

Walking for a Cause

Sara's annual walk at suny new paltz helps to fight epilepsy *by Erlin Quinn*
Photo by Lauren Thomas

hudson v@lley times
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Sara-Elizabeth Clark awards raffle prizes at the end of 'Sara's Annual Walk for Epilepsy' held last Sunday afternoon on the SUNY New Paltz

Dozens of people with epilepsy and those with family members or friends with the disorder gathered together Sunday afternoon, June 5, for the sixth annual "It's Not Who I Am" epilepsy walk at SUNY New Paltz. The event was founded by then ten-year old and now 16-year-old Sara Elizabeth Clark, who experienced her first seizure when she was 16 months old.

Clark, a New Paltz High School student, has helped raise \$60,000 for regional epilepsy foundations through her annual walk. She recently published a book, "Being Sara," launched the website www.itsnotwhoiam.com, and won numerous awards. Most important to her and her family, she has been seizure-free since 1999.

The money her first five walks raised went toward programming in the Hudson Valley, she said. "I hope this year's walk will be even more successful in helping others with seizure disorders and to demystify the ever-present stigma that some people have regarding people with epilepsy," said the energetic and joyous young girl as she greeted friends, supporters and walkers at the SUNY New Paltz outdoor track.

One out of 50 children and one out of 100 adults in this country are affected by epilepsy. "Yet people know so little about it. There are stigmas attached to the disorder like we're bewitched or strange," said Clark, whose grandfather, father and mother were proudly snapping pictures, operating the sign-in table, and doing whatever else they could to ensure the walk would be a success. "Epilepsy is what I have. It's not who I am and it's not who people who have it

are. But many things people take for granted we can't. Driving, swimming, walking...you don't know when a seizure might strike."

Before the two-mile walk, Clark invited the Harlem Wizards pro basketball player "Mighty Mike" Simmel to speak. Simmel, diagnosed with epilepsy as a young child, has since gone on to start several basketball camps for children with special needs. An ambassador for epilepsy awareness and understanding, he goes to various schools and also does half-time shows on epilepsy for the NBA.

"I began having drop seizures at age two through age six," said the Harlem Wizard. "My motor skills and motor coordination were slow, I was put into special ed classes, had to wear a helmet, and was teased, bullied. But one day my dad got this idea. He bought me a basketball because he thought it might help me with my motor skills...I guess he was right!" he said with a laugh. "I dribbled that ball everywhere I went, walking my dog, going to school, home from school, on the sidewalk, the court...and I was seizure-free until I was 16 years old."

At an elite basketball camp Simmel unexpectedly had a seizure. "They [the camp directors] wanted to kick me out of the camp," he said. "They didn't know what it was. I vowed then that when I grew up I would do something to help kids that suffered from the same disorder."

Mighty Mike now has four basketball camps throughout New Jersey for kids with special needs. He has also founded the "Bounce Out the Stigma" project (www.mightymike.com).

Simmel met Clark at a Kids Speak Up convention twice. He was inspired by her enthusiasm and desire to do whatever she could to foster awareness and to raise money towards programming and a cure. Mighty Mike has also been seizure-free for years. "I take my anti-convulsion medicine every night, I try to have a good diet, get rest, listen to my doctors...all of the things I encourage children with epilepsy to do"

Epilepsy is a brain disorder involving repeated, spontaneous seizures of any type. Seizures ("fits," convulsions) are episodes of disturbed brain function that cause changes in attention or behavior. They are caused by abnormally excited electrical signals in the brain. While there is no cure as of yet, anti-convulsion medications, diets, and a host of other preventive measures can help to make those who are diagnosed with epilepsy seizure-free. The seizures usually begin between the ages of five and 20 but can happen at any age, without warning. While there is sometimes a family history or genetic link, epilepsy can be idiopathic, without any identified known cause.

Many of the walkers, runners and bikers who came out to support the cause had been touched by epilepsy in one way or another. Fourteen-year-old Griffin Silvestro's twin brother Cesare suffers from the disorder. "I'm here because it feels good to be doing something to help my brother and the entire community of people with epilepsy," he said. Many of his friends were also walking in support of raising awareness and money for the cause.

Cynthia McCulster, a teacher in the Wappingers Falls school district, said she came out to walk for several reasons. She had epilepsy but "thankfully out-grew it," she said. "I'm also a teacher and I hear the stigmas, the bullying that goes on. I want to do whatever I can to educate my students, to support outreach programs because I know what it's like to live with epilepsy."

McCulster thought her first seizure at 16 was a fluke, but then had another seizure at 17. "It was a lifelong battle of educating myself, being responsible, and taking the anti-convulsion medication, which often had terrible side effects. You live with the anxiety of when a seizure might strike — if you're driving, swimming, near anything dangerous where you could fall."

After ten years, McCulster went to Columbia Presbyterian Hospital's epilepsy center, where she was carefully weaned off her medication. She was hooked up to an EEG (various suction-like cups on her head to monitor brain activity 24 hours a day for a week.) "If you have a seizure, you're in a safe, controlled environment, but I didn't have a seizure and they said it was very possible that I'd outgrown the disorder. I've been medication-and-seizure-free for six years."

One of the advocacy groups there to host Sara's Walk was the Northeast Regional Epilepsy Group, which sponsors programs, support groups, and cutting-edge medical treatment. Ann Marie Bezuyen, the executive director of the group, said that good news was that technology has improved in terms of diagnosing epilepsy. "There's better diagnosis, more treatment tools, new medications that have fewer side effects, and research studies that study how diet, sleep and many other ways of combating seizures can help," Bezuyen said.

"I took anti-convulsion medication," said Clark. "But there are many, many approaches to epilepsy; some that include specific diets that have proven to be effective, others that involve brain surgery where they take out a piece of your brain that causes the seizures. It sounds scary, I know, but it has proven to be very effective. The key is awareness, diagnosis, support, research and better treatments. And hopefully a cure."