

Prep swimmer raises awareness of pain disease

Reflex sympathetic dystrophy described

BY TROY PIEPER

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When Wayzata High School student Traci Maccoux broke her toe at a swim meet in 2001, the 14-year-old never imagined she would develop another affliction, or that she would be asked to help publicize it.

But even after her toe was healed, Traci still experienced pain – for three years. In October, she saw a south Minneapolis doctor who specializes in reflex sympathetic dystrophy (RSD). He diagnosed her with the disease and treated her, and she is now in remission.

RSD is a progressive, neurological disease with constant, severe, burning pain as its main symptom, according to Cynthia Toussaint, founder of For Grace, a non-profit group that campaigns to raise awareness of the disease. As a 21-year-old ballerina at the University of California-Irvine, Toussaint tore her hamstring, ending her career as a dancer forever. The injury quickly turned into the most excruciating pain she'd ever felt, she said.

But doctors said the pain was all in her head, because the injury was gone. Over 14 years, the pain, which Toussaint likens to being doused with gasoline and lit on fire, spread to her entire body, rendering her immobile and extremely depressed.

Toussaint said that when RSD occurs, the sympathetic nerves around an injury keep sending pain impulses to the brain after the injury is healed. Nerves around the affected nerves learn to send the pain impulses, as well, which is how the disease spreads.

According to www.forgrace.org, RSD pain can be exacerbated by the slightest stimulus: vibrations, a gentle breeze.

Between 1.5 million and 6 million Americans have RSD, Toussaint said, and it occurs three times more often in women. She said that many healthcare professionals mistakenly believe the disease is a psychological condition rather than a physiological one.

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She said that because more of the sufferers are women, fewer of them are correctly diagnosed, citing the gender bias she said exists in the medical community. "When you're a woman, everything's in your head," she said.

She said the disease wreaks havoc on the lives of RSD sufferers. They often develop psychological problems when they are not believed, and severe depression from the disease's 24-hour excruciating pain. The suicide rate among RSD sufferers is extremely high, she said. Many patients experience prolonged family disruption, as well. Toussaint said she has lost her entire family except for her partner John, the reason she did not commit suicide.

Fortunately, Toussaint said, the disease is curable. If diagnosed early enough, as Traci's RSD was, it can be treated with pain blocks, drug cocktails that block the pain impulse from the afflicted area to the brain, sometimes forever. However, once the disease has spread to the central nervous system, it cannot be cured. It can, however, be stopped from spreading and localized through treatments like implanted morphine pumps like catheters, which deliver morphine directly to the affected areas.

Anticonvulsants also help, said Toussaint, whose RSD has spread to her entire body, and who now uses a wheelchair. She said only her eyes are without pain.

Traci was once a top swimmer in the state, and is now working her way back to a competitive level. "It's hard to come back and try it again, to try to get back to

where everyone else is," she said. She trains about four hours a day to compete in the 50- and 100-meter front crawl events.

At school, she said she is in the special education program because she has missed so much class. About a year before she went into remission, Traci was often in the hospital. When she did attend school, she was in a wheelchair. She still has relapses, she said, when she feels twinges of pain or gets a rash and her parents rush her to the hospital for more treatment. "My [swimming] times go down when I'm in the hospital," she said.

Traci said that a lot of people don't understand the disease, because they can't see it. A girl in school once threatened to beat her, because she thought Traci was lying about having a disease. But, Traci said, her parents and friends have been very supportive. And her boyfriend

comes to visit her every day. Traci has also found consolation on the Internet. She found chatrooms and sites like For Grace, and talked to other people with the disease.

She is also helping with For Grace's national awareness campaign to raise awareness of the disease. She hands out cards at school explaining RSD, and talks to the media about the disease. She is also planning to make bracelets promoting awareness.

Toussaint said she hopes the campaign will lead to a quicker diagnosis, effective treatment implemented sooner, and ultimately, a much better quality of life for those afflicted with RSD.

"There's not much I can do about [my RSD]," Traci said, "I feel very, very fortunate I was diagnosed when I was."

For more information about RSD and For Grace, visit www.forgrace.org.