

Website eases some of the chronic pain of RSD

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NEPEAN THIS WEEK

A website originally suggested by her doctor to help 12-year-old Aya Ravek spread information about Reflex Sympathetic Dystrophy (RSD) has had the effect of bringing together children in Ottawa-Carleton and beyond who live with chronic pain.

The website is called Ayala's No Pain Zone (www.ordesign.com/NoPainZone/) and it is dedicated to spreading information about how RSD affects children.

RSD is considered a disease of the sympathetic nervous system. It is usually caused by an injury or trauma of some sort to a part of the body, and it results in continuous pain for those who live with it.

Aya, who has lived with RSD for the past 18 months, created the website in the spring on the advice of her Toronto-based psychiatrist Dr. Arlette Lefebvre - Aya calls her Dr. Froggie. Lefebvre told Aya she should do something to inform others about RSD as there was little or no information for children and their parents. It is considered very rare in children and there is not much knowledge or medical research for children.

"She suggested the site because there were no sites from a kids' point of view," says Aya, who has lived in Nepean with her parents Oded and Pamela, as well as two younger siblings, for the past 10 years.

"(Dr. Lefebvre) wanted me to think of ways to help people understand it, and let kids with RSD know they're not the only ones, and give them someone to talk to or email to."

Her parents helped her build the site, and they answer many of the letters and emails that have been rolling in over the past few months.

"I feel much better," says Aya. "It just really feels good when I get an email from someone who has the same experience as I have."

The other benefit of the website has been an increase in communication among young people who have RSD, both in the Ottawa area and elsewhere.

There are several girls in the



Twelve year old Aya Ravek started her own website, called Aya's No Pain Zone, to provide information on Reflex Sympathetic Dystrophy (RSD) for children. Because of it, she has become aware of others who face similar daily challenges.

region who live with it, but until Aya's website and the resulting publicity from the site, they were not aware of each other. As a result, the girls and their families are hoping to get together Thanksgiving weekend or soon after to share their experiences.

"I thought few other people have it and that it's a rare disease," says Liz Ruyter, 13, of Barrhaven, who has lived with RSD for four years. "I found out through Aya that there's a lot of people who do (have RSD)."

The website, complete with a colourful and cheerful homepage, contains an introduction by Aya about the impact of RSD on her life, medical information and treatments, and related links to other sites for more detailed information.

"This (website) showed me there are different ways to get through the pain," says Liz.

The frightening part about RSD is it can happen suddenly, it is not easily diagnosed and it can result in constant pain from even the slightest touch - something as soft as raindrops or grabbing the arm of someone with RSD can cause excruciating and lasting discomfort.

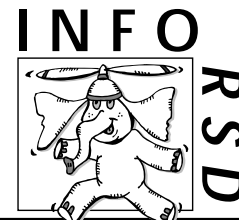
doesn't heal right away, especially among girls, who seem to be more susceptible to RSD than boys of the same age.

Exercise is a key means of treatment, as both Aya and Liz have extensive daily exercise regimens of swimming, stretching, walking a treadmill and riding a stationary bike.

Although Aya's lifestyle has changed, her career goals have not. Three years ago, she decided she wanted to be a solo singer, and/or a fashion designer, and one or both of those continue to be her goals.

And she started a recent composition at school as why she is the luckiest person in the world, because of her website and being featured in local newspapers recently.

Dr. Lefebvre, one of her biggest supporters, has also nominated her for a young person's achievement award.



Do you have difficulties explaining RSD or dealing with pain in school? Send me an e-mail; perhaps I can help.
www.ordesign.com/NoPainZone/



Need advice on setting up your own website? Send me an e-mail through my site with the details and I'd be glad to consult with you!
www.ordesign.com/NoPainZone/

"It's like an invisible disease, but there's pain all the time," says Aya.

Her injury occurred during a floor hockey game in gym class in March 1998 when she was hit in the knee by a slapshot. Her first diagnosis was a broken kneecap and it took several months before she was diagnosed with RSD.

Liz says she suffered her injury four years ago when she jumped into the pool at the Walter Baker Sports Centre and jammed her ankle on the floor of the pool.

Aya's father Oded says if RSD can be diagnosed within a week, or even a month of an injury occurring, the chances of treating it successfully is much greater. Her mother Pamela says parents should be aware of any injury that