

I N M Y O W N W O R D S

BY SARA-ELIZABETH CLARK



Sara-Elizabeth (right) with Joyce Bender, chair of the Epilepsy Foundation, at Kids Speak Up! 2009

Sara-Elizabeth Clark is 14 years old and lives in upstate New York. She will be attending New Paltz High School in New Paltz, N.Y., this fall. Once she graduates from high school, she plans on continuing her education to become an actress or a rabbi. She also plans to continue being an activist in her community for epilepsy.

Once while playing with my sisters, I crawled under my bed and started having a seizure. This is dangerous enough, now add in the intense movements in a confined space. Noticing my distress, my sister dragged me out from under the bed. The seizure stopped in the open safety of my bedroom. My sisters' quick thinking saved me from any injury.

Some consider the physical aspects of epilepsy to be most serious; I feel the emotional side impacts me most. Some think because you have epilepsy it's okay to act like a jerk—regrettably being different often makes you a target for jokes. I've come across a few kids who have gone out of their way to be cruel. One even fell to the ground, shaking uncontrollably in front of me, imitating what it looks like when someone has a seizure. Despite some scary moments and notwithstanding occasional ridicule, I try to keep smiling.

Over time, my seizures began responding to treatment, and they trailed off. They didn't go away at once—there were setbacks—but

eventually they stopped. After two years without any seizures, the doctors said that they were most likely a thing of the past. They decreased my medications a little at a time until I was off medication completely.

Today, I can be found plotting my takeover of the world with my friends, practicing to keep my percussion skills sharp, playing with my pets, acting in my local theater and school, or driving the grown-ups around me crazy. Maybe I am not exactly a typical teen, but I still have a good time!

continued on page 14

I want to share my feelings on being considered different because I have epilepsy. I enjoy being called different, not because I have epilepsy, but because I AM different in many other ways. That's what makes me who I am.

Once upon a time, my seizures came as often as four or five times a day. Living with epilepsy isn't easy, but I still lead a normal life, never letting my epilepsy define me. I enjoy spending time with my family and friends, listening to music, animal rescue, acting, singing, playing drums and I play a mean game of backgammon! You know, "typical" teen stuff.

While I lead a unique life separate from my epilepsy, it sometimes finds ways to remind me that it's still there.

Be proud to be called different—I am. We can all hold our heads high and talk about it, there is nothing to be embarrassed or ashamed of.

In My Own Words

Continued from page 3

Being different is why I became an advocate. My goal is to break the stigma that surrounds epilepsy. I held my first event in 2006: *Sara's Walk for Epilepsy* one year before the National Walk for Epilepsy in D.C. I now have four Walks, a Race, a Breakfast, two trips to D.C. to speak with my representatives with *Kids Speak Up!*, two National Radio Shows with the Epilepsy Foundation's Chair, Joyce Bender, a book coming out this fall, my Web site www.itsnotwhoiam.com and much more.

My fund raising events have raised nearly \$50,000 to support programming for people with epilepsy.

Be proud to be called different—I am. We can all hold our heads high and talk about it, there is nothing to be embarrassed or ashamed of. In the words of the Epilepsy Foundation Chair, Joyce Bender: "We are all Champions!"

The In My Own Words column gives people whose lives are affected by epilepsy the chance to share experiences and solutions to their problems. These are real stories by real people that show strength, resilience, optimism and courage. We hope they will inspire others.



www.epilepsyfoundation.org
1-800-332-1000