

Connor is definitely one of a kind. Everyone who ever met him would say he is unique. People rarely forget Connor. We have always said Connor told the doctor how the delivery could have been better. He sang happy birthday to himself on his first birthday. He had an unrelenting zest for life. He loved to meet new people, go to new places, have new experiences, and try new things. He goes to Bethlehem Public schools but he wrestled with Colonie Peewees, and he played baseball in Albany. He wanted to be with a variety of people. Connor always had great self confidence. He could strike out, get pined, or walk 5 batters and he'd come out the next time thinking he could win. He never got discouraged. In third grade when asked to write down what he liked best about himself he wrote simply me. When asked to explain he said "I like everything about me." He'd try anything, talk with everyone, and find good in everything. That was Connor prior to Complex Region Pain Syndrome (CRPS).

Connor was always involved in sports. Freshman year he played football, wrestled and played baseball at the high school. That was the end of his athletic career. Since then he has been unable to participate and now he fights just to walk.

Connor's progression into CRPS started with multiple injuries to his left leg and foot. He broke his knee at the growth plate at thirteen, 2005. He broke bones in his foot and tore the ligaments in September 2007. He had a stress fracture of the left knee April 2008. The foot was very slow to heal. He was in a boot from September 2007 into February 2008. We thought that the residual pain in the leg would go away. On January 9, 2009, Connor walked to work. He called us from work to say he had a lot of pain in the left leg and was having a hard time even standing on it. This was the official start of his CRPS.

CRPS is a chronic pain disorder with no cure. The disorder causes severe burning pain in the effected area. The patient becomes hypersensitive to touch. The effected limb turns blue/purple and is cold due to decreased blood flow to the area. There is no one definitive test for CRPS, it is diagnosed by ruling out other causes of the pain. A bone scan is used to diagnose CRPS because it shows the decreased blood flow to the area. The extremity swells and the patient is unable to move the joints due to pain. This causes deformity in the joints causing more pain. The less the joint is moved the worse the pain gets and the worse the pain the more difficult it is to move the joint. This causes the down ward spiral of the patients. The disorder is rare and even more uncommon in children.

We brought Connor to the doctor the next day. He underwent multiple MRIs, x-rays, Doppler and a bone scan. The doctor concluded he had CRPS, by the time he was diagnosed he could bare no weight on the leg. He only wore shorts and no shoes or socks. He would not cover the leg with a blanket. The leg was swollen blue/purple and mottled. The temperature difference between his two feet was 20 degrees. He had become unable to attend school, due to pain and mobility issues.

He underwent 4 lumbar sympathetic blocks. Each caused vasodilatation which helped with color and temperature but did nothing for pain. The doctor next tried an epidural catheter. He placed the catheter and we went twice daily for boluses of medication into

the catheter. Connor had experienced some relief with the boluses. The first catheter broke in Connor's back. The second lasted for a week, but a more permanent one was needed because the doctor wanted a 24 hour a day infusion. Connor went into the hospital on February 13 for the catheter placement. The catheter did not work as hoped and Connor's pain level remained high. Connor began experiencing muscle spasms so great that he was given IV valium keep him asleep. He was discharged with home care on February 17th. He was in so much pain that the doctor had us bring him back to the hospital 3 hours after he was discharged. In the ER they gave him enough dilaudid and ativan to knock him out. They kept him on the medication for 2 days. A klonopin patch was removed and the spasms stopped. The spasms stopped but the CRPS pain was so great he was started on a morphine pca. At that point he was getting morphine, and valium IV. He was also taking baclofen, lyrica, and cymbalta by mouth. He was getting marcaine and fentanyl through his epidural catheter. He remained in such pain if you walked by him to fast he would yell out in pain. Any air movement in the room caused pain. Every time he had to get up to use the urinal he was in agony.

The doctors decided to try a temporary spinal cord stimulator. The stimulator was placed and Connor started working with it. He tried so hard to find a setting that would give him some relief. The stimulator was not helpful and the doctor's felt Connor needed a more drastic treatment. He was started on a continuous infusion of Ketamine, with the plan for a Ketamine induced coma. He was transferred to Albany Medical Centers PICU on March 8.

Connor was going to be only the 2nd patient in the area to undergo a ketamine induced coma. While intubated Connor had a difficult time he ran fevers, reacted to the stopping of morphine, and was agitated the entire time. He required two people to sit with him at all times even with him restrained at the wrist. When he awoke from the coma he had no CRPS pain. His pain was from the months of no movement in the joints of his left leg. He had extensive left foot drop. His doctors said he next needed to go to the Cleveland Clinics Pediatric Pain Rehab Unit to complete his treatment. Our insurance would not pay for any of this because we didn't have inpatient rehab coverage. He was sent to Sunnyview Rehab hosp in Schenectady on April 2. Within 3 days of being there his CRPS pain was back and he was battling even walking. He did progress and was able to walk with a cane. He was discharged on April 17. He started to deteriorate quickly after discharge. He started to have much more pain and the swelling and the blue/purple color got worse. His walking was getting more labored and much more stiff.

His condition has continued to get worse. He now has CRPS in his left hand and arm. He is starting to get symptoms in his right hand. We are desperate and going to borrow from everyone we can and get him to Cleveland as fast as we can. The Cleveland program our doctors have said all along was needed for Connor. It is a very specialized program for patients with CRPS. Since CRPS is rare, it is very important to be treated by providers well versed in the treatment of this specific disorder. We are devastated that the delay in getting to Cleveland maybe what caused Connor's relapse and progression. We do not have the money to pay for this clinic but we are doing everything we can for our son. The clinic is \$38,700 for the three weeks and more if they think he'll need

longer. If you pay it all up front they give you a discount and it is \$25,870. This is way above our means, but let me tell you about Connor now.

Connor is in constant unrelenting pain to walk is a great effort and he can no longer walk any distance. His face shows signs of pain even in his sleep. He is afraid to go anywhere for fear he will be into much pain. He no longer even carries his phone because he doesn't want to talk with his friends. He doesn't want his friends to see him at all. He wants us next to him at all times in case he needs us. He looks defeated and sad all the time; he has no interest in anything. He is a shell of the person he was. He is riddled with anxiety, he's even afraid to sleep because the pain comes back so hard. He can do little by himself now that his hands are involved.

We would be grateful for anything you could do to help. Our son is in desperate need of treatment. He is progressing at a staggering rate. His case is more critical by the day.