

Straight Talk with the Curvy Girls

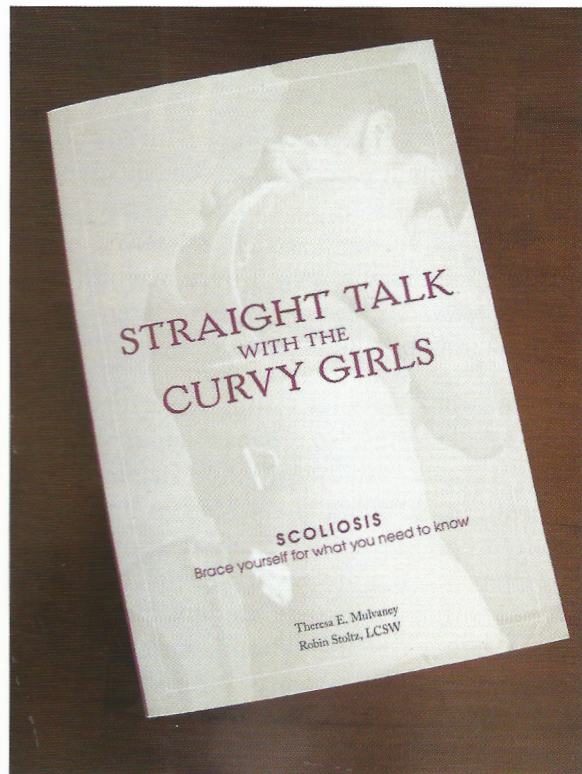
New book confronts the fears and celebrates the triumphs of teen scoliosis

by Mary H. Dyer

Straight Talk with the Curvy Girls is a down-to-earth book filled with practical tips, and without a lot of complicated medical jargon. Got ten minutes at the dentist's office? Do you enjoy lunch more with a book in your hand? Jump in anywhere and read a paragraph, a page, or a chapter. You'll be informed and inspired, even if you don't know anybody with scoliosis.

Coming from a perspective of two parents of children with scoliosis, *Straight Talk with the Curvy Girls* is co-authored by Robin Stoltz, a licensed clinical social worker, and Theresa Mulvaney, who has worked as an advocate for families with learning disabilities. Within the pages of the book, Stoltz and Mulvaney, along with daughters Leah and Rachel, join forces with other moms and daughters to describe their varied scoliosis experiences.

Along with personal stories and thorough conversations with highly recognized professionals, *Straight Talk with the Curvy Girls*, published in 2013, provides solid information about diagnostic equipment, bracing, surgery, growth factors, physical therapy, exercise, alternative treatments, psychological support, and doctor-patient relation-



ships. However, at the heart of the book are the personal memoirs of teen girls (the Curvy Girls of the title), who bravely share their perspectives with warmth and honesty.

Divided into six parts, the first, a section of memoirs, features the point-blank perspectives of eight different adolescents. Remaining sections address fashion, perspectives on taking charge through treatment and surgery, parental support, medical and healthcare professional viewpoints, and psychological guidance.

Girls who live with scoliosis grow up quickly as they learn to cope with very adult issues. In her memoir section, Leah Stoltz describes how she decided to reach out to other girls who shared the feelings of confusion, anger, fear, and loneliness that often accompany scoliosis. Gathering a small group of others with scoliosis, Stoltz formed the first Curvy Girls support group eight years ago, just before her fourteenth birthday. When four girls showed up for the first meeting, the topic of conversation was fashion – or more precisely, how to look good while using a layering technique to disguise the brace and prevent it from rubbing holes in clothing. After the first get-together,

Stoltz continued to organize meetings and the Curvy Girls groups grew.

Stoltz, along with Rachel Mulvaney, Alyssa Mignong, Esther Beck, Danielle Landau, Danielle Greenberg, Jenna Stern, Deanna Albro, and Olivia Loeb-Mevorach make up the Curvy Girl group members who share their stories and experiences in the book.

Although the support groups have changed considerably since the original Curvy Girls meeting, fashion remains an important concern for girls with scoliosis. Mulvaney expands on that theme in the book, with *EmBracing Fashion*, a lighthearted chapter that helps other young scoliosis fashionistas think outside the box.

The adolescent contributors frankly express the down sides to scoliosis and treatments. A common thread running through each short memoir is that scoliosis sucks. The examinations suck. The diagnosis sucks. Going to medical appointments instead of hanging with friends really sucks. Surviving the teen years isn't for sissies. Being a teenager is even more complicated for girls with scoliosis. Braces, which one girl compares to a "suit of armor," are uncomfortable. Breathing can be difficult. Sleeping becomes a new challenge and many nights are spent struggling to find a restful position.

A supportive medical team is critical, but in the book, the girls and their families share the discovery that sometimes finding the right doctors isn't a walk in the park. While most medical providers are knowledgeable and compassionate, in the book, some of the girls are blunt about having met more than their share of insensitive, dismissive, sometimes condescending professionals. And some express having experienced educators displaying little patience for anyone with the need to sit, stand, or walk around to relieve discomfort.

Yet there are silver linings to these experiences. One girl tells the story of being diagnosed with an inflamed appendix, and an emergency room doctor noticed red marks on her abdomen determining that the rubbing of the brace was responsible, not the appendix. A new specialist made a

positive difference, listening to her concerns and including her as a valued member of her own medical team. "I actually felt confident for the first time that I might be able to do this," she writes.

Woven throughout the personal stories within the book, mothers share what it's like to support their daughters, and they express their own feelings of confusion and fear. Parents of girls with scoliosis learn quickly that it's impossible to kiss away the pain, and that all the love in the world won't make it go away. And they sometimes blame themselves for failing to recognize signs of the disease earlier, or because they didn't listen, attributing complaints of an aching back to normal adolescent growing pains. One mother relates that discovering the truth of a scoliosis diagnosis was like a "punch in the stomach."

Straight Talk with the Curvy Girls guides parents toward knowing what questions to ask of health-care professionals, and how to make sure schools provide necessary accommodations. For example, a girl with scoliosis may need a second set of books to avoid having to carry them. She may need a safe place to store a brace when it isn't being worn, or a locker assignment that requires minimal bending.

In one invaluable section, surgery tips are shared by parents, including details that might not otherwise be considered. And the latter part of the book features conversations with an orthotist, a radiology technologist, orthopedic surgeons, and a physical therapist.

According to *Straight Talk with the Curvy Girls*, scoliosis affects nearly seven million adolescents, children, and adults in the United States. Since it is more likely to affect girls than boys, that means there are a lot of curvy girls out there. To those, the message of the *Straight Talk with the Curvy Girls* book is ultimately one of hope, resilience, and ultimate triumph. It's about how discoveries of strength and inspiration are made from within.

Much wisdom can be gleaned from the book. "Obstacles are our greatest teachers," is a message from one girl who writes, "Try not to look at what scoliosis has taken away from you; remember to notice all the gifts it has given you." **sq**