

Innovative spinal stapling leads to astonishing outcome for little girl

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Grace Rego and her little brother Henry enjoy a sunny day in San Francisco.

Four-year-old Grace Rego had been complaining about back pain for several months. She had trouble sitting in the car, even for short periods of time, and told her parents Jennifer and Chad her back felt “spicy” and “hot.”

Soon after the Regos received a diagnosis they were not prepared for: scoliosis or a curvature of the spine.

The Regos consulted several specialists who said Grace would have to wear a brace until she was an adolescent, perhaps 10 years or so, a “hope and wait” approach as Grace's mother Jennifer puts it, that still carried a high likelihood she would need a spinal fusion and unknown psychological ramifications. Many might have resigned themselves to

this fate, but the Regos aren't like most people. "Hope and wait" wasn't in their vocabulary.

It is because of this refusal to give in to that approach that the Regos are being honored on September 1 with the second annual UCSF Colin Powell Courage Award at the Concert for UCSF Benioff Children's Hospital.

The Regos sought the care of UCSF's Mohammad Diab, MD, a pediatric orthopaedic surgeon with a special interest in spinal deformities who offered a more innovative approach to her care.

Desperate for an appointment, Jennifer called Diab's office on a Friday morning, crying on the phone with the scheduler. She told them to be at the office the same day at 3:15 p.m.

"My policy is I will see anybody who wants to see me right away," said Diab. "Even though we are a big institution, we are nimble. I continually remind our staff that we are here to serve our community and society, and work with them to make sure we provide individualized and personal care that is responsive to what our patients need and want."

On that Friday afternoon, Diab took a look at Grace, her X-rays and paused. "He took a deep breath and started outlining what this means," said Jennifer. "He talked about scoliosis in ways we can understand it. About how rare it is and what it means for Grace. In literally two minutes, our world went from falling apart and looking at surgeries until she's 13 to thinking, 'We have a plan and have this guy on our side.'"

Six weeks ago Diab performed a rare surgical procedure on Grace called vertebral body stapling at UCSF Benioff Children's Hospital, the only hospital West of the Mississippi to perform the surgery. While vertebral body stapling is a "newer" operative option, it was first developed in the

1950's. In its original iteration, the surgery failed because the staples were too weak to hold the vertebrae and migrated out of the bone and floated around the chest.

In the late 1990's, the staples were reinvented using a shape changing mixed metal made of nickel and titanium, and manufactured with curved prongs. The staple is frozen and the prongs are straightened, and stay straight while the staple is on ice on the instrument table in the operating room. Once inserted into the spine of the child, the prongs then warm to body temperature, which causes them to curve back to the original shape. Stronger than the original, the new staples can't back out of the spine due to the curved prongs lodged in the bone. Only after Diab's research team at UCSF did the only cadaveric study on the staples did he feel it was safe to introduce this new procedure to patients.

Keeping Lines of Communication Open

Throughout the process Diab remained in constant contact with the Regos, often calling on evenings and weekends to monitor Grace's symptoms and answer questions. "He said he would hold her together with bubble gum and string if that's what it takes to get her to 13-years-old, when they typically can fuse the bones," said Jennifer. "During Grace's five days in the hospital Dr. Diab would always come in to check on her. I was always so impressed with his dedication and personal touch. He never let on what a big deal this was."

Jennifer and Chad credit Diab with keeping them calm and allowing them to focus on the most important thing: Grace. "People would tell me I seemed so strong, and I'd say it's because I talk to my doctor comfortably," she said. "It's different when you have your doctor who is zoned in and on it. We always had constant flow of communication."

It was those open lines of communication that lead to a dramatically

improved outcome. While Grace's surgery was originally scheduled for August, Jennifer had a "gut instinct" that Grace's curvature was rapidly progressing, and it would be too late. Originally, Diab believed there was still time to observe Grace for signs of worsening, but heeded Jennifer's concerns. "He listened to me. He didn't let his ego get in the way."

"This is a mother who proves the principle in my clinic that mothers rule," said Diab. "Ms. Rego is a very proactive person and clear thinker and wanted to go ahead with surgery." By the time Grace came for her follow-up the curve had increased from 27 to 38 degrees. "That's why I listen to the mothers because they know their children better than I could ever hope to," said Diab. "They are colleagues in the care of my patients."

Now, six weeks post surgery, Grace has bounced back like a champ, including attending summer camp and preparing to start Pre-K on September 12. Her curve is now in the low 20 degrees, a difference Jennifer calls "astonishing."

"Grace is terrific, and a better kid for it," said Jennifer. "She's shy, but somehow this is making her a better person and seeing the silver lining in it. She knows she needs to take care of her body, not go swimming right now or go in jumpy houses. Grace talks about how she's so special because she has staples in her back."

While the staples may be keeping Grace's back straight, it's her [parents](#) perseverance and courage that keeps her moving forward.

Provided by University of California, San Francisco

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