

# Living with and learning about a painful disease

## OUR STORY

Kallyn Jacobson was your typical 14-year-old girl. She was a good student at Kennmore Junior High and she loved playing soccer, until last year on Sept. 9.

During the first soccer game of the season, she kicked an air ball and heard and felt her ankle pop. Because of the adrenaline of the game, she kept running for about 20 more minutes. She came off the field and said to her mom, "I think I sprained my ankle again." She often sprained her ankles, so it was not that big of a deal. However, when she got in the car and took off her shin guards, her foot started to swell rapidly. By that evening, she was sure it was more than a sprain. It felt broken.

When she went to her orthopedic doctor, he told her she had severely sprained it in an untypical way. She looked at her mom and they both said, "Of course!" that was how the

Jacobson family seems to do everything—in the untypical way. She had hyper-extended the nerves and ligaments along the top of the foot, compressed the bone in her heel, and the doctor said her joint was likely bleeding. But it was still a sprain, not a break.

Eight weeks later, she woke up screaming in pain. Her foot was getting worse, not better. She had more X-rays and an MRI. They just showed that her bone was still bruised. The first doctor thought she should see a doctor with more foot experience.

By mid-December, her foot was even worse. Her foot was discolored. It would be red, green, yellow and change colors all the time. It was ice cold. She had a lot of dryness, her toenails had not grown since the injury and her foot was

hypersensitive to touch—just the air sent it in burning pain so she wore an Ace bandage all the time.

She had a bone scan that did not show anything, but she had all the symptoms of Reflex Sympathetic Dystrophy (RSD). Simply put, RSD, now is referred to as Complex Regional Pain Syndrome (CRPS).

It is a progressive disease of the autonomic nervous system with its key component being damage to a nerve, either major or minor. There are four main symptoms/criteria for a diagnosis of RSD:

- Constant chronic burning pain.
- Inflammation
- Spasms—in blood vessels and muscles of the extremities
- Insomnia/emotional disturbance

Between December 2006 and March 2007, Kallyn had five try to "reset" the nervous system. They helped to alleviate the pain, but only for 1-2 weeks. On a scale of 1-10, her pain level was about an 8.5 most of the

time. A couple of 10-plus times sent her to the ER, but there was nothing they could do for her. They would give her IV pain medicine and send her home in as much pain as she was when she arrived.

RSD can spread to other limbs. In April 2007, the pain spread to her left foot. Instead of crutches, she was now in a wheelchair. She had missed so much school that she entered home school to try to salvage her freshman year. Her current pain doctor suggested a spinal-cord stimulator. They are one of the few options for patients with extreme pain that no longer responds to drugs.

Implanted near the base of the spinal cord, the devices deliver electrical impulses to specific nerves and block pain signals from reaching the brain. Often times, there are complications or they only work well for a year and then often diminish. Kallyn's mom, Demery, decided to search the Internet for other alternatives. She came up with the option of Hyperbaric Oxygen Therapy (HBOT). HBOT is used to treat more than 100 conditions, but the

FDA has only approved its use for 14 conditions. Therefore, insurance would not cover it and it is costly, with \$120-\$150 per treatment and an average of 40 treatments needed.

But it is non-invasive and seemed like a good idea to try. So in May, Kallyn and her mom traveled to San Bernardino, Calif. There, they stayed for nine weeks while Kallyn underwent HBOT 5-6 days a week for 60-90 minutes a treatment.

Kallyn's pain kept diminishing. She got out of the Ace bandages, then out of the wheelchair. By the time they got home, her foot pain was averaging a 3-4 instead of 8.5-10 pain level. Kallyn still has a long road to recovery—she needs to do physical therapy to get back her muscle tone and balance from being in a wheelchair and crutches for so long. She was not able to do her school work and now has several credits to make up in the next three years before she graduates.

She still takes a lot of medication. RSD is not usually cured, but put into remission so overdoing it, or injuring it, can flare up the pain. She is continuing to get "maintenance" HBOT treatments done at a local naturopath to keep the pain at bay.

Because insurance does not cover the HBOT treatments, and even with insurance, the copays on other medical procedures and medication, the Jacobsons have many medical expenses. We are holding a fund-raising yard and bake sale on from 9 a.m. to 4 p.m. Aug. 25-26 at 18902 101st Ave. N.E., Bothell.

Demery Jacobson  
Bothell

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