

Health

Ottawa girl shares medical condition on the Web

By DIANE KOVEN
Ottawa Correspondent

OTTAWA -- A 12-year-old girl who lives with constant pain has created a Web site support group which has attracted children from around the world.

Aya Ravek was diagnosed a year and a half ago with Reflex Sympathetic Dystrophy (RSD), a condition of the sympathetic nervous system. The condition, considered very rare in children, occurs suddenly, is difficult to diagnose and can result in constant pain from even the slightest touch.

Aya's mother, Pamela, says "the nerves are out of whack. The nervous system doesn't reset and the brain is still getting the message of pain, acting as though the injury is still there."

The Ravek family's odyssey began in March, 1998 when Aya was hit in the knee during a floor hockey game in gym class. The injury didn't heal and it took months until the proper diagnosis was

made.

The length of time between onset and diagnosis is crucial in terms of successful treatment, Pamela said, and Aya suffered both physically and emotionally as they searched for help.

Aya and her parents have been travelling to Toronto where Aya is being treated at the Hospital for Sick Children by a team of physicians.

Her Toronto psychiatrist, Dr. Arlette Lefebvre, suggested that Aya put together a scrapbook to help her explain to schoolmates what she is going through.

She and her parents then did extensive research on the condition.

The scrapbook explains that even the spray of water from a shower can cause her excruciating pain. It has helped Aya answer other children's questions such as, "Is it contagious?" and "Are you going to die from this?" The answer to both is no.

The idea of the Web site, called Aya's No Pain Zone (www.ordesign.com/NoPainZone/) evolved from the success of the scrapbook.

"We thought of the Web site as being a scrapbook on-line," says Aya's father, Oded, "but, to our amazement, it turned out to be a tool. We get so many responses from kids with RSD and other chronic illnesses who have derived comfort from communicating with Aya.

"The site is really being used now as a healing tool. Aya gets so many e-mails from children and she has become a source of comfort. This site explains the disease from a kid's point of view rather than a medical text."

Aya has also developed a form which she distributed to her Grade 7 class describing what it is like for her to have RSD so that the children will understand that she cannot be touched or bumped.

She will be adding this form



Aya Ravek

to her Web site to be used by other children as a starting point for their own personalized forms. Although she has been studying the proper key-boarding technique in order to work on her Web site, it is sometimes too painful for her to use her fingers. She then dictates to her parents who help her with the input.

She answers all her e-mails and has heard from children as far away as Australia, although she has only found two other girls in the Ottawa area with RSD.

Lefebvre, who the Raveks laughingly call "Aya's agent" because of her tremendous support and encouragement, has nominated Aya for a Young Achievement Award. She has also been nominated for the Ontario Junior Citizen of the Year Award through the community newspaper association.

Although she struggles daily with pain, takes 20 pills a day, does extensive exercises and spends a great deal of time working with medical professionals, Aya has also managed to develop and maintain the Web site.

"We started out with the idea that this would help Aya," says Pamela. "It is quite wonderful that it has ended up helping others."