

Student uses poetry and music to fight against a world of pain



Aya Ravek, 13, began her personal fight for more research into the little understood reflex sympathetic dystrophy (RSD) with her Web site, above. She's now completed a collection of poems she hopes to publish to raise funds for the fight against the disease.

Aya Ravek's fight against little-understood RSD has brought out her artistic voice, which she hopes to use to raise funds to help others, writes **Bev Wake**.

Aya Ravek has found an upside to the disorder that struck her more than three years ago, despite the fact that at one point it was the source of severe pain, 24 hours a day.

It helped her find her voice.

Aya, 13, has always been artistic and dreams of making a career as a singer one day. But it was only after she was diagnosed with reflex sympathetic dystrophy (RSD) that she started to write. It began with her Web site www.NoPainZone.com, designed to help others with the disorder, and progressed to poetry.

Now, she hopes to publish her poems in a book, with proceeds going towards research into the little-known disease.

"We were trying to think of ways to raise money for RSD and since I've already written poems, we thought it would be a good idea to put them into a book," Aya said, acknowledging the role of her parents in the fundraising effort.

"The first draft is almost finished and I hope to get it published and sell quite a few. There just isn't enough research being done and so many people are suffering." RSD, also known as complex regional

pain syndrome, is an extremely painful neuromuscular disorder that can simultaneously affect the nerves, muscles, blood vessels, skin, joints and bones in progressively severe stages. Symptoms include various degrees of pain, swelling, stiffness and, in some cases, diminished motor function.

There is no known cause for the disorder, which is usually triggered by a leg or arm injury. Neither is there a cure, although it can be treated with physical therapy and a range of pain management techniques.

Aya was diagnosed with RSD in November 1998, eight painful months after she took a slapshot to the kneecap while playing hockey with her Grade 5 physical education class.

"Basically you're in pain 24 hours a day -- hot pain, cold pain, you look normal but you don't feel normal," said Mel Martin, president of the Canadian Reflex Sympathetic Dystrophy Network.

Mr. Martin estimates five to 10 per cent of Canadians suffer from the disorder in varying degrees. Despite the prevalence, he said there is no research being done on the disorder, no funding for groups like his own, and many doctors are unaware of its existence.

"It's unrecognized in Canada, which is unfortunate. Many doctors think it's a head problem, and it's not a head problem," he said. "People are spending tens of thousands of dollars going for treatment in the U.S."

Mr. Martin said he's "almost broke" after putting about \$30,000 of his own money into trying to raise awareness about the disorder and welcomes Aya's efforts and others.

"I've had RSD for 20 years and the only thing that gets me through the pain is helping others and that's what our friend in Ottawa is doing."

Aya said that over the last year she's learned how to control her pain, which landed her at Sick Kids in Toronto for a few months in 1999, through meditation, guided imagery, reflexology, massage and Reiki.

When she begins Grade 9 at Canterbury High School next year, she'll take up the piano again, along with the violin she had to give up when she developed symptoms of RSD.

But for now, her focus is on the poetry, putting into words her thoughts about everyday life -- from love to the environment, to living with pain.

"I've been fortunate to be able to control my pain and be able to do something positive with the pain," Aya said.