

Epilepsy walk organizer won't let illness define her

BY GREG MARANO • POUGHKEEPSIE JOURNAL •
APRIL 28, 2008

GARDINER - This is not a story about the hundreds of volunteers, the donors, the committee, SUNY New Paltz staff, nonprofit groups or national radio personalities who have all gotten behind a walk to raise money for epilepsy patients on Saturday.

This is a story about the 13-year-old girl who put it all together.

Sara-Elizabeth Clark, a seventh-grader at New Paltz Middle School, is organizing the third annual Sara's Walk for Epilepsy at the SUNY New Paltz campus Saturday to benefit the Epilepsy Foundation of Northeastern New York.

She said she got the idea when she saw her family participating in events to raise money for autism, breast cancer and other conditions.

"I wanted to know why there weren't any epilepsy walks," she said.

Clark has idiopathic benign childhood epilepsy, but the address for her Web site - www.itsnotwhoiam.com - underscores her refusal to be defined by it. She'd rather be known for what she does; hence the walk.

When planning for the first walk, she met with SUNY New Paltz President Steven Poskanzer and college staff in November 2005 to discuss her idea.

"Sara conducted her meeting, and every person there said 'Absolutely,'" said her father, Shawn Clark.

She heads the seven-person committee that runs the event, and has final say over all decisions.

Imus pledges \$1,000

The walk has raised a combined \$25,000 in 2006 and 2007, and Sara's goal is to make another \$25,000 with this year's walk alone. Radio talk show host Don Imus has pledged \$1,000 and mentioned the walk several times on his show, she said. An estimated 300 people came last year.

"I didn't think it would get this big this quickly," she said.

In March, she participated in the National Walk for Epilepsy in Washington and met with staffers of the offices of U.S. Sens. Hillary Rodham Clinton and Charles Schumer, and Reps. Maurice Hinchey, D-Hurley, and Kirsten Gillibrand, D-Hudson. She used that time to push for passage of the Americans with Disabilities Act Restoration Act of 2007, which aims to ensure protection

against discrimination for people whose medical conditions are controlled by medication.

At 4, she was taking an adult's dose of medication to control her seizures. Clark has been seizure-free since she was 5, and medication-free since she was 6. She still experiences occasional short-term memory lapses, but nothing that prevents her from making the high honor roll at school - or organizing major fundraisers.

"Epilepsy hasn't changed my life in any way besides the fact that I'm helping others with it," she said. "It's a good thing, if you put it to the right use."



Clark has final say over all decisions about the epilepsy walk. (Courtesy photo)

PROFILE

Name: Sara-Elizabeth Clark.

Age: 13.

Home: Gardiner.

Epilepsy walk

Sara's third annual Walk for Epilepsy will be held from noon to 2 p.m. Saturday starting at the Elting Gymnasium on the SUNY New Paltz campus.

For information, visit www.itsnotwhoiam.com or call 1-518-456-7501.

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