

May 2008 Website of the Month

Northeast Center for Special Care is pleased to feature:

Its Not Who I Am

<http://www.itsnotwhoiam.com/>

At northeastcenter.com we are always in search of unique sites that would be of interest to our visitors and our community here at the Northeast Center. Our website of the month for May is unique and very special. It is a site created by a thirteen year-old, and while wisdom bespeaks age and experience, this is a unique young lady.

Sara-Elizabeth and her dad created the site we feature this month: *Its Not Who I Am*. Thirteen year-old Sara-Elizabeth has epilepsy.

According to the Epilepsy Foundation, epilepsy affects more people than Parkinson's disease, cerebral palsy, multiple sclerosis, and muscular dystrophy combined. It affects 2.3 million people of all ages.

At the fragile age of sixteen months Sara-Elizabeth had her first seizure. She experienced tonic-clinic and partial complex seizures. By age two her seizures had become uncontrollable. Because of the seizures and the medication used to control them, Sara-Elizabeth started pre-school in a special needs class and required extra assistance up until the first grade.



Screenshot of the *Its Not Who I Am* homepage.

Gradually, as her seizures were able to be controlled, Sara-Elizabeth was able to get off medication. Sara-Elizabeth is now seizure-free. She was able to start living life like any young person her age and today is a high honor roll student. Her story is an excellent example of overcoming barriers and is a story other young people with epilepsy should hear.

Having epilepsy, however, did bring stigma which even someone as young as Sara-Elizabeth could sense, so at age ten she became an advocate and an activist with the purpose of changing how people with epilepsy are perceived by society and how they see themselves.

Its Not Who I Am is a website that tells Sara-Elizabeth's story. It is also an interactive site where other young people with epilepsy (as well as their siblings, family members, parents, and friends) can visit and learn about how to move beyond being "someone with epilepsy." It is as much about self-awareness as it is about societal awareness. It is about self-perception and societal perception. Sara-Elizabeth reminds us that epilepsy does not define the person who has it. She tells us:

“The main reason I started my website with my dad was to help break the stigma that surrounds epilepsy. This is very important, so people will not judge those with epilepsy wrongly. People with epilepsy are not any different from people that do not have epilepsy.”

When you visit *Its Not Who I Am* you will find some interesting sections. The home page tells you about Sara-Elizabeth, the site itself, along with current information, and some favorite links. The menu takes you to other parts of the site.

This IS who I am is a feature of the site where Sara-Elizabeth invites visitors who are advocates or volunteers to share their own experiences about what they have done to make a difference. Young people and adults have shared experiences, such as an 8 year old girl who sold lemonade over the summer and then donated the money she made to breast cancer research. Or, a young man who relates how he helped put together packages with his church to send to our troops overseas. This is really a wonderful part of [Its Not Who I Am](#) and there are many more experiences that you can read when you visit the site.

Because adults as well as young people visit [Its Not Who I Am](#), there is a section called *Ask Mom*, where Sara-Elizabeth's mom answers questions from visitors and assists them with information, and dispenses wisdom and advice from a mother who has been down a difficult road with her child and has seen a positive outcome.

What's happening Now lets you know what events or projects Sara-Elizabeth is involved in, and *Past Happenings* chronicles the past two years - as you will learn she has been very busy! If that wasn't enough, in the section entitled *My Acting*, we learn that Sara-Elizabeth has a passion for acting and participates in a community theatre.

[Its Not Who I Am](#) is a website that lets you peer into the life of a young person with a disability, who is able to manage that disability and live her life while growing up and accomplishing many things. An important message Sara-Elizabeth and her website send to all her visitors is that stigmas should mean nothing; everyone can have a full and independent life. That message is emphasized through a real life example.

And people have reacted to Sara-Elizabeth's story as she noted:

"Everyone has given me positive reactions. This is great because it means that people understand my position when it comes to epilepsy. I have gotten emails from all over the country, England, friends, relatives and strangers. My dad explained that this is important that others find out what I am doing to spread the word, and this will help break the stigma soon."

One of the accomplishments of Sara-Elizabeth and her family was starting an annual walk for Epilepsy. Established in 2006 the first two walks raised nearly \$25,000. At the time of this writing a third walk is scheduled for May 3, 2008 with money raised benefiting the Epilepsy Foundation of Northeastern New York. You can read about the walk as well as learn how to participate or become a sponsor on the [Its Not Who I Am](#) website and you can even donate through PayPal directly from the site.

Sara-Elizabeth's story is also the subject of a new book written by Chris Passudetti, and published by Scobri Press. *Its Not Who I Am - The Sara-Elizabeth Story* (the working title) is scheduled to be released in September 2008. You can learn about the book as well as its release on the site.

We like to feature home-grown websites created by individuals or family members that tell a personal story about overcoming disability and obstacles. [Its Not Who I Am](#) is a wonderful example of that kind of site and it has been attracting a lot of attention. We asked Sara-Elizabeth what she has learned so far from being an activist and advocate on the web? She told us:

"I learned that everyone has a voice and everyone has a right to be heard, and we must all speak up for what we believe in, or no one will get the message and things will never move forward."

And what has surprised her about the work she does through [Its Not Who I Am](#)? Sara-Elizabeth said:

"I found it surprising that others, including adults, cared about what I had to say and really listened to me. Many asked questions and many joined me in helping to break the stigma that surrounds epilepsy."

What good work is being done by Sara-Elizabeth and her family. Please take the time to visit [Its Not Who I Am](#). You won't be disappointed. It's our website of the month for May 2008 and they are just a click away; don't forget to bookmark them so you can visit again.