

Hi, my name is Sara-Elizabeth, but most people just call me Sara. I am 13 years old & I have epilepsy. Please, take your time looking around my website, let me know what you think, and please stop back often. We are always upgrading and adding something.

I had my first seizure at 16 months old. Shortly after my first seizure I was diagnosed with Idiopathic Benign Childhood Epilepsy. I experienced both Tonic-Clonic & Partial Complex Seizures. Because of my seizures I did spend extended periods of time in hospitals. I was on adult doses of anticonvulsant medications just to keep my seizures under control.

Today I am seizure free and off of all medication. My last documented seizure was when I was five years old. At the age of six it was agreed by my doctors that I could slowly be taken off my medication.



I barely remember what it felt like to have a seizure now. But I have not forgotten that I had them. As well, many other people do remember what it was like to see me have a seizure. I have been told that some people looked at me with pity in their eyes, while others looked at me with disgust. I have also been told about the difficult times I had when my parents tried to set up play dates with my friends. Some families did not want me to come to play at their homes because they were afraid I would have a seizure and they would not know what to do. These are just two of the things that caused personal stigma in my life. I know that others with epilepsy have experienced their own stigmas when it comes to others perceptions when it comes to their epilepsy. To this day some people still treat me different once I tell them I have epilepsy.

At the age of 10 I decided I had enough and I started educating others. I told them that just because I have epilepsy I am no different then they are. I told everyone that I had epilepsy and if they had questions I answered them if they did not have questions I offered information. Most people were receptive, some people were not.

Around the same time I decided that I could also help others that have epilepsy by reaching further. I decided to put together what has become "Sara's Annual Walk for Epilepsy". I worked with a local agency that served individuals with epilepsy and The State University of New York at New Paltz (SUNY) to organize and promote my walk. My first walk was held April 30, 2006 and raised over \$15,000.00. My second walk was held on May 5, 2007 and raised an additional \$10,000.00. And most recently I teamed up with the Epilepsy Foundation of Northeastern New York (EFNENY) and held my third walk on May 3, 2008 again at SUNY. Together we raised over \$15,000.00 and donations are still coming in. EFNENY has agreed that all monies raised by Sara's Walks will be used to directly support consumers within the 22 counties they serve here in New York State.



Sara's Walk for Epilepsy also does many other things besides raising funds for better services and support. It also promoted general awareness, educated people, and per my personal mission, it helps break the stigma that surrounds epilepsy. My website "It's Not who I Am" promotes the idea and belief that I will not let my epilepsy define me as a person. I ask that no one judge a person wrongly because they have epilepsy or anything else that makes them different. What a boring world it would be if we were all the same!



Beyond my walks, and because of the generosity of Abbott Laboratories, I also participated in two ad campaigns in 2007, to help generate general awareness for epilepsy. One was a print campaign which included posters on busses, taxis, subway cars and in malls, as well as highway billboards. These ads were seen from NYC to Albany NY. I also did a television public service announcement which aired on several television stations throughout New York, Connecticut and New Jersey. You can see the TV commercial by clicking the link at the bottom of this page .

I receive emails from different people around the world; many ask me what they can do to make a difference. I encourage everyone to support a cause close to their heart and organize an event around it to make a difference in their community in any way possible.

Sara

