

Cole's story of hope and success....written by Brenda Brookins

It was May 2013 when Cole fell playing basketball in school and sprained his ankle. Being a teenage boy, almost 15 years old, he had his share of bumps and bruises and sprains. We didn't think much of it, and did not do physical therapy as prescribed by the orthopedist. Looking back, that was mistake #1. After several weeks, the sprain did not get better. X-ray's and MRIs showed no injury. His doctor said it is in his head and prescribed him Cymbalta....mistake #2. In an effort to make things better, after 4 months we decided to try physical therapy. His therapist took one look at him and said he has CRPS! She didn't know much about it, as we are finding that most doctors don't. She had done some reading on it, and gave us things to do at home – desensitization, hot/cold therapy – mistake #3. I learned after that research has shown hot/cold therapy will cause CRPS to spread. In a matter of a few weeks, the amplified pain went from his left foot, up his left leg, across back, down right leg and foot, up spinal cord, down left arm and hand, and up neck. He was almost full body RSD.

Cole was walking with crutches, then advanced to a cane in an effort to be able to do more. The pain was still there...he was just choosing to push on. We stopped going to PT as the therapist got angry with me when I questioned some of the treatments. Sometimes Cole's pain was so bad that he had to go back to crutches and swing his legs to move. We cried, we prayed. I imagined him never driving a car, never dancing at a prom, never firing a .22 with his brother. I imagined him living a life of pain.

Internet searches were depressing, with little hope. However, I found a few articles regarding success in children. Now 15 and a half, was he still considered a child? I wanted him to be one....and have hope.

With Cymbalta causing issues in school – short term memory loss, short attention span – his grades were suffering. We found a new doctor who immediately took him off Cymbalta, and tested him for other things. This doctor did not believe in something called CRPS. He was tested for diabetes, Lyme disease, Stiff Man Syndrome...he was given gabapentin, and gab, and numerous other “test” drugs. I finally insisted that we see a neurologist. We were sent to Strong Memorial in Rochester NY where the diagnosis of CRPS was confirmed. They have a treatment center through their rheumatology department. We met with them, they assessed Cole's condition and said he would do best in a resident program. That led us to Children's Hospital of Philadelphia (CHOP). They have an amplified pain clinic (AMPS) in their rheumatology department. The doctor is Dr. David Sherry. They are awesome! Their program consists of PT for 8 hours a day, 5 days a week for 4 weeks. They have great success. We met them, and they said Cole could do the work at home, as we live 6 hours away.

They were kind enough to connect with a new PT locally, and they emailed regularly regarding Cole's progress. This was in August of 2014. By October 2014, Cole was walking, sometimes unassisted. By January 2015 he was totally pain free and now walks unassisted, marches in marching band, bowls, drives a car – everything a teenage boy should do!!

A big part of the healing process is also a mental health counselor. That is very very important. So please, if a doctor suggests you see a therapist, do it!

I know there are other places that offer this therapy besides Philadelphia. There is a treatment center in Boston's Children's Hospital, one in Pittsburgh, one in New Jersey somewhere, and one in California at CHOC.

If you are interested in learning about this program, the CHOP website has information. When you get to the amplified pain section, there is an opportunity to purchase a DVD so you can see what goes on. It is a great buy! I bought 3 copies. Cole and I watched it together and it stimulated him to have more hope. I also circulate the other copies around to PT and hospitals and church members, hoping to get someone else interested in starting a local clinic.

If you would like to contact me, please email me at [brookins34@live.com](mailto:brookins34@live.com) and put CRPS in the subject line. I would love to share what little knowledge I have. Perhaps someone can be helped by it.