hole on his back and two days later, he had surgery to have a shunt, or tube, placed in his brain to drain the excess fluid into his abdominal cavity. He did very well and was only in the hospital five days. At ten months old, he had to have his shunt replaced. He recently had surgery to stretch the muscles and tendons in his hips and ankles, allowing his legs to straighten out all the way. Zachary can't walk, but thanks to amazing therapists, he is very strong and mobile in his own way. He likes to show-off in his wheelchair and "run" as fast as he can in it. He has had and will have many challenges and disappointments, but that is part of life for all of us. He has a strong spirit and by no means has a "poor quality of life." He is our hero and our inspiration and we love him and his brothers so much.

To read more stories about families like yours, go to: <https://www.cdc.gov/ncbddd/birthdefects/stories/spinabifida.html>

Available Resources

First Steps is a statewide early intervention system that provides services to children with developmental disabilities from birth to age 3, along with their families. Participating in early intervention can cause significant improvements in development and learning, which can reduce the need for special education programs later in life. You can receive services at the home, in a childcare center, or other community setting. <http://chfs.ky.gov/dph/firststeps.htm>

The Commission for Children with Special Health Care Needs has a mission to enhance the quality of life for Kentucky's children with special health care needs through quality service, leadership, advocacy, education and collaboration. Eleven offices and seven satellite clinic locations serve children across the state. Commission staff work with families to help them get the care their children need. Nurse care coordinators assist families with medical needs and Family to Family mentors are able to guide families seeking answers to educational, social, and emotional concerns. <http://chfs.ky.gov/ccshcn/>

The Spina Bifida Association of Kentucky (SBAK) is a resource center for children, their families and adults affected by Spina Bifida. SBAK educates parents how to be the best advocate for their child, and helps children and adults overcome physical, cognitive and social challenges to become successful and independent. <http://spinabifidakentucky.org/welcome.html>

Additional Information

The Kentucky Birth Surveillance Registry (KBSR) is dedicated to preventing birth defects through ensuring timely, complete, and accurate birth defects surveillance; referring children with birth defects to appropriate services; providing data for research studies after appropriate review; and implementing birth defects prevention programs in Kentucky. You can contact Kentucky's Birth Surveillance Registry at kbsr@ky.gov.

For more information about spina bifida, visit:

<http://spinabifidaassociation.org/>

<https://www.cdc.gov/ncbddd/spinabifida/index.html>

Information adapted from: <https://www.cdc.gov/ncbddd/birthdefects/types.html>



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