



MY STORY

One to two children in every 1,000 births are diagnosed with Spina Bifida

*Our Daughter's*

# TRAGIC DIAGNOSIS

*Living with Spina Bifida*

My name is Cara Neff and I have a story of encouragement to share with you. My husband Bret and I have three daughters, Mackenzie, Kendall, and Bailey. Kendall Grace is the star of our story. She is a little ray of sunshine, a ball of energy, and a very happy child. She also lives with *Spina Bifida*, which is one of the most common birth defects, with an average worldwide incidence of one to two cases per 1,000 births.



Kendall endured her first of many surgeries when she was just three days old



Kendall amazed everyone when she began walking just after her second birthday

*Written by Guest Contributor Cara Neff*

## Overcoming the Obstacles

It's rare to see articles on SB and many people have never heard of it. SB happens when the spinal cord does not develop fully or there is a hole in the spine. Most of these babies undergo surgery when they are just a few days old to repair damage and to close the opening. Many children are paralyzed from the waist down and if they aren't, they may have challenges walking. Many are also mentally challenged. Even though Kendall's condition is the most severe form of SB, she has overcome several obstacles. She has been walking since she turned two, but she does have leg braces and will need many hours of therapy to maintain her ability to walk. She also has a shunt in her head to prevent brain damage and will have to deal with bladder and bowel problems throughout her lifetime. We, like most SB families in our community, are at Texas Children's Hospital quite often. It is vital to continually be monitoring these children because throughout their development new challenges are constantly arising.

## Preparing for the Inevitable

When I was seven months pregnant we were told that Kendall would be born with SB. We were also told that the ultrasound showed that she would probably have brain damage and may never walk. For two months I spent hours on the computer and the phone trying to learn everything I could about what this would mean to our child and to our family. It was a very difficult two months, but on June 16, 2004 Kendall was born and the adventure began.

## Daddy's Girl

Kendall had her daddy wrapped around her finger from the first time he held her. She was such a little trooper, enduring surgery when she was three days old and later in the year a shunt was put

in her head. She also had to have a bladder procedure done. She has undergone many physicals, MRI's, and CT Scans. Throughout the last four years we have had many moments that presented situations that have made us face the fact that Kendall will never be a "normal" child.

## First Steps

One example is the day that a tiny walker arrived in the mail. Along with it came the reality that Kendall might not ever walk. This is just one of the harsh realities that SB patients and their families face. Shortly after her second birthday Kendall amazed everyone—she took her first steps! Not only that, when she was three she was accidentally put into a dance class at her preschool. I called the teacher and explained that she should not have attended but the dance teacher was thrilled to have her and encouraged me to continue bringing Kendall because she loved to dance. The day her grandmother bought her that first little pair of ballet slippers and tutu was proof that doctors don't always know everything. Kendall not only walks, she dances!

## Facing New Challenges

Kendall is now four and a half and will go to kindergarten in the fall. With the start of school there will be many new challenges so we have been exploring ways to boost her self-confidence and independence. She has participated in several children's beauty pageants that emphasize the natural look and personality. She has won two overalls for her age group and placed well in each of the other pageants. Though she does not have the poise and balance that the other girls have, she sparkles when she gets on that stage! She has a very colorful vocabulary, vivid imagination and is very observant and outgoing. From the time she was very little she has had the "I can do it" attitude. I contribute this to Bret. He has been the strongest to encourage her independence that has led to her strong sense of self-confidence.

## Hope for Other Families

Bret and I have chosen to share our story to give hope and encouragement to other parents who may be facing what seems to be a terrible twist of fate for themselves, their families, and their precious child. It is devastating to be told that the baby you have or will bring into the world will be faced with so many challenges. It is almost unbearable at first, but we have realized as we have faced some of these challenges, that the love for Kendall and the strong will to thrive that she displays is all we need to keep facing the difficulties that this cruel birth defect can cause.

## Go With Your Intuition

We share our story because we know the fears, the loneliness, and helpless feelings that parents have when they are faced with having a child that will have special needs. We want to encourage parents to educate themselves about their child's problems, ask all the questions but most important, rely on their own instincts. I am convinced that my "mother's intuition" is one of the best guides I have.

## All in the Family

We have two other children. Mackenzie is 9 and Bailey is 11 months. Like other families with a child that has special needs it is often difficult to give adequate attention to the needs of the entire family. However, we realize that the other girls require special attention also. Mackenzie swims on a USA Swim Team and Bret is very dedicated to her program. He spends many hours at the pool and swim meets. I have the tough job of keeping up with Kendall

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and Bailey, who is now crawling everywhere and is into everything. In many ways having a child with special needs has made us better parents and our family is a stronger family unit. Though Kendall's future is uncertain we know that our faith and love will make us strong and we are learning to appreciate every aspect and moment of our children's development. The gift that living with and loving a special needs child is the growing appreciation of "living for the moment" and appreciating all the "little things" life gives us. **CFM**



Cara and Bret with daughters Mackenzie, Kendall, and Bailey

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## What You Need to Know about Spina Bifida

- In the United States, the average incidence is 0.7 per 1,000 live births. The incidence is higher on the East Coast than on the West Coast, and higher in whites (1 case per 1,000 live births) than in blacks (0.1–0.4 case per 1,000 live births).
- There is no single cause of spina bifida nor any known way to prevent it entirely. However, dietary supplementation with folic acid has been shown to be helpful in preventing spina bifida.
- There is no known cure for nerve damage due to spina bifida. To prevent further damage of the nervous tissue and to prevent infection, pediatric neurosurgeons operate to close the opening on the back.
- According to the Spina Bifida Association of America, over 73% of people with spina bifida develop an allergy to latex, ranging from mild to life-threatening.



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