Lexington eighth-grader named an ambassador for Tourette Syndrome awareness

By Al Gentile
agentile@wickedlocal.com
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LEXINGTON

Nathan Swirnoff is using his daily experience to lobby for change on the national stage as well as provide support to his peers nationwide.
On March 10, Swirnoff went to Capitol Hill as National Youth Ambassador for the Tourette Association's National Advocacy Day. The event was designed to lobby Congress members to support H.S. 292, An Act Advancing Research for Neurological Disease Act - Inclusion for TS Prevalence.

“I went to Washington, D.C., to advocate for the problem I have, Tourette Syndrome,” said Swirnoff, of Marlboro Road. “I want to spread awareness to people who don’t really know about it.”

As a youth ambassador, Swirnoff received training in D.C. about how to lobby as well as gets to attend ongoing education program to receive tools to educate others about Tourette Syndrome and how interact with people who have the syndrome.

“I wanted to build awareness because if people know about this, they’ll be more understanding,” Swirnoff said.

Swirnoff is an eighth-grader at Clarke Middle School.

The National Institute for Neurological Disorders and Stroke describes Tourette Syndrome as a neurological disorder characterized by “repetitive, stereotyped, involuntary movements and vocalizations called tics.” The disorder is often referred to as Tourette's because of the medical scholar who first described the symptoms.

The Center for Disease Control reports 1 in every 360 children between the ages of 6 and 17 have been diagnosed, totaling approximately 136,000 children. The Tourette Association of America estimates 1 in every 100 school-aged children have Tourette Syndrome.

Meeting with the likes of Sen. Elizabeth Warren, D-Massachusetts, and several other legislators, Swirnoff said the experience was overwhelming.

“That’s what really changed my experience. I wasn’t expecting anything, and she was a really nice person,” Swirnoff said.

The aim of the national youth ambassadors is to combat one of the most common problems for people living with Tourettes, bullying. Bullying is an issue many of Swirnoff’s friends living with the disorder have dealt with.

“Bullying comes from a lack of understanding. That’s one of the reasons kids are getting bullied,” Swirnoff said. “If they’re bullying someone with a problem they probably don’t understand. They’re just making it worse for them.”

Lexington’s school system has been supportive and receptive to his disorder, according to Swirnoff. He is fighting for those who are not as fortunate.

“It’s kind of awkward talking about it with other people,” Swirnoff said. “Tell people that you trust, like your friends so they can understand what’s going on. You could lose your friend if they don’t know what’s going on. They could be making an excuse up in their head that is not correct.”
Being an ambassador is, something Swirnoff he takes seriously.

“People really look up to you, and think you’re a role model,” Swirnoff said. “You have to be responsible if you’re going to be an ambassador.”

For those dealing with Tourette Syndrome, Swirnoff has only words of hope.

“It gets better as you get older,” Swirnoff said. “Try to get through it. It’s OK, what’s happening.”