



Sara-Elizabeth Clark

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Hi, my name is Sara-Elizabeth. I am 16 years old and I have epilepsy. Please, take your time looking around my website, and let me know what you think, and please stop back often. We are always changing and/or adding something. Within my website you can read about my advocacy work in Washington D.C., My Book, The It's Not Who I Am Epilepsy Fund, Sara's Annual Walk for Epilepsy, and so much more!

I was diagnosed with Idiopathic Benign Childhood Epilepsy at 16 months old. While I am currently seizure free, I do still have residual side effects from my seizure disorder, and I am still under the care of a Neurologist. I experienced both Tonic-Clonic and 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.

I don't remember how others treated me because of my seizures when I was younger, but 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 their own stigmas when it comes to their personal experiences with epilepsy. Through my outreach with the It's Not Who I Am Epilepsy Fund I help educate others, raise funds and I hope it will have a positive affect on how people with epilepsy are treated. This is a journey I share with millions of people worldwide.

At the age of 10 I started educating others. I told everyone that just because I had epilepsy I was no different then they were, and if they had questions I would 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 to put together my first fund raising event, "Sara's Annual Walk for Epilepsy" in my hometown of New Paltz, New York. I worked with local agencies that served individuals with epilepsy and the State University of New York at New Paltz (SUNY) to organize and promote my walks To date, I have held six walks and several other events, collectively they have raised approximately \$70,000.00. All monies raised went to support those with epilepsy. My next event will be November 19, 2011—Called "Sara's Strikes for Seizures" and my next walk will be Spring 2012!

"The Its Not Who I am - Epilepsy Fund", "Sara's Walk for Epilepsy" and all of my other fund raising events do many other things besides raising funds for better services and support. They also promoted general awareness, educated people, and per my personal mission, they 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!

In addition to my fund raising I have participated in regional print and television ads (You can see the TV commercial on [MY ACTING](#) page), held a breakfast, two races, been on local and national radio programs, visited Washington D.C. on two occasions to meet with my representatives, and spoke to children from all around the country. All of this was to encourage others to talk about epilepsy, raise awareness and break the stigmas that surround it.

Because of my hard work, I was contacted by a local author, Chris Passudetti, who was working with a publisher, Scobre Press. Together they wanted to write my story. I was more then excited to work with them on this project. It took two years and lots of work but the story "Being Sara" is now available! It is my hopes that my story will inspire others to talk about epilepsy and how it affects their life and inspire others to reach out and make a difference in their own communities. The Author of "Being Sara", Chris Passudetti once told me that, "growing up is difficult but if you see your difficulties as opportunities rather than burdens, there is no limit to the positive impact you can have on your community, no matter how old you are". It is my hopes that everyone that reads "Being Sara" will come away with this message.

I receive emails from hundreds of people from all around the world and I do answer each and every one personally. So feel free to drop me a note and I will get back to you!

Sara-Elizabeth

Sara-Elizabeth Clark is the subject of the high interest fiction book titled '*Being Sara*', written by Christopher Passudetti and published by Scobre Press. Her website, www.itsnotwhoiam.com is the winner of the 'Website of the Month, May 2008' —Northeast Center for Special Care. Sara Elizabeth is also the recipient of the 2008 'Kohl's Kids that Care' National Scholarship and The Epilepsy Foundation 2008 'Raising Awareness Award'. Sara-Elizabeth was honored on March 20, 2009 by The Epilepsy Foundation of Northeastern New York for 'Increasing Awareness of Epilepsy In Our Community', as well as receiving many other honors, achievements and awards. Please visit www.itsnotwhoiam.com for details and more information.