

## A Visit to Aya's World

by Debra Nelson-Hogan

If you want to know what RSD is like from a child's perspective, visit [www.NoPainZone.com](http://www.NoPainZone.com) and have a look at the world of Ayala ("Aya") Ravek.

Aya, now 13, developed RSD three years ago and as part of her coping mechanism created a website to express her feelings and, at the same time, communicate with others. Moreover, she and her parents were particularly frustrated by the lack of information on pediatric RSD written in layman's terms.

Aya, who lives in Nepean, Ottawa, Canada, created the website on the advice of her psychiatrist, Dr. Arlette Lefebvre. The colorful homepage directs the visitor to sections describing the impact RSD has had on her life, medical treatments, photos and links to other information sites. How refreshing it is to get a perspective from a young adult!

Her parents, Pamela and Oded, helped her build the website and continue to answer many of the letters and e-mails that have come in since it was launched in Spring 1999. The site has had hundreds of responses from people aged "nine to 66," she says, and from all over the world.

This open communication has helped Aya feel less isolated about having RSD and has greatly increased communication among young people who also suffer from RSD or other chronic pain diseases.

What Aya called "an invisible disease" is becoming more visible, in no small part through her work. Her efforts have gained her nominations for two Young Achievement Awards and a Junior Citizen of the Year Award. She has been featured in various media, including an interview by CBC Radio for a program called *Ordinary Kids Doing Extraordinary Things*.

Although Aya's response to RSD was extraordinary, her early experience with RSD eight months after she was injured playing floor hockey and after going through the MRIs, bone scans and other diagnostic tests that failed to reveal RSD. Of course, she was told it was all in her head. She says, "I used to wish that I had broken a leg or something so



Aya Ravek, award-winning creator of [www.NoPainZone.com](http://www.NoPainZone.com) communicates with other RSD sufferers worldwide.

people could see I was hurt. One of the problems with RSD is that it is an invisible disorder, so people don't believe you're in pain."

What does she tell her friends about RSD? "That I'm in pain from my neck to my toes, and then let them know that if they want more information they can find it

on my website," she says. Right now her pain level is down to six (out of 10) and she isn't using crutches or a wheelchair. Although at one time she was taking 21 pills a day, she is doing what she can to stay off traditional medications, wherever possible. Aya turns to alternative methods of handling her pain, relying on guided imagery and Reiki massage.

She is blunt about the outside world's reaction to her chronic pain at school, describing her teachers as uninterested and inflexible and some of her fellow classmates as downright brutal. "I felt teased and tormented. Like an outcast." A different school delivered more understanding teachers and an administration willing to accommodate her RSD. Although she is exempt from gym class and some other physical activities, she is very involved in other areas, most notably music.

Her mother, Pamela adds "She was accepted at Canterbury, this region's only arts specialty High School. It only accepts 200 kids out of over 600 who apply." Aya will be in the vocal music program, which is an additional two hours a day of the specialty, in addition to the regular academic classes.

We can learn many things from Aya and her website about dealing with chronic pain. She's telling the world her story. She has taken the Internet, a medium without boundaries and is making it her own.