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—**BENJAMIN D. ROYE, MD-MPH**

# IDIOPATHIC SCOLIOSIS

Understanding  
and managing the  
condition:  
A practical guide  
for families

Tenner J. Guillaume, MD  
Walter H. Truong, MD  
Danielle Harding, PA-C  
Michaela Hingtgen, MS  
The VanGoethem Family

**Editors**

Lily Collison, MA, MSc  
Elizabeth R. Boyer, PhD  
Tom F. Novacheck, MD

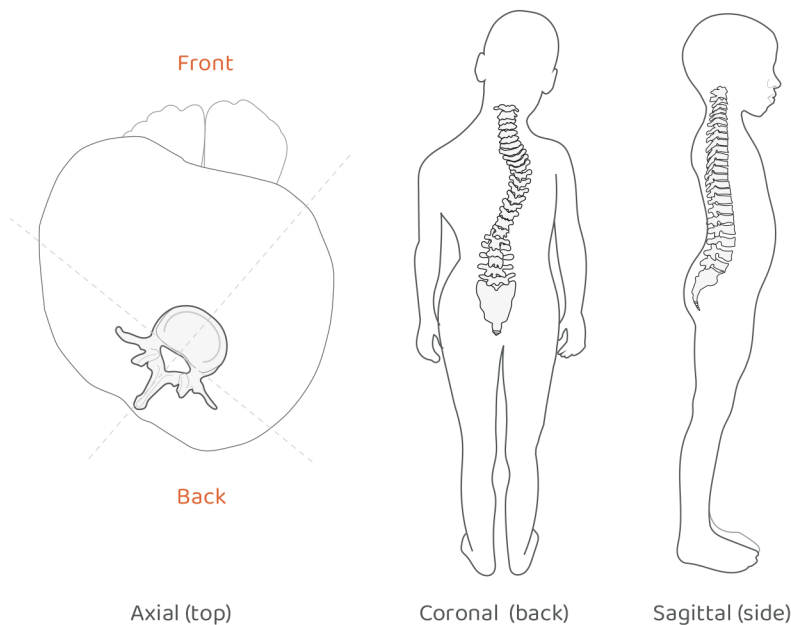
**GILLETTE CHILDREN'S**

If you were to look up the definition of scoliosis (pronounced SKOL-ee-oh-sis, with the capital letters showing the emphasis on that syllable), you would find many sources defining it as a sideways curvature of the spine. This is generally correct, but a more accurate definition of scoliosis is a condition in which there is an atypical three-dimensional curvature and rotation of the spine.<sup>2</sup>

There are many types of scoliosis with varied causes. This book focuses on a type of scoliosis called idiopathic scoliosis. The term “idiopathic” is defined as “relating to a disease of unknown cause,” and it is used in the context of many medical conditions for which the cause is unclear or unknown. Idiopathic scoliosis is, therefore, scoliosis that develops from an unknown cause. There are a few theories about the mechanisms that cause the spine to grow in a curved and rotated fashion in idiopathic scoliosis; perhaps the most accepted is that the front of the spine grows faster than the back of the spine.<sup>3</sup> As the front grows faster, the spine begins to rotate, twist, and curve to the side. However, ultimately, it is unclear what causes these mechanisms to develop in the first place. Individuals with idiopathic scoliosis are otherwise typically developing with no related underlying medical conditions.

Idiopathic scoliosis is the most common type of scoliosis, accounting for an estimated 80 percent of all scoliosis cases.<sup>4</sup> Idiopathic scoliosis affects between 0.5 and 3.0 percent of children.<sup>3</sup> For the large majority, no specific intervention is needed at all. For others, treatment such as bracing or surgery is needed to effectively manage the condition. While diagnosis and treatment can be challenging, individuals with idiopathic scoliosis can expect to lead typical lives.

Scoliosis is characterized by rotation (twisting) in the axial plane, sideways curvature in the coronal plane, and flattening or exaggeration of curvature in the sagittal plane (Figure 1.3.3). While the largest change from typical spine curvature occurs in the coronal plane, scoliosis is described as three dimensional because it affects the spine in all three anatomical planes.



**Figure 1.3.3** An example of spinal curvature associated with scoliosis in the axial, coronal, and sagittal planes.

There are five types of scoliosis classified by cause:

- Idiopathic
- Congenital
- Neuromuscular
- Syndromic
- Other

Scoliosis can also be classified by the age of diagnosis. One age-based classification is early-onset scoliosis (EOS), which is defined as scoliosis that is diagnosed prior to 10 years of age, regardless of cause or type.

There are also age-based classifications specific to idiopathic scoliosis:

- Infantile idiopathic scoliosis (IIS)—age of diagnosis 0 to 3 years
- Juvenile idiopathic scoliosis (JIS)—age of diagnosis 4 to 9 years
- Adolescent idiopathic scoliosis (AIS)—age of diagnosis 10 to 18 years

## Tana

Lila was 12 years old when she was diagnosed, although her pediatrician had been monitoring her for potential scoliosis for years. Shortly after her diagnosis, Lila was fitted for a brace, and eventually she had both a daytime and a nighttime brace. While Lila wore her braces regularly for about 18 months, her curve continued to worsen. With the guidance of her doctor, we made the decision for Lila to have vertebral body tethering surgery. Today, nearly 20 months after her surgery, Lila is a happy, healthy, very active teenager. We are thankful for the care from her doctor and the care team, and grateful for Lila to have had the opportunity to have this surgery. While Lila is still a growing teen and her scoliosis journey continues, we are confident in our decisions and believe we have done everything we can to support her.

I encourage all parents and caregivers to ask questions of your care team and take in all the information (buying this book is a great step in that direction). Once you have all the information and know your options, use that knowledge to make the best decision available for your child at the time. No one knows your child as well as you do. If your child is able to weigh in on that decision, allow them to also hear the information and ask questions. Stay positive, and be brave with them through all phases of the journey. Wearing a brace in middle school is a very brave thing for a teen to do. As parents and caregivers, we can support our child by reassuring them that this time in their life does not define them, and that having to wear a brace is most often a phase. Ask your child what they need to get through this time. It may be as simple as wearing a large sweatshirt over their brace at school. And have hope. Lila's scoliosis diagnosis has been (ironically) such a positive part of her life story. It has given her fortitude, confidence, and a positive attitude.



## Lila

I would tell a kid who recently got diagnosed with scoliosis to stay strong and to not focus on it too much. I thought when I got diagnosed that it was scary, and I didn't know what was going to happen to me. But it ended up not being scary at all because of all the amazing doctors (and my family) to help me through it. I always felt better knowing that although this was really hard to deal with right now, and it's an experience that most kids don't have to go through, it will be over quicker than you realize and you will feel better about your back in the end. Every kid that I ended up eventually telling about my back braces afterwards said that they were sorry I had to go through that and they are amazed at how well I did while I was diagnosed, and now.

"Our daughter was diagnosed with juvenile idiopathic scoliosis right before she started kindergarten, and we were so worried. We wish we had this book during that time as it answers so many questions."

—AMBER MARLATT, PARENT

"As up-to-date and inclusive as a textbook written for medical professionals while being as easily readable as a novel for children with scoliosis and their families. An indispensable source of comfort for all scoliosis patients."

—MUHARREM YAZICI, MD

Idiopathic scoliosis is a condition in which, for no known reason, there is an atypical three-dimensional curvature and rotation of the spine. Idiopathic scoliosis is the most common type of scoliosis. For the large majority of people with this condition, no specific intervention is needed. For others, treatment such as bracing or surgery is needed to effectively manage the condition. While diagnosis and treatment can be challenging, individuals with idiopathic scoliosis can expect to lead typical lives. This practical guide explains idiopathic scoliosis and the evidence-based, best-practice treatments. It also includes the lived experience of families.

The writing of *Idiopathic Scoliosis* was led by Tenner J. Guillaume, MD, Walter H. Truong, MD, and Danielle Harding, PA-C, spine specialists at Gillette Children's, a world-renowned center of excellence for the treatment of brain, bone, and movement conditions. *Idiopathic Scoliosis* is part of the **Gillette Children's Healthcare Series**, a series of books for families who are looking for clear, comprehensive information. Health care professionals, researchers, educators, students, and extended family members will also benefit from reading *Idiopathic Scoliosis*.

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