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—TIMOTHY BREI, MD, FAAP

# SPINA BIFIDA

Understanding  
and managing the  
condition across  
the lifespan:  
A practical guide  
for families

Kelly Cho, MD  
Cheryl Tveit, RN, MSN, CNML  
Rachelle Lavalier, Parent

**Editors**

Lily Collison, MA, MSc  
Linda E. Krach, MD  
Tom F. Novacheck, MD

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*To individuals and families whose lives are affected by these conditions, to professionals who serve our community, and to all clinicians and researchers who push the knowledge base forward, we hope the books in this Healthcare Series serve you very well.*

*All proceeds from the books in this series at Gillette Children's go to research.*

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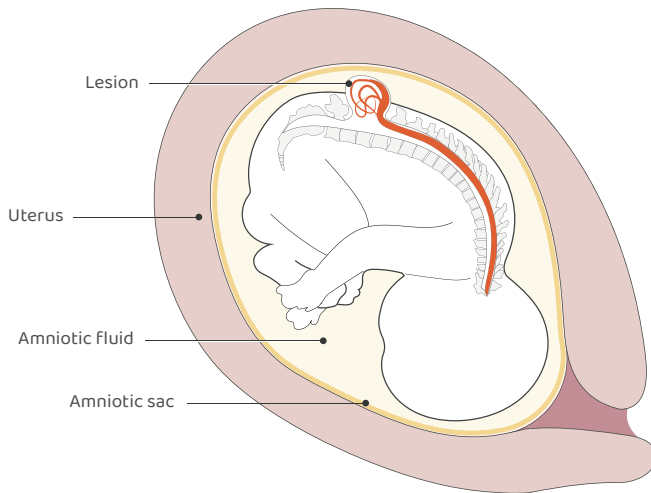
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Spina bifida is the most common type of neural tube defect and is the focus of this book. “Spina bifida” means split spine (“bifida” means split; “spina” means spine), referring to an opening, or split, that occurs in the spine.<sup>2</sup>

The spinal cord is a cylindrical column of nerves that form the main communication pathway between the brain and the rest of the body. An atypical opening in the spine (called a “lesion”) in an individual with spina bifida allows the spinal cord and nerves to herniate\* into a bulging sac. When that happens, the spinal cord and nerves are damaged by several factors, including pressure on the spinal cord and other structures from the uterine wall (during fetal movement or uterine contractions), and exposure to amniotic fluid (especially if the lining around the sac ruptures).<sup>3-5</sup> Figure 1.1.1 shows a developing fetus with spina bifida.



**Figure 1.1.1** Fetus with spina bifida.

Spina bifida is considered a neuromuscular condition, which is a condition that affects the nervous system and muscles, and the communication between them. It is a complex, chronic medical condition that requires lifelong management. While the condition is challenging, with appropriate management, individuals with spina bifida can live a full life. Many finish high school, obtain a college degree, are employed, and live independently.<sup>6</sup>

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\* Be displaced from their normal position.

The opposite of courage isn't cowardice;  
it's conformity.

**Jim Hightower**

My name is Rachelle, and I am the proud mama of a very capable, intelligent, and sassy 17-year-old named Madeline (Maddy) who loves theater, does modeling, is active in extracurricular school programs such as the speech team, and has spina bifida. I share this to let you know that if you have a child with spina bifida, the road ahead may look daunting, and yes, there will be tears. There is also a beautifully complex human that will move mountains in this world with your love, support, and advocacy.

I was 21 years old when I found out I was pregnant: unmarried, financially unstable, and on a path of a “party first” mentality. After the shock and fear of finding out I was going to be a parent wore off, I began to embrace pregnancy. I bought maternity clothes, started reading *What to Expect When You're Expecting*, and best of all, began feeling I was ready to be a mother. I had lots of family support and I couldn't have been happier. Every time I saw a baby or toddler doing something cute, I thought, I can't wait until my baby does that. It was an excitement I had never felt before.

About halfway through my pregnancy, in August 2007, my dad, who had just finished his first tour in Iraq with the military, took us on a vacation to Hawaii. It was amazing, but the entire time I kept thinking, I can't wait to get back home for my upcoming doctor's appointment. It would be at that appointment that I would hear the heartbeat of my child, see a picture of them, and find out if I was having a boy or a girl. My life would be forever changed.

That ultrasound appointment was certainly not what I expected. I had anticipated it with excitement but quickly noted that the technician seemed to spend quite a while looking at the fetus and taking various measurements. She seemed confused and even a little concerned. When she told me that she was going to have the doctor come in and talk to me about a few things, I thought, okay, no big deal. Maybe he will be the one to tell me the sex of the baby and set me up for follow-up appointments or discuss the coming months of pregnancy. But when

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