

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.

Randi's Story Nikia's Story Daily's Story Eli's Story **Elley's Story** Katie's Story Zachary's Story

Beth's Story Henry's story Renee's Story Clark's Story Anifa's Story

Elley's Story—Written by her mom, Maryanne

Maryanne shares the story of her daughter, Elley, who was born with [spina bifida](#). While Elley has experienced many challenges, her family has chosen not to allow her disability to determine who she is, but rather what she has to overcome to live life to the fullest. Read more of her story.

I was about 26 weeks pregnant when my O.B. ordered a more detailed ultrasound. It was then that we discovered that our daughter, Elley, had [spina bifida](#) (a neural tube birth defect) and also hydrocephalus (excess fluid in the brain), along with several other related diagnoses. That day, my husband and I were given some tough news. But, we knew that God had fearfully and wonderfully created Elley just as she was. And, by His strength and grace, we would do everything we could to give her quality of life. We began seeking any resource possible to prepare us for her birth and the concerns that we may encounter as a result of her spina bifida.

Elley has had such a positive impact on our family. Of course, there are many challenges that can occur with spina bifida. However, we have chosen not to allow her disability to determine who she is, but what she has to overcome to live life to the fullest. Elley is in a wheelchair and that has impacted our family to some degree. We have to make alterations here and there to maneuver her around, but we try to treat her as normal as possible and not make her feel as if she is a burden in any way! We take family vacations and get her out of the house as much as possible. She loves to go to church, and we try to include her in all the activities with her age group.

She has taught us to not let anything get in the way of what you truly want to accomplish in life. Yes, heads turn when a wheelchair rolls into a room, but she uses that attention to force people to talk to her. She is a social butterfly! Elley has an older brother, Luke, and they are best friends. She has impacted his life in many ways. He has had to be very understanding, as we have to extend more time and energy to meeting Elley's needs. At times it is difficult as parents to balance our time between the two children. We look for ways to do special things with Luke and include him in the tough medical decisions that have had to be made over the last 10 years. He has had to see his sister endure about 17 surgeries in her lifetime and he has been a tremendous support system. Living with a sibling who has special needs has made Luke be more sensitive to other children with special needs at his school, who also may have developmental and learning challenges and delays like his sister.

Elley has impacted us by her sweet and sensitive spirit. She is extremely brave and although she has times of anxiety about the unknowns that may be facing her, she presses on with a courageous heart. Elley has taught us the importance of counting every victory and being thankful for every day that we are given.



