

## Birth Defects

# Real Stories: Living with 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). To learn what it's like to live with this condition or how families are affected, read these real stories from people living with spina bifida.

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## Beth's Story—In her own words

People living with a birth defect like [spina bifida](#) can face many challenges, like numerous surgeries. Read Beth's story to see how she overcame these challenges and leads a full life with spina bifida.

My name is Beth Bryant. I am a 45-year old adult with spina bifida. I was born at a time when only 10% of babies born with spina bifida survived. Growing up wasn't easy. I had many surgeries over the years. I had to wear special shoes and leg braces, and I often felt like an outcast. Despite these challenges, I have always been active to keep up with my peers.

After having many surgeries over the years, in 1995 I had my first tethered cord surgery on my back. Many people with spina bifida have tethered spinal cords. Normally, the bottom of the spinal cord floats around freely in the spinal canal. A tethered spinal cord is attached to the spinal canal. When this happens, the spinal cord can stretch as a person grows and can cause damage to spinal nerves. Surgery can help treat it. During my surgery, the doctor also had to remove a cancerous cyst. Fortunately, he was able to safely remove it and all the cancer.

After the surgery, I had to retrain my brain to learn to walk again. My biggest challenge came when I once again had to have tethered cord surgery with a removal of a cyst. I didn't bounce back quite like I had the first time. This surgery left me using a wheelchair during most of my day. When I woke up from this 2<sup>nd</sup> tethered cord surgery, I could not feel anything from my waist down. After a very long recovery, I did eventually regain some feeling, but not enough to use a walker for very long.

Despite numerous surgeries and challenges, I do live a very full life. I volunteer for the Spina Bifida Association of Kentucky and with my church as well. I am very active in adaptive sports, including hand cycling, wheelchair basketball, and rowing. I also zip around in my wheelchair to get around in my community. I feel like I have a very positive outlook on life. Without the struggles in my life, I would not have the strength that I have.

