COURTESY

Qualters Middle School student Jackie Staffier, left, Senator John Kerry, Alex Parenteau of Scituate and Tim Johnson of Ashland meet in Washington D.C. where Staffier trained to be a youth ambassador for those with Tourette’s syndrome.

Mansfield teen trained as Tourette syndrome Youth Ambassador

By Rachael Bolden

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Mansfield -

Jackie Staffier, 14, lives in Mansfield with her parents and a younger sister who sometimes gets on her nerves. She attends eighth grade at the Qualters Middle School, where her favorite subject is science. She’s a vegetarian animal-lover who hopes to work with horses one day. She also happens to have Tourette’s syndrome.

TS is a neurological condition which can manifest in a wide range of involuntary motor and verbal tics. It has been heavily misrepresented in the media as a humorous condition that causes one to shout obscenities.

“People don’t understand the whole concept of Tourette’s,” Jackie said. “Just like people can’t control how much their asthma affects them, I can’t control how much my Tourette’s affects me.”
Jackie, whose diagnosis came when she was only nine, says that the biggest challenge is not in the disorder, but in people’s reactions to it. Growing up, she was often the subject of teasing by peers who didn’t understand her tics.

“I want people to understand TS so that they’re not so mean about it to other kids,” she said.

To that end, she recently completed a program in Washington, D.C. to become a Youth Ambassador for those with the disorder.

Jackie joined a group of 20 of her peers for a three-day training seminar hosted by the National Tourette Syndrome Association. All were chosen based on the strength of the personal essays they wrote detailing their lives with Tourette’s and their aims to educate others about the disorder.

“It’s hard to sit in school and concentrate,” said Jackie, who recently received high honors for her school’s second term. “I’m mentally and physically exhausted all day.”

The TSA Youth Ambassadors learned techniques for educating their peers about the symptoms and stereotypes commonly associated with TS. They also took a field trip to Capitol Hill, where they had the chance to share their personal experiences with senators and congressmen, including Sen. John Kerry, in an effort to raise awareness about TS.

“I loved it,” Jackie said of her trip to the nation’s capital. “Meeting John Kerry was so cool. I made a lot of friends and it was such a great experience.”

Now that she’s back home, Jackie is preparing several presentations at local schools, where she will share her story with students and provide them with accurate information about the disorder. She hopes, if nothing else, that her experiences help her peers learn the most important lesson of all.

“We’re just like everybody else.”

For more information about TS, call 1-888-4-TOURET or visit www.tsa-usa.org.