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Toughing it out

Bothell girls deal with RSD

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Fifteen-year-old Kallyn Jacobson keeps telling herself the pain of her disorder isn't real. She's right.

The severe aching and burning in her limbs isn't caused by a lingering injury. Her nerves are just going haywire.

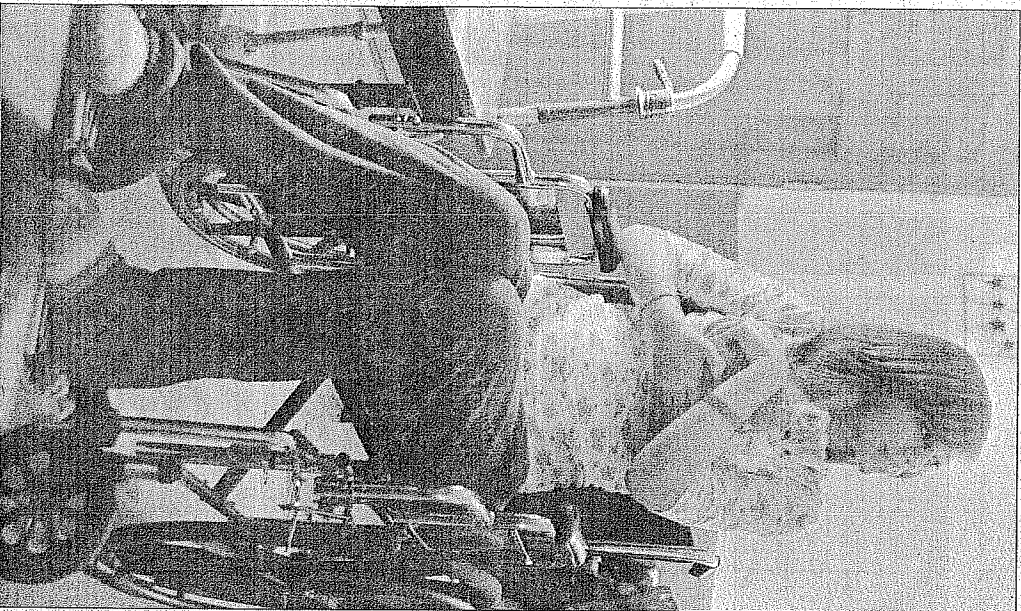
Thirteen-year-old Hanna Lynn has the same problem, only it generates from her abdomen. She makes frequent visits to a chiropractor, who performs a series of cranial massages until her pain level drops from a 10 — the highest degree — to a four.

Like Kallyn, she is willing to try anything. Living with chronic pain is no way to spend one's youth.

Both teens suffer from reflex sympathetic dystrophy (RSD), a malfunctioning of the nervous system set off by simple trauma to the body.

It was a sports injury that sent Kallyn into a downward spiral. She sprained her ankle while kicking an air ball during a soccer game in September 2006.

The injury didn't set off any alarms. Jacobson managed to play another 20 minutes because of the adrenaline coursing through her body. It wasn't until she removed her shin guards after the game that severe swelling started to occur.



Fumiko Yaita / Reporter
Kallyn Jacobson sits in a wheelchair at home. She suffers from a rare condition called reflex sympathetic dystrophy syndrome.

RSD
from page 1

Orthopedic doctors told her it was a hyper-extension of the nerves and tendons on top of her foot. At worst, she had a severe sprain with bleeding of the joint.

Kallyn's foot felt worse eight weeks later. It was ice cold and changing colors from red to green to yellow. A slight breeze would cause her skin to burn.

More than a year has passed since Kallyn injured her foot. The pain now affects both legs, as well as her hips and lower back. This is more than a sprain.

"I wouldn't wish this on Timothy McVeigh," said Kallyn's dad, Jake Jacobson. "No one deserves to go through this pain and frustration."

Kallyn now uses a wheelchair to get around. Walking is too excruciating.

There are times when the discomfort is so extreme she can only lie in bed crying, repeating that phrase: "The pain isn't real."

"I get so frustrated and confused," Kallyn said. "I can tell myself I'm not in pain, but that doesn't stop it."

Neither do all the pain medications, supplements and sleeping pills she's taking.

Doctors know little about how to treat RSD effectively, although a few things have been known to help reduce the agony it causes like nerve blocking, physical therapy and spinal-cord stimulation. A combination of techniques is normally required to achieve positive results.

Hanna, who has been dealing with RSD for more than two years, lowered her average pain level from seven to six with chiropractic treatments, hyperbaric oxygen therapy, electronic spinal stimulation and a cocktail of prescription medications. But the condition is spreading to other areas like her head, face and left arm.

"It's painful and discouraging to see it get worse and know there's nothing you can do," said Hanna's mother, Chris Lynn. "She's trying so hard to be a normal kid, but this is just an awful disease."

There are times when a slight touch, noise or vibration sends shock waves through Hanna's body. Even a comforting hug can be overwhelming.

"As a parent, that's excruciating," Chris said. "It's a parent's first instinct. All I can give her during those times is my presence and my prayers. I just turn off the lights, block out all the stimulators and hold her good hand."

Hanna developed RSD after surgeons removed a non-cancerous tumor from her stomach at the age of 11. The operation caused stress ulcers, which doctors treated with medication.

The internal stomach sores went away, but Hanna's pain increased.

"Nobody really believed me, but the pain was getting worse," she said. "Doctors thought it was

just the pain as normal, which, of course, it wasn't."

Both Hanna and Kallyn saw several specialists before doctors finally diagnosed them with RSD.

"It's really discrediting to the parent and child," Chris said. "They need to be better educated on RSD. I think they did their best with the knowledge they had, but I'm really interested in spreading the knowledge so it's considered more in diagnosis and treatment."

People with RSD report seeing an average of five physicians before receiving an accurate diagnosis, according to the Reflex Sympathetic Dystrophy Syndrome Association.

The Jacobsons will host a spaghetti feed at the American Legion hall in Bothell Nov. 2 to spread awareness about RSD and raise funds for Kallyn's various treatments, which include visits with naturopathic doctors at the Bastyr Health Clinic, hyperbaric oxygen therapy in California and specialized chiropractic care from Dr. Bruce Davis, the same craniofacial physician that Hanna uses.

Insurance companies don't cover most RSD treatments, since the methods haven't been proven to work.

Kallyn's condition isn't getting any better. Her average pain level is higher than it was a few months ago.

But encouragement has come from many directions. The Jacobsons' previous fund-raiser, a yard and bake sale in August, netted \$5,000.

"People were dropping off checks without even buying anything," said Kallyn's mother, Denny Jacobson. "The support was amazing."

Kallyn and her boyfriend also attended their first homecoming dance at Inglemoor High this month.

"I was definitely in a ton of pain, but it was worth it," Kallyn said. "That was my best day in like a year. I had a date with Prince Charming, that's how I would describe it."

Kallyn claims that her family, above all, makes RSD bearable.

"I have a loving home, and great support," she said. "I don't feel like I'm going through this alone."

"There are people who have it way worse in this world. I actually have a great life if you put the RSD aside."

- The Jacobsons' spaghetti feed fund-raiser takes place from 6-9 p.m. Nov. 2 at the Bothell American Legion hall (19213. Bothell Way N.E., Bothell).

Donors can also contribute to Kallyn's benevolent account at Washington Mutual. Checks should be made to: FBO Kallyn Jacobson.

For information on RSD, visit www.RSDHope.org.

See RSD page 11