

Birth Defects

Real Stories: Living with Spina Bifida

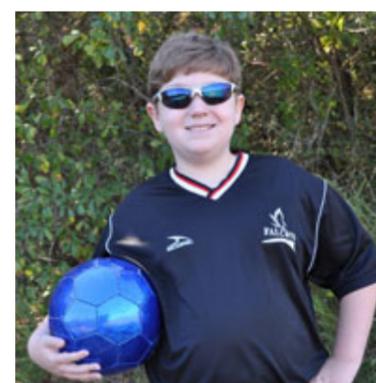
Spina bifida is a condition that affects the spine and is usually apparent at birth. It is a type of neural tube defect (NTD). To learn what it's like to live with this condition or how families are affected, read these real stories from people living with spina bifida.

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Clark's Story—Written by his mom, Nancy

Nancy shares the story of her son Clark, who was born with spina bifida. Although [spina bifida](#) impacts his life every day, Clark does not let it define who he is. Read his story below.

Nancy went for her five-month ultrasound to find out whether she was expecting a boy or a girl. "They kept repeating the ultrasound over and over. I knew from a mother's instinct, and from being a nurse, that something was wrong. The doctor walked in and said your son's going to have spina bifida. I had briefly studied spina bifida in nursing school, only hearing about the worst-case scenarios, so immediately I thought that's what my child would be facing."



Nancy was referred to a high risk obstetrician and the spina bifida clinic at Children's Hospital of Alabama in Birmingham. At her prenatal consultation in the clinic she went with questions about her son's prognosis. "The pediatric neurosurgeon told me to put away all my questions and said I don't know, I don't know." Nancy and her husband were very scared and shaken.

Nancy shares that the staff at Children's Hospital were wonderful, "...but the lack of research when Clark was born meant there were so many 'don't knows.' It would have been so helpful to have a better roadmap based on research. More spina bifida research would give parents definite steps to take at each milestone to ensure the best results for their child. It would also help manage the secondary conditions. Every issue is just as important as the next. Some families might deal more with neurological symptoms, while others struggle daily with bowel and bladder concerns. Nutrition and physical activity are also important when it comes to living with the condition. Clark is ambulatory and goes to the gym but it's still very difficult for him to get his heart rate up. I'm constantly watching his weight. For us, the closest accessible sports are an hour and fifteen minutes away. There are not enough resources available."

Clark loves watching college football and he's the assistant coach of his younger brother's soccer team. He likes to hang out with his friends. Although spina bifida impacts his life every day, Clark does not let it define who he is.

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