

# Mailbag



## DEAR RSDSA:

This is the story of my son Devin who, at the age of 13, developed CRPS after a minor injury, and how he lived with constant, unbearable pain for two full years.

Devin was invited to go with his big brother to a high school soccer game between our small town rivals, Central and West. On this cool fall night, Devin innocently hopped onto his brother's shoulders; as they both cheered for the home team, Devin fell off of his six foot brother and landed flat on his tail bone onto the hard, packed soil.

Prior to this fall, Devin was an active 13-year-old boy who was an accomplished piano player and dreamed of attending a high school for the performing arts the following year. He loved tennis and fly fishing with his father; swimming, skiing, bike riding, and sailing; and just hanging out with his friends.

Soon after his fall, however, Devin began to describe severe burning and pain traveling from his low back to his right foot, and was having a very difficult time putting weight on that leg. As a physical therapist, I was able to quickly assess his leg and noticed that he had significant weakness and pain following a specific nerve pattern. I was pretty sure there was

some degree of nerve damage from the impact of the fall.

After many tests with normal results, we were told by his physician that Devin had a nerve root contusion. He said it would take about six to eight weeks to heal, and then Devin would be back on the tennis

approaches, including: four different sympathetic and lumbar blocks, a spinal cord stimulator trial, an intrathecal catheter, intravenous Solu-Medrol® and bisphosphonate drips, 14 medication trials, and months of physical therapy. Some of these treatments worked better than others, but none were able to



court and moving around again with no pain. Instead his pain worsened—he was putting less and less weight on that leg, it was bright red and cold all of the time, and he would cringe at the slightest touch. After a difficult search, we finally found a pediatric orthopedic surgeon, who diagnosed Devin with CRPS.

Like many other families, our search for a physician who understood this syndrome took us an exceedingly long period of time. As we went from physician to physician, Devin was involved in many different treatment

eradicate the pain or return him to his normal self.

Devin was also on pain medications that, although they provided some pain relief, were affecting his schoolwork, vision, memory, attention, and ability to process information. He was falling asleep in class, always nauseous, and extremely light headed from the medication, and was often in too much pain to concentrate. He was missing a tremendous amount of school and, once an all A student in the talented and gifted program, was now failing the eighth grade.

Next we tried a five-day, low-dose ketamine infusion at the ICU of our local hospital, following the guidelines of Robert Schwartzman, MD, in Philadelphia. The ketamine infusion team included a pediatrician, an anesthesiologist, an intensivist, a pharmacist, and the nursing staff at the ICU. After having this somewhat controversial treatment approved by the hospital review committee, our doctor managed to get our Blue Cross/Blue Shield (BC/BS) insurance company to cover the week-long ketamine infusion—not once but twice—along with four booster infusions.

Devin's first ketamine infusion was a huge success and afterwards he was off all of his medications, since his pain dropped to a 2.5/10 on the pain scale. Unfortunately, his pain returned a short one month later, and Devin went for a second ketamine infusion that was not as effective as the first. Following this

second infusion, Devin also received booster infusions, and all of this was covered by our insurance.

As we became more and more desperate, we began to consider putting Devin on the waiting list for the ketamine coma in Mexico. At this time, however, we learned about the Reflex Neurovascular Dystrophy (RND) Program of David Sherry, MD, at the Children's Hospital of Philadelphia (CHOP). Devin participated in the day program at CHOP, consisting of six hours per day of intense physical and occupational therapy, and rigorous desensitization. It also includes art and music therapy and psychology; and is designed specifically for children and adolescents with CRPS, or RND as Dr. Sherry calls it. The amount of physical therapy and exercise that Devin was receiving up until now was nowhere near the amount or intensity at the CHOP program. It might be the hardest thing Devin will ever have to do in his life, but

with the help of this program and with Devin's unbelievable determination, he left the program five weeks later with very little pain, and normal strength and function.

Devin is now a 16-year-old sophomore in high school, and can run, ski, and even roughhouse with his friends. He plays tennis regularly and cannot wait to be on the tennis team next fall. Even his dream of attending the performing arts high school may become a reality—something he could have never done in his prior state. He is on no medication and is back to the bright young man we once knew. He's back on track at school getting good grades, attending everyday with very little pain and no fear of being bumped into in the halls. I only wish we had found the CHOP program earlier, so that Devin could have avoided many invasive medical procedures, as well as two years of lost time and stress. We have our son back and, more importantly, Devin has his life back. ■

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she enjoys helping her mother with her handmade jewelry business when her CRPS symptoms allow, Kristen was inspired to try her own hand at designing as well. "One day, I just decided to make an RSD bracelet. I have a medical ID bracelet, and it's rather ugly, so I decided to convert my medical bracelet into my RSD bracelet design," she explains. Kristen is very proud of her creation, stating, "It's different."

After finishing her bracelet, Kristen concluded that others might be interested in having one as well. "I just decided to start making them and selling them on my own." She has been creating the CRPS bracelets for eight months, and is selling her labors of love at craft fairs. She has plans to

branch into consignment stores, as well as developing a website. In addition, she has started an online support group on Facebook, RSD Battle with Double Trouble, where she also sells her bracelets. The profits are donated to fund CRPS research.

To date, Kristen has sold more than 50 items, and she intends to keep crafting jewelry for the cause. In addition to her bracelets, she plans to make necklaces and earrings as well. Because all items are handmade, they can be customized, and Kristen is able to incorporate medical-alert tags into the pieces.

Although Kristen is adept at making the jewelry, she admits she occasionally has to call in reinforcements. "There are times when Mom has to help.... She has lots of patience, which I don't have," Kristen says with a laugh.

Through this project, Kristen remains both physically and psychologically active. "Making jewelry keeps me busy, which also keeps my mind off RSD. It is a way for me to mentally get away." She also appreciates the flexibility that jewelry making allows. "It's not something that I have to do all the time. I can do it when I'm feeling good," she says.

What started as a way to improve the medical alert ID tag on her own wrist has evolved not only into a fund-raising and awareness campaign, but also into something highly personal for Kristen: a way of striking back at CRPS. "Making jewelry allows me to put my energy into something. There are a lot of days when you feel really powerless. But this makes me feel that I'm fighting this disease and accomplishing something at the same time," she proclaims. ■