

A Family For Every Child Matching Assistance



*"We should not be asking who this child belongs to,
but who belongs to this child."*

Spina Bifida

Recently, a few MAP families have adopted children with Spina Bifida. While the name may sound daunting to some, all of them noted in their emails to me that caring for a child with Spina Bifida is "relatively easy". While I have not come across many children in the foster care system diagnosed with Spina Bifida, it does affect between 1,500 and 2,000 of the 4 million babies born every year [[source](#)].

The more you know about a diagnosis, the less "scary" it may seem. This holds true for all diagnoses foster children have. My goal with these newsletters is to provide you with information about a certain diagnosis or challenge, and have you do some research on the topic and become educated. The more you know!

If you have adopted a child with Spina Bifida and would like to share your story and resources you have found helpful, please email me at nora.sharp@afamilyforeverychild.org

What is Spina Bifida?

Spina Bifida, or "split spine", occurs when a baby is in his/her mother's womb and his/her spinal column does not close all the way. It is hypothesized that both genetics and environmental factors play a role in Spina Bifida, although no exact cause has been identified.

There are four different types of Spina Bifida:

- **Occult Spinal Dysraphism (OSD):** In babies with OSD, the spinal cord may not grow the right way, causing serious problems later as the child grows up. One of the more common signs of OSD is a dimple on the child's back, however, not all babies with a back dimple have OSD. Other signs include red marks, small lumps, tufts of hair or hyperpigmented marks. Your doctor can recommend tests to confirm if your baby has OSD.

- **Spina Bifida Occulta:** This type of Spina Bifida is often known as "hidden Spina Bifida" because people can have it and not know it. It is estimated that 15% of healthy people have this form of Spina Bifida and don't even realize it. Spina Bifida Occulta does not cause any harm to the person who has it, and shows no visible signs. Some people with Spina Bifida Occulta have reported pain and some neurological symptoms. Spina Bifida Occulta is diagnosed after an x-ray is taken of someone's back.
- **Meningocele:** In Meningocele, part of a person's spinal cord is pushed through the spine. There is usually no nerve damage, although people with Meningocele may have minor disabilities.
- **Myelomeningocele, or Spina Bifida Cystica:** Spina Bifida Cystica occurs when parts of the spinal cord come through open parts of the spine. This is the most severe type of Spina Bifida, and causes nerve damage and other disabilities. About 70-90% of children with this type of Spina Bifida are born with fluid on their brains, since the fluid that protects the brain is unable to drain properly. If left untreated, the child's head will grow to be too big and they may end up with brain damage.

Treatments for Spina Bifida

All forms of Spina Bifida, except for Spina Bifida Occulta, are treated with surgery. Children diagnosed with **OSD** should see a surgeon as soon as possible, as many experts believe surgery is necessary to prevent brain and nerve damage as the child grows. Children who have **Meningocele** should also undergo surgery. However, it is important that they have regular check ups to make sure they do not have other serious problems. Children who have **Spina Bifida Cystica** are often operated on within 2-3 days after they are born to prevent infections and more damage to the spinal cord.

Effects of Spina Bifida

The most common effects of Spina Bifida are problems with walking and getting around. Other common effects include problems using the bathroom, obesity, learning disabilities, social and mental health problems, depression and gastrointestinal issues to name a few.

Children with Spina Bifida may use the help of wheelchairs, crutches and braces to get around on their own. With assistance, they are often able to learn to use the bathroom by themselves. Parents should recognize what the child's strengths and limitations are, work together with the child's doctors and nurses to help the child become strong and

independent. Depending on the severity of the child's Spina Bifida, parents may reach out to neurosurgeons, orthopedists, psychologists, occupational therapists, urologists, and physical therapists for assistance.

Most children diagnosed with Spina Bifida do well in school and live full lives. About 75% of children diagnosed with Spina Bifida play sports; 80% have normal intelligence levels; and 90% of babies born with Spina Bifida today live to be adults.

Support and Resources

Spina Bifida clinics are available to families in almost all 50 states, and the District of Columbia. To find a clinic in your home state or near you, please click [here](#). Families may also join [online support groups](#) to connect with other families and individuals who have/have experience with Spina Bifida.

Some of the more common topics that the Spina Bifida Association answers can be found on their [Resource Directory](#) page. Families may also view some [FAQs](#) about Spina Bifida to learn more. If your question is not answered on the Resource Directory of FAQ page, you may [contact](#) the Spina Bifida Association to connect with experts to answer your question.

For more information about Spina Bifida, ways to give, how to advocate for those with Spina Bifida and to connect with others, please visit the Spina Bifida Association's [website](#).

You may want to check out two families stories about adopting a child with Spina Bifida:

[Our Son, Our Hero](#) by Ingrid Bakis-Ray for Rainbow Kids

[And Then We Found Kimi](#) by Kathy P. for Rainbow Kids

Stay Connected!

