

Teen spreads awareness of Tourette She teaches kids, and they teach other kids about involuntary tics

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Jennifer Zwilling stood before the class of fifth-graders at the Mamaroneck Avenue Elementary School in White Plains on a recent morning.

The children squatted on the floor of the activity room and looked up at her. At 16, she was barely six years older than they but poised, authoritative and friendly.

Zwilling, of Brookville, began by telling the class she was diagnosed at age 7 with something called Tourette syndrome, or TS. She doesn't mention that she was thrown out of a second-grade science class because of a tic she couldn't control.

Teacher misunderstood

"The teacher thought I was rolling my eyes over something she said," Zwilling recalled.

The incident ignited her mission: to make the world more aware of Tourette syndrome, a disorder that can cause involuntary motor or vocal tics.

By the next fall, she was speaking to teachers and students in the Robert Seaman Elementary School and later other schools in the Jericho school district. She became a sought-after presenter.

The Jericho High School junior doesn't roll her eyes anymore. Her tics are mostly internal now. But she knows the disorder is lifelong and that tics can return. About 200,000 people in the United States are known to have the neurobiological disorder.

As founder of the national Tourette Syndrome Association Youth Ambassador program, Zwilling recently was named a BR!CK award winner, one of 12 young people from around the country picked for their efforts to "build a better world." Like the other 11 winners, Zwilling received a \$10,000 community grant to continue her work and she appeared on a CW Network TV program. She also was cited by the Prudential Co. as one of eight Spirit of Community Service winners from New York State.

Faces on bags of tortilla chips

And to top it all, her smiling face and story now appear on millions of bags of Doritos tortilla chips. (Each BR!CK winner appears on a different flavor; Zwilling's is the popular nacho cheese flavor.)

Through it all, Zwilling hasn't lost sight of her mission: educating people to recognize Tourette tics and treat the TS person with respect. Although she has trained more than 100 ambassadors to carry on her work, she still gives presentations.

At the White Plains school, Zwilling compared TS to other chronic diseases such as asthma. "Do you know anyone who has asthma?" she asked the class. Hands shot up. "Did they do anything wrong to get it? Did they want to get asthma?"

Her presentation was simple. No electronic props, slides or PowerPoints. She used pictures and posters to illustrate her explanation about how everyone has "little messengers" in their brains but most people's messengers have stop signs. People with TS have little messengers with no stop signs.

Then she had the students play a game. She told them to pretend they had TS and to write the Pledge of Allegiance, which normally takes a minute and a half. But Zwilling instructed the students to erase every third word and rewrite it, and touch the floor every time she clapped her hands. She walked among them, clapping. The children wrote, erased, rewrote, touched the floor, wrote, erased, touched the floor. No one got past the second line.

"Nobody has ever finished," said Zwilling with a mischievous grin.

Do Something, the Manhattan-based nonprofit organization that presents the BR!CK awards, "looks for young people who are leaders and are making a tangible impact on the world," said award coordinator Emily Luke. Zwilling was selected from among 1,000 applicants younger than 25. "We love what she's

doing to make life brighter for people who have Tourette," Luke said.

Zwilling and other winners have been invited to help select next year's winners, Luke said. "We see it as the old cream of the crop choosing the new cream of the crop," she said. Applications for BR!CK awards can be found on the Web site, dosomething.org.

Teaching kids to teach others

"Jennifer has really made an impact because she teaches other kids to teach other kids," said Tracy Colletti-Flynn, spokeswoman for the Tourette Syndrome Association, based in Bayside.

Zwilling developed a training program for the association's Web site, tsa-usa.org. It includes a video she created with the aid of her sister, Amanda, 19, and brother, Eric, 14, neither of whom have Tourette.

For the Westchester school program, Zwilling brought along three trainees from Long Island: Katie Szanto, an eighth-grader, and Brian Wedeking, a 10th-grader, both Port Washington students who do not have Tourette, and eighth-grader Lee Gochman, 14, of Huntington Station, who does have the disorder.

Gochman said he has some classic symptoms, such as head jerking, finger tapping "and yelling out things that don't make sense." Many of his fellow students at Candlewood Middle School in Dix Hills don't understand these involuntary tics, he said.

"Some make fun of me," he said. "I'm treated differently."

Like Zwilling, he wants to educate young people to erase myths and stereotypes about the syndrome.

"She is my mentor," he said.

When Zwilling had finished her presentations before a succession of classes at the Mamaroneck Avenue school, it was evident her message had reached the students.

"If I see someone who has TS, I'll be nice to him," said Matthew Whitaker, 10. "If he says something he doesn't mean, I'll say it's OK," he added. "And if anyone makes fun of |

up for him and tell them to stop."

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