

What is Spina Bifida?

Thomas May's Story

Spina Bifida is the most common neural tube birth defect in the United States which affects the brain and spinal cord. It occurs in an estimated 3,000 pregnancies each year. Spina bifida begins in the womb, when the tissues that fold to form the neural tube do not close or do not stay closed completely. This causes an opening in the vertebrae, which surround and protect the spinal cord. This occurs just a few weeks after conception, usually before the woman knows that she is pregnant.

In this most severe form, Myelomeningocele, the cyst holds both the membranes and nerve roots of the spinal cord and, often, the cord itself. Or there may be no cyst, but only a fully exposed section of the spinal cord and nerves.

Affected babies are at high risk of infection until the back is closed surgically. The effects of Spina Bifida are different for every person. Up to 90 percent of children with the worst form of Spina Bifida have hydrocephalus (fluid on the brain) and must have surgery to insert a "shunt" that helps drain the fluid — the shunt stays in place for the lifetime of the person.

Thomas May was born on July 20, 2005 with Spina Bifida. He had a myelomeningocele at the L5-S1 (lumbar/sacral) portion of his spine, which was surgically repaired the day after his birth. He was hospitalized for 10 days after his surgery, but returned to the hospital at 3 weeks of age after developing hydrocephalus. Thomas was also suffering from failure to thrive at that time.

After five more days in the hospital, he was able to come home and was closely monitored for his hydrocephalus for 14 months before surgery was required to place a shunt in his brain in September 2006. Over the last year and a half, Thomas has endured a great deal of medical treatments. He receives CAT scans on a regular basis to monitor the pressure in his brain and also undergoes testing on his bladder and kidneys to make sure there is no kidney damage.

Thomas, fortunately, has "normal" kidneys meaning that they are of proper size and function. His bladder, however, is "neurogenic" in nature, meaning that it cannot hold normal pressures of urine requiring him to be catheterized on a strict schedule each day. His bowels also do not function normally which requires him to be on a special diet. Since 3 months of age, Thomas has received physical therapy on a weekly basis to strengthen his legs, ankles and feet, which have been affected by his condition. He has limited function in his feet and ankles, which in the coming months will mean bracing for him to learn to walk independently.

As for the other "symptoms" of Spina Bifida, we have to just wait and see. He is too young to determine whether or not he will have learning disabilities and even his long-term prognosis for his mobility issues and bowel/bladder are unknown. The problem with Spina Bifida is that no child is alike. Despite all of his obstacles, Thomas is the most outgoing, affectionate, intelligent and sweet child we have ever met. We have been blessed to have him in our family and couldn't imagine life without him.



Clinical Symptoms

- Full or partial paralysis, loss of sensation
- Bladder and bowel control issues
- Hydrocephalus (fluid on the brain)
- Learning disabilities
- Latex allergy
- Sexual dysfunction
- Depression
- Social issues