SPINA BIFIDA
ASSOCIATION
OF IOWA

Expectant & New Parent Guide to Spina Bifida

Dear Expectant Parent,

Today, you begin a journey you never expected to take: welcoming and raising a child with Spina Bifida. No one can promise you it will be easy, but know that you will experience support, encouragement, rest, and many blessings along the way.

At this moment, you may feel overwhelmed with fear, anger, guilt, bewilderment, grief, or depression. These emotions often accompany the shock of such a diagnosis. No matter how you feel right now, it is okay. Your horizon, and with it your perspective, will change with time.

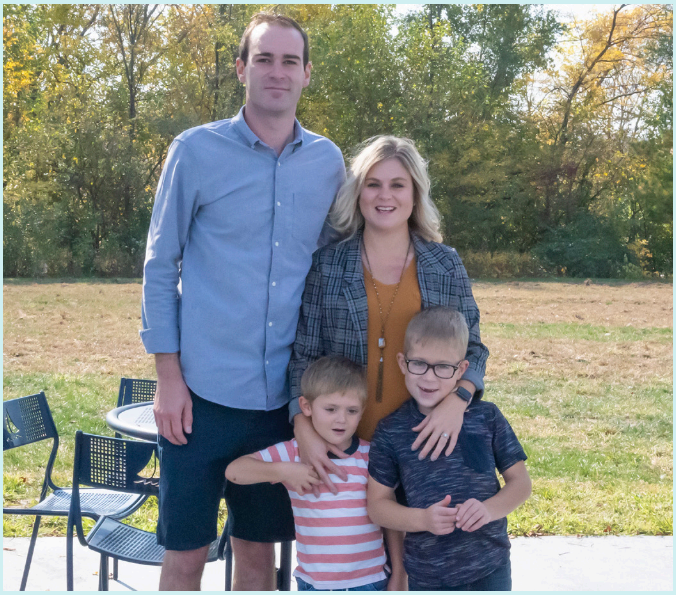
Every baby born with spina bifida is unique and requires specialized care, yet you have reason to be hopeful. Children with Spina Bifida grow up to be capable adults with normal lifespans.

Take this journey one step, one day at a time. Read the information in this brochure and check out the additional resources recommended. Not every internet search will produce helpful or accurate research. Ask for and welcome help. The Spina Bifida Association of Iowa can connect you with an experienced parent to walk with you as you learn.

Do the normal things other mothers do: allow your friends to give you a baby shower, prepare the nursery, take classes offered by your hospital, go on a "babymoon" trip. Most of all, take care of yourself. Staying healthy is important for both you and your baby.

After you review the following information, please contact us so that we can help you prepare for and welcome your new baby.

Scan to get more information



"I have been in your shoes. I am here as a cheerleader, listener, and advocate."

Read Amy's story here ›

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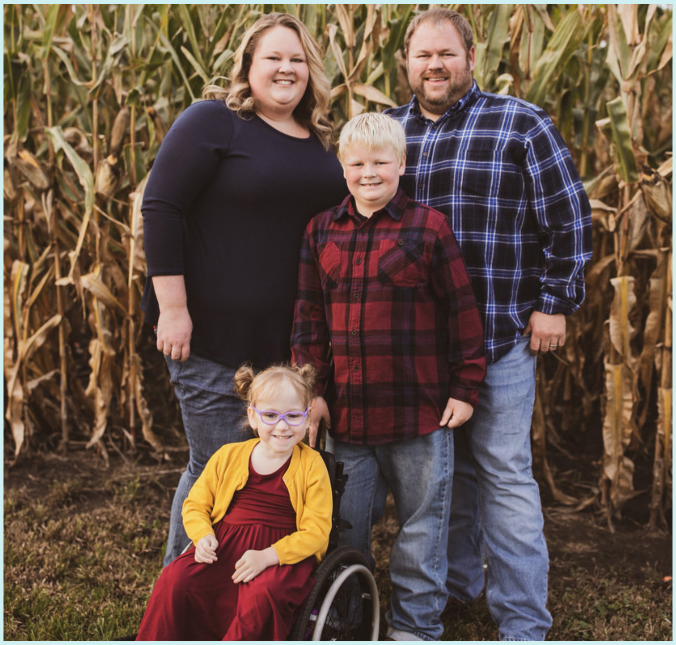

"Take a deep breath (or maybe 10). Know that you are not alone."

Read Ashley's story here ›

The answers to your questions

What is Spina Bifida?

Spina Bifida is a condition that affects the spine and is usually apparent at birth. It is a type of neural tube defect (NTD).

Spina Bifida can happen anywhere along the spine if the neural tube does not close all the way. When the neural tube doesn't close all the way, the backbone that protects the spinal cord doesn't form and close as it should. This often results in damage to the spinal cord and nerves.

Spina Bifida might cause physical and intellectual disabilities that range from mild to severe. The severity depends on:

- The size and location of the opening in the spine.
- Whether part of the spinal cord and nerves are affected.

What causes Spina Bifida?

No one knows for certain what causes Spina Bifida. The role that genetics and the environment play in causing Spina Bifida needs to be studied further.

Spina bifida happens in the first few weeks of pregnancy, often before a woman knows she's pregnant. Although folic acid is not a guarantee that a woman will have a healthy pregnancy, taking folic acid can help reduce a woman's risk of having a pregnancy affected by Spina Bifida. Because half of all pregnancies in the United States are unplanned, it is important that all women who can become pregnant take 400 mcg of folic acid daily.

How is SB diagnosed?

There are 3 tests, but, it is important to remember that no medical test is perfect and the results are not always 100 percent accurate. Spina Bifida can be detected in utero by one or more of the following:

1. A blood test during the 16th to 18th weeks of pregnancy that measures alpha-fetoprotein (AFP screening test). AFP is higher in about 75–80 % of women who have a fetus with Spina Bifida.
2. An ultrasound of the fetus. This is also called a sonogram and can show signs of Spina Bifida such as the open spine.
3. A test where a small amount of the fluid from the womb is taken through a thin needle. This is called maternal amniocentesis and can be used to look at protein levels.

What medical issues do people with SB encounter?

People with SB face a number of medical issues to deal with throughout their lives. SB lesions need to be closed within 72 hours after birth to prevent infection and further damage to the spinal cord.

Hydrocephalus is an excessive amount of spinal fluid (CSF) collecting in the ventricles of the brain. It occurs in approximately 80% of people with SB. Sometimes it occurs before birth, but most often it happens after the back has been closed. Hydrocephalus is usually treated by surgery to place a hollow tube, called a ventriculoperitoneal (VP) shunt, that transfers the fluid from the head to an empty space in the abdomen to prevent brain damage.

Neurogenic bowel and bladder and are caused by damage to the nerves that control the function of the bladder and the bottom section of bowel and anus. In recent years, treatments have been developed which allow individuals to achieve varying levels of functional continence.

- SB issues are dependent on the spinal level of the SB lesion. Most children can walk (though usually with the aid of orthopedic bracing and often with assistive devices such as crutches). Some are full-time walkers, but many walk short distances and choose a wheelchair for long distances. It is generally only those with thoracic or high lumbar spinal lesions who end up using the wheelchair as their only method of mobility.
- Most people with SB have normal IQ scores. They may have learning difficulties; but these can often be addressed when parents and teachers understand the issues and work together.

Every individual with SB is affected differently, and it is impossible to predict a child's outcome before or at birth. Outcomes have improved over the 50 years due to medical advancements. Also, cultural attitudes toward individuals with disabilities have also changed, resulting in improved services. While some individuals with SB have significant disabilities, others are less severely affected. Many attain advanced education and have careers and families of their own. They become doctors, teachers, artists, athletes, and parents. Spina Bifida is only one part of their lives; it does not define them.

After you find out you're having a baby with SB, what are the next steps?

It is recommended that you meet with a pediatric neurosurgeon and/or SB clinic as soon as possible. You will also need to meet with a maternal-fetal specialist or perinatologist to closely follow your pregnancy. You may also need to meet other specialists to learn as much as you can and understand the kind of care your child may need.

Prenatal or Postnatal surgery

For pregnancies diagnosed earlier than 25 weeks gestation, in-utero fetal surgery may be an option to close the baby's back before birth. There are potential risks and benefits of fetal surgery, and it is not appropriate for all women. For those who choose and qualify, an immediate referral must be made to a medical center where the where the operation is performed.

Post-natal care

Babies with SB should be delivered at a medical center that specializes in SB so they can receive specialty care during and after birth. This gives you and the specialists every chance to prepare for the best outcome. After surgery, the baby will be monitored in the neonatal intensive care unit (NICU). The average length of stay is 2 weeks, but this varies based on the child's needs. When the baby is discharged from the hospital, he or she will have periodic follow-up appointments with a pediatric neurosurgeon, orthopedist, urologist, and possibly other specialists. Appointments will be frequent in the first year, and usually less often as time passes.

Scan to get more information

> *"Remember that first and foremost your baby will be just that – a baby whose primary needs will be nourishment, safety and love. He or she may just happen to have additional needs due to Spina Bifida."*

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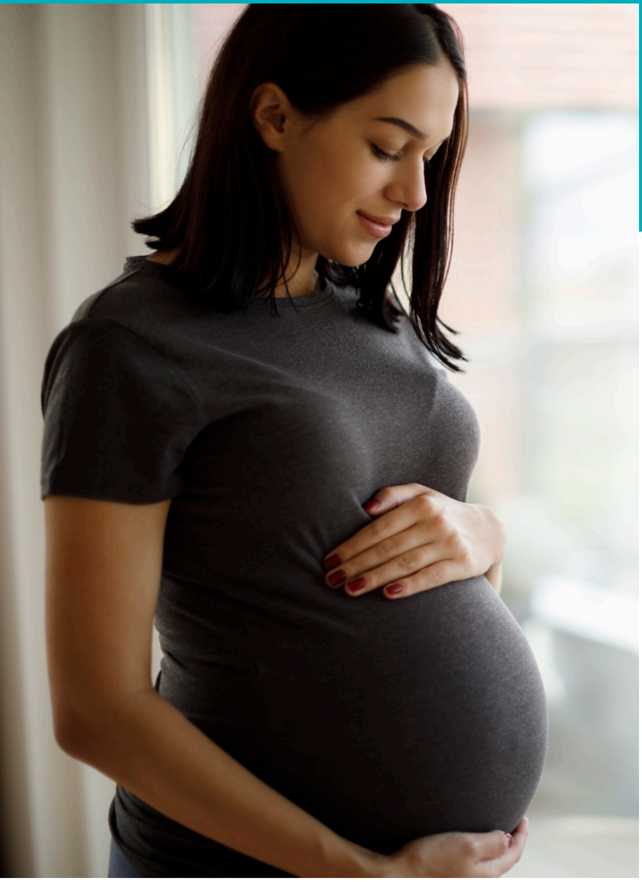
More information is available on these topics on the Spina Bifida Association web site

www.spinabifidaassociation.org

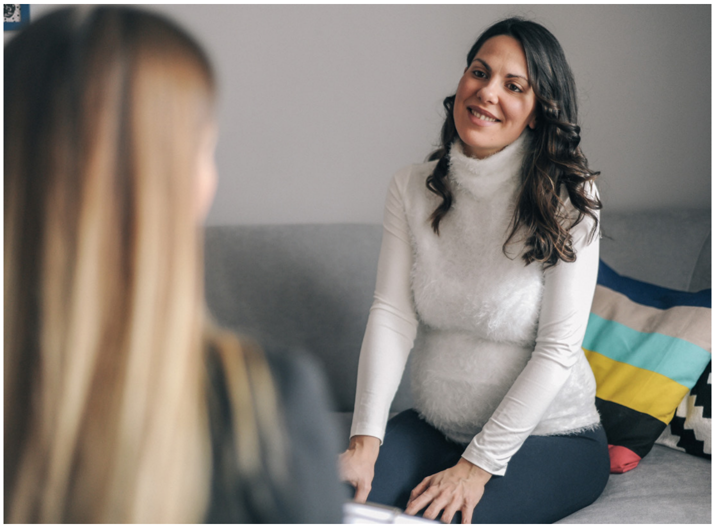
This information does not constitute medical advice for any individual. As special cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.



Spina Bifida Resources

Building Better and Brighter Futures

> *"Remember that you are an equal member of your child's care team. Your concerns matter and your questions need to be addressed. As the parent, you rely on the expertise of the medical team, but you ultimately make decisions for your baby."*



You are not alone on this Journey

We are here for you with:

- Parent Mentor Program for new parents to meet experienced parents
- community of people with similar experiences
- care, support and guidance
- connections to other parents, families and experts
- answers (if we don't have them we'll help you find them)
- the resources of a national organization dedicated to Spina Bifida

Contact us for your **free care package** for you and your baby! We look forward to meeting you and your new bundle of joy!

Scan to get more information

Thank you to:
American Legion
Child Welfare Foundation
CWF

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Building a better and brighter future for all those impacted by Spina Bifida