

Natalia's Story

One day anyone's life can change as the result of a trivial thing... December 15, 2012 is a date we will never forget. After a happy Saturday night with friends, my daughter was playing with her dad and she fell. Her immediate reaction was to put her hand down to support her body, and that was when our lives changed. Up to that day Natalia have always been very healthy, an A student, swimmer, student council, a "social butterfly," just a happy girl.

She told me that her hand hurt, and my reaction was take an ibuprofen, elevate it, and ice it. "You'll see that tomorrow everything will be ok..." But it wasn't. Her hand was incredibly swollen and painful. A wrist band, ER visit for x-rays, visits to her pediatrician, more x-rays again but nothing. Then Natalia was referred to Sports & Medicine. When the doctor saw Natalia, his immediate reaction was: "This is out of my league" and called rheumatology. A few minutes later, the room was full of doctors. I remembered one of the things they kept pointing out was the difference of temperature between one hand and the other. Same day she got her first MRI, was prescribed many medications for pain and cortiosteroid infusions, but nothing helped. After seeing my daughter walking like her complete left arm was not part of her body anymore, I decided to take her to occupational therapy. I had never witnessed the look of pain in Natalia's face when the therapist tried to measure her hand. The rheumatologist consulted with the chief of plastic surgery. When he evaluated Natalia, he said: "She doesn't have what they think. She has Reflex Sympathetic Dystrophy, and let me know if you want to get in contact with the director of chronic pain." We did. The pain doctor confirmed the diagnosis and admitted her immediately for an epidural catheter. This was the beginning of many hospitalizations, procedures, inpatient and outpatient rehabilitation, and fights to help control the pain and regain function.

Seven months after Natalia's diagnosis (a week after her 13th birthday), her school bus was involved in an accident that caused the RSD to spread to her lower extremities. Although she left the scene walking that same afternoon, it was the last time she was able to walk. The accident left her wheelchair bound. We started aqua and physical therapy but without much improvement. Three months later, she was back in the hospital for an epidural and spent two weeks in an inpatient rehab program. After slowly starting to walk again with assistance of a walker, she sprained her ankle for the third time. More physical therapy followed by three weeks of inpatient rehabilitation again. Unfortunately, despite pharmaceutical treatments and daily physical therapy, her CRPS kept spreading rapidly and became systemic.

The emotional toll this disease has brought is tremendous. Natalia's classmates bullied her at school. Her teachers, school staff, and school nurse didn't understand, and some doctors questioned her validity. She felt rejected, discouraged, lost her friends, and even lost hope.

And then, we met Dr. Ashraf Hanna and he offered ketamine infusions. Ketamine has changed the course of this disease. It took a doctor who would not give up on her. After many treatments of high-dose ketamine, physical therapy, and a doctor willing to research all options, her pain in the lower extremities was reduced to a 4 from the high pain which was taking over her life. Furthermore, she got into remission in her upper extremities too! Her hands are free of pain, and now she can hold her dog, paint, write; and for me I can hug her and hold her hand again without the fear of causing her more pain.

Natalia's journey has had many turns as experienced by many other kids who have suffered from this debilitating disease. Today my daughter is 14 years old and she fights many battles along with Complex Regional Pain Syndrome such as Dysautonomia, Gastroparesis, and connective tissue disorder. Regardless of all the challenges, she find joy in arts, cooking despite the fact that she can't eat, playing with her dog, painting her nails, reading, volunteering as a patient advisory council. Her dream is to become a doctor or medical reporter. In the meantime, we need more awareness; we need to educate the medical community, and the future doctors; we need support and many partners to continue to fight.