

By ROCHELLE RISERVATO, Correspondent, The Daily Freeman

Reprinted with permission of Rochelle Riservato

A site called "Everyday Health" states: "Epilepsy is a common but frequently misunderstood brain disorder. In all, an estimated 2.7 million American children and adults have been diagnosed with epilepsy. People with epilepsy continue to encounter persistent old-fashioned, hurtful misconceptions, including the mistaken belief that epilepsy is a form of mental illness."

Such archaic and erroneous beliefs are what led Sara-Elizabeth Clark, diagnosed with the disorder at 16 months old and seizure-free for the past nine years, to take action.

What's unique about this 14-year-old is that she started her journey of advocacy by bringing awareness to the populace at age 10 with her annual event, "Sara's Walk".

"My mom was going to many other walks for autism, heart (disease), etc.," she said. "and I asked if there was one for epilepsy and she said she didn't think so, so I decided one was needed. And Sara's Walk was born."

With the support of her two sisters Kym and Machele; her mom, Tanya Yuro-Clark; and her dad, Shawn — along with the State University of New York at New Paltz campus and the Epilepsy Foundation — her first walk took place on April 25, 2006, and raised \$15,000. The next year, \$10,000 was realized. Last year saw some \$15,000 raised, bringing the total to around \$40,000.

As for publicity, she said, "The Walk and Sprint have a committee that works very closely together and works hard to get the word out to everyone."

One of the highlights of last year's walk was when the executive director from the Epilepsy Foundation, Jeannine Garab, read three letters addressed to Clark. One of them is posted on Clark's Web site: "Your hard work and dedication has paid off. Your inspiring example and determination demonstrates how a single individual can make a remarkable difference. Best wishes for a successful event. Sincerely yours, Hillary Rodham Clinton."

The other letters were a New York State Assembly citation and a state legislative resolution that recognized Clark's efforts.

Clark is not now on any medications for epilepsy. "I was on several medications when I was first diagnosed," she said. The doctors settled on one medication that worked best for me, and I remained on it for several years until I was slowly weaned from all meds."

As for her 2009 walk, Clark said it would premiere a new 5K sprint (3.1 miles), along with a kick-off breakfast called "Applebee's Flapjack Fundraiser Breakfast" at the town of Ulster restaurant from 8 to 10 a.m. on April 25 as the first part of a two-week awareness campaign.

The next walk is scheduled for May 2. Clark, who has set a goal of \$20,000, said the proceeds stay in the local area.

"All monies raised by my outreach are to go back to the community for awareness," she said. A lot of the money raised by my walk goes to educational programs that happen right in our schools. An educator comes into the classrooms and talks to the students."

Notwithstanding this enormous undertaking, Clark has numerous achievements to her credit. Last July, Kohl's Department Stores, which sponsors an annual scholarship program called Kohl's Cares for Kids, awarded Clark with one of ten \$5,000 scholarships given out from more than 13,000 youth nominations. The program's slogan is "Stand-up Kids Deserve to Stand Out." Additionally, Kohl's donated an additional \$1,000 to The Epilepsy Foundation of Northeastern New York, in Sara's name.

On March 31, for the second straight year, Clark will return to Capitol Hill in Washington, D.C., as a participant of the National Epilepsy Foundation's "Kids Speak-Up" program.

Her 2008 journey included a visit to the offices of then-U.S. Sen. Hillary Rodham Clinton, U.S. Sen. Charles Schumer, then-U.S. Rep. Kirsten Gillibrand and U.S. Rep. Maurice Hinchey, D-Hurley. Her visit included speaking before Congress to discuss the Epilepsy Foundation's message regarding the ADA Restoration Act (H.R.3195), the Americans with Disabilities Act (S. 1881) and the VA Epilepsy Centers of Excellence Act 2007.

"The ADA Restoration Act (H.R.3195) and the Americans with Disabilities Act Restoration Act (S. 1881) were made to restore the original ADA, as over 10 years, the U.S. Supreme court changed the original meaning and many people were not protected under the law as it stood last year, including me!" Clark said.

Since then the ADA Restoration Act has been enacted upon.

"This year, I will be accompanying my friend, Ryan, who was the 2008 Winning Kid for the Epilepsy Foundation of Northeastern New York. Together, we will be



The Clark family poses with actor Greg Grunberg, fourth from left, of the NBC series "Heros" last year in Washington D.C. From Left, Shawn Clark, Kym Clark, Sara-Elizabeth Clark, Grunberg, Machele Clark and Tanya Yuro-Clark. Grunberg, whose son Jake, has epilepsy, is the National Walk for Epilepsy chair.

visiting Capitol Hill to meet with our respective senators and Congressional leaders to discuss epilepsy and the impact it has on one's life."

Does she have a subject in mind for this year's visit?

"At this time, I am going to talk about the stigma associated with having epilepsy and the importance for continued funding for research for this disorder that affects millions of people in the United States," she said.

In addition to speaking to members of Congress, Clark will be addressing a group of her peers and adults from around the country on the topic, "Why is being different not a bad thing?" It's a subject she wrote about being considered different due to difficulties and falsehoods surrounding epilepsy.

What inspired this Gardiner resident and New Paltz Middle School student to take on such enormous objectives with such ferocity?

Well aware of the lingering presence of old-fashioned idioms and attitudes born out of old practices, such as the early 20th century institutionalizing of those with epilepsy, as if they were mentally ill, Clark used part of a popular tagline, "It's not who I am; it's what I have," in her efforts to expand awareness. She started www.itsnotwhoiam.com. The Web site reaches out to not only those with epilepsy, but it contains a blog for people advocating for other causes.

"I believe that people can make a difference in their own communities," she said. "I ask everyone to find a cause that is close to their heart and build a program around it to help others. This could be helping at a food bank, cleaning a park, helping a local charity, etc."

The site also features an Epilepsy Q&A section, what she's all about, upcoming events and updates on her activities — and that includes a book being written about her.

California-based Scobre Press has started a new series of books on children and young adults doing extraordinary things. Clark's story was chosen to be first in this series and is being written by author Chris Passudetti, who, according to Clark, "saw one of the posters from my 2nd Annual Walk for Epilepsy, was looking for an inspirational story to write about and contacted me thinking my story was exactly what he was looking for."

Currently, the book's working title is "It Is Not Who I Am: The Sara-Elizabeth Story." It is due to be released this September. Although that's Clark's favorite title, the publisher is still considering others. The book is now in its final edit stage, and a "teaser" chapter can be read on her Web site.

The book aspires to break stigmas surrounding epilepsy and common allegations made about those with the disorder. Clark said one often-said statement is, "People with epilepsy are stupid and incapable of doing anything someone without epilepsy can do."

She added that she expects the book will present a new awareness. "I want people to understand that just because I have epilepsy I am no different. It would be like saying someone with dyslexia is incapable of learning to read or that someone with only one leg can't run a marathon."

Clark also possesses many non-activist accomplishments. She is an aspiring actress, in addition to being multilingual, speaking varying levels of Spanish, Hebrew, French and sign language.

Starting at age 8, she's performed in many productions with 90 Miles Off Broadway, a New Paltz-based community theater. Her credits include "Cheaper by the Dozen," "Sleeping Beauty" and "The Adventures of Cinderella."

She's currently preparing for the March 13 and 14 production of "Annie Jr.," which will be performed at New Paltz Middle School.

This young girl can tire one out by simply reading her resume — but there's more.

Clark has also done local print and Internet acting when the Smiley family of Mohonk Mountain House fame hired photographer Steve Jordan for a print and online ad campaign. She starred in a public service announcement for epilepsy that featured the slogan, "It is what we have — not who we are," which inspired her Web site's name. She also appeared in a trailer filmed in Walden for a book titled "The Garden of Eve" by K.L. Going.

As if all that wasn't enough, Clark also did a taping for "The Montel Williams Show," plays xylophone and percussion, is self-taught on the piano and sings soprano.

Where does she see herself in 10 years?

"I will be 24 and I will have graduated from college and plan on acting on Broadway and being an activist," she said, adding that being an activist will always come first.

To learn more about Sara-Elizabeth Clark, reserve tickets for the "Kick-Off Breakfast" or support "Sara's Walk" go to www.itsnotwhoiam.com.



Sara-Elizabeth Clark on the set of "The Montel Williams Show" in 2007