

## KENNEDY: Suffered unbearable pain following a sprained ankle

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But Michelle Kennedy said the battle to reach a diagnosis, an understanding and a treatment, nearly matched the battle to reach remission.

Her daughter suffered unbearable pain following the sprain, and as the two watched the affected ankle turn from purple to bright pink to ash within minutes one day, Michelle Kennedy became a "mom on a mission" to discover what was happening.

Anna Kennedy's doctor told them it looked like reflex sympathetic dystrophy, another name for CRPS, but it would take a neurologist to determine this diagnosis for sure.

"I was scared to death. I read about (CRPS) online, and I thought my daughter would be dead from pain and all the medication it required," Michelle Kennedy said.

It took weeks to deal with doctors and finally see professionals at Children's Hospital,

and in the meantime, people in Anna Kennedy's elementary school began thinking she faked the pain and teachers often took her crutches away.

Her grades plummeted from A's to C's, and in time she became depressed. She took any over-the-counter medicine she could to lessen the pain so she could sleep at night.

Once a neurologist at Children's Hospital confirmed her diagnosis, Anna Kennedy began physical therapy to retrain her muscles, and essentially relearn to walk.

The months of immobilization began to atrophy the muscles in her leg.

"If the illness is not treated, the person will lose function of the extremity," Weisman said.

"I teach people different cognitive behavioral management techniques, like breathing, meditation, self-hypnosis, all of which work together to get the



mind off of the pain and to get the brain to perceive the pain as less intense."

According to the Reflex Sympathetic Dystrophy Syndrome Association, people between ages 25 and 55 most commonly suffer from CRPS and it is more frequently seen in women.

There is no cure for the physical disease, but advances in research have found more effective treatments, such as medications, nerve blocks, physical therapy and psychological support.

"I think CRPS is more common than we would normally guess," Weisman said of the disease, which affects as many as six million Americans.

"It's one of the most common diagnoses in the pain center."

Anna Kennedy has suffered little-to-no flare-ups of the pain, she said.

In eighth-grade she played on

the basketball team and last fall, she wore high heels to a formal dance — both things she thought she might never do.

Anna Kennedy will pass another milestone this year when she turns 16 years old and gets her driver's license.

"My anger turned to tears of joy and relief," said Michelle Kennedy, who has since started a Web site for family and friends of people with CRPS.

"But I feel such sorrow for other people going through this."

About 200 members have joined the support group on the Web site, she said.

Orange bracelets also are being sold to promote awareness and to benefit RSDSA.

"People don't understand the pain, the sleepless nights, the worry; but we got through this," Michelle Kennedy said.

"I keep saying 'we,' but really, Anna got through this."

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