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'No Pain Zone' web site continues to be a support channel for chronic pain sufferers



'Aya's No Pain Zone'
Ayala Ravek's web site designed for people suffering with RSD is proving to be successful....
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NEPEAN THIS WEEK

More than a year after the initial start up of her web page, 'Aya's No Pain Zone', an information and communication site for people suffering from Reflex Sympathetic Dystrophy, 12-year-old Ayala Ravek says she has been receiving hundreds of e-mails and letters from people all over the world.

"I have been receiving letters from people who are nine to 66-years-old. Some are from as far away as Australia and Israel," she says. "It's really exciting to hear from people who understand what I am experiencing."

Suffering from RSD, a rare disorder of the sympathetic nervous system caused by an injury or trauma to a part of the body that results in continuous pain for those who live with it, Ayala decided to make the site so she could explain what the disease is, its symptoms, and how to live with it.

The web site describes her journey to find help and provides a description of RSD-- all from her point of view. Recently she upgraded the site and location to include a place for parents to talk, published newspaper articles about the disease, information



Ayala Ravek says her web site, which offers support to people suffering from RSD, has been successful.

about alternative treatments, as well as conventional treatments. The new site can be reached by typing in www.NoPainZone.com.

"The great thing is that by meeting people who have RSD (or fibromyalgia, arthritis, and other conditions), I have found people who understand, empathize, and we encourage one another," she says.

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.

Her parents, Pamela and Oded Ravek, helped her build the site, and they answer many of the letters and e-mails that have been rolling in over the past year.

"From a parent's perspective, we know what a maze it is out there in finding out the information needed," says Pamela.

"That's why the web site is beneficial for parents and the children who are living with RSD."

Ayala's 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.

"It took us eight months for Ayala to be properly diagnosed. A lot of the doctors don't know what it is or what the symptoms are," Pamela says.

Some of the common symptoms are hot and cold flashes, sharp pains or tingles at the limb and skin discolouration.

Oded adds that the key to treating the pain is to catch it immediately and to begin physiotherapy.

When she was first diagnosed, Ayala says she was taking about 21 different pills a day for the pain. However, through the use of various methods of pain management such as relaxation techniques, she says the pain isn't as bad and she no longer needs to take as many drugs.

"We are very optimistic about her progress and chances are it will go away," says Ayala's father.

The most annoying thing about

RSD is that it is invisible, says Ayala.

"There are many nights when I am awake because of the pain, and I used to wish I had broken my legs so everyone could actually see an injury and understand my pain," she says.

While her web site continues to be a success, Ayala has also been considering organizing some type of fundraising event to raise money for the RSD Association of Ontario, which is presenting its RSD International Conference 2000 from July 27 to 29 at the Toronto Airport Marriott Hotel.

The Ravek family, who plan to attend the three-day conference, say it will provide delegates, parents and patients with up-to-date information on current treatments, resources and the latest research developments in RSD.

For more information about the conference visit <http://people.becon.org/~rsdinfo>.

"We encourage anyone who is suffering from chronic pain or knows someone who is, to attend the conference where there will be terrific experts speaking," says Oded.

Ayala adds that along with her fundraising ideas, she has also considered holding a conference for children with RSD.

"There are so many possibilities, but for now I am going to continue to concentrate on my web site," she says.