



# Living— *and playing to win—* with scoliosis

HIGH SCHOOL STUDENT'S  
SCHOOL PROJECT RAISES MONEY  
FOR ORTHOPAEDIC RESEARCH

▲ Ms. Distefano considered placing “have their back” on the scoliosis awareness bracelets she created for a school project, but ultimately chose “love their curves.”

For three years, **Taylor Distefano** knew she would need to complete a project worth a good portion of her senior English grade. But when it came time to develop a concept, she wanted to do more than get an “A.”

Ms. Distefano decided to raise money by selling awareness bracelets for scoliosis—a disease she’s had firsthand experience with since being diagnosed at age 13—and giving the proceeds to OREF.

“I always wanted to make my project worth something rather than going with the flow for a few months and turning something in,” Ms. Distefano explained.

Scoliosis, an s- or c-shaped curvature of the spine, often does not appear until a child reaches adolescence, and it can become more pronounced during the child’s last major growth spurt. Ms. Distefano was screened in elementary school as recommended by the American Academy of Pediatrics, but it wasn’t until her pediatrician examined her during a junior high school sports physical that she was diagnosed with an abnormal spinal curvature of 12 degrees.

## TAKING RIGHT FIELD

Orthopaedic surgeons consider family history, age of the child when the curve began, and location and severity of the curve to determine the best treatment protocol for each patient. Spinal curvatures between 10 and 20 degrees usually are monitored, and curvatures between 20 degrees and 45 degrees can be braced to prevent progression of, but not reverse curvature.

When first diagnosed, Ms. Distefano’s degree of curvature wasn’t severe enough to warrant intervention. By her senior year in high school, however, her curvature had progressed to 32 degrees.

Ms. Distefano’s mother, **Patricia Distefano**, a physical therapist, theorizes that her daughter’s increased spinal curvature is linked to her being checked into the boards while playing on a boys ice hockey team. Because Ms. Distefano is no longer growing, bracing now will be ineffective, but her orthopaedist believes the curve should not become any worse. Surgical intervention, or spine fusion, is usually reserved only for patients whose spinal curvature exceeds 45 degrees.

So, Ms. Distefano simply lives with her curvature. Although scoliosis isn’t usually painful, some patients do experience severe chronic back pain, deformity and difficulty breathing. In Ms. Distefano’s case, her spine presses on nerves causing low back pain and occasional loss of feeling in her legs. At times it is difficult for her to even

lie down comfortably, and severe pain prevented her from pitching for her Gloucester High School, Gloucester, Va., softball team her junior year. She wasn’t out of play completely, but was moved to right field.

“I just stood there the whole year,” Ms. Distefano said. “It was frustrating not being able to pitch because it’s what I’ve done since I was 7 years old. I’m known for pitching where I live, so that was hard.”

Her year off the pitcher’s mound gave another starter a shot, and, while Ms. Distefano did pitch a few games her senior year, she decided not to risk hurting herself again, and played first base instead.

### LOVE THEIR CURVES

Her struggles during her junior year helped inform Ms. Distefano’s senior

project to raise money for scoliosis research and awareness. Abbreviated as SIRS, the senior independent research study project is mandatory for all seniors at Gloucester High School. Students choose the project focus, which can be anything from shadowing a mentor in the profession they’re considering to teaching another student how to play an instrument. Ms. Distefano knew she wanted to raise money, but needed to do it in a way that wouldn’t interfere with softball practice, other extracurricular activities or applying for college. A story about a boy who had raised money for diabetes by selling awareness bracelets inspired her.

Ms. Distefano found a style of bracelet she liked online and ordered 200 that she arranged to have customized with one of several slogans suggested by her father, **Stephen Distefano**.

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◀ From the age of 7 until her junior year in high school, when the pain from scoliosis made her switch to right field and then first base, Ms. Distefano was an all-region pitcher.

Although Ms. Distefano did not pitch her senior year, she was able to continue playing softball despite low back pain and occasional loss of feeling in her legs caused by her spine pressing on her nerves.

The bracelet inscription reads “love their curves” on one side and “spinal curvatures” on the other.

## KNOCKING ON DOORS

Ms. Distefano sold the bracelets for \$3 apiece to fellow seniors familiar with the SIRS project, to peers on her softball team and clubs to which she belonged, and by giving some to her grandparents to sell at church and her parents to sell at work. She also knocked on doors throughout her neighborhood, which she said took hours, but brought in a lot of money.

However, Ms. Distefano found that raising money was more difficult than she expected. Some people thought she was charging too much for the bracelets, and she didn't sell as many to her friends as she had anticipated. If she had to do the project again, she said, she would target an audience older than her peers, to whom \$3 meant possibly forfeiting a fast food lunch. But she did find some generous donors.

“I've had people hand me \$20 and say, ‘I want just one bracelet,’” Ms. Distefano

said. “I've had a lot of people help me who know someone with scoliosis, which made me realize how many people have it. Some people would buy three bracelets and say, ‘I have a cousin or aunt with scoliosis, so I'll get one for them.’”

To determine where to donate the proceeds, Ms. Distefano searched online for organizations that support scoliosis research, and, based on her interest in both scoliosis and lordosis—an inward curvature of the spine—she decided to make the contribution to OREF.

“I chose to make the donation to OREF because it isn't focused on just scoliosis, but a whole spectrum of [orthopaedic] problems,” she explained.

Via e-mail, Ms. Distefano alerted OREF to the project and her plans to make a contribution. She was pleased to receive a response and materials she could add to the presentation portion of her project, which consisted of PowerPoint slides and a poster board on which she placed photos of stretches recommended for scoliosis

patients and a cut-out of an *Impact* magazine cover to show where the money would be donated.

“After I presented, a few people wanted to buy bracelets and I got positive feedback from them and my teacher,” Ms. Distefano said.

## LIVING WITH SCOLIOSIS

Ms. Distefano, who now attends West Virginia University as a political science major on a pre-law track, thinks that children should be checked for scoliosis when they're young so that they can be braced if it will prevent their curvatures from progressing. And she wants children who are diagnosed to know that having scoliosis doesn't mean they have to give up everything they love.

“When the nurse told me that I might not be able to play my sport—ice hockey at the time—I was really scared. I'd like kids to know that if you have scoliosis you might have to deal with some pain, but if you want to play, you can.” ■