Teen says Washington, D.C., trip helped him open up about Tourette syndrome

By Aaron Wasserman
DAILY NEWS STAFF

ASHLAND — Since returning from Washington, D.C., recently, Tim Johnson finds he is more comfortable talking openly about his Tourette syndrome.

Friends who didn’t realize Johnson, 17, an Ashland High School junior, has Tourette syndrome now know, and he’s eager to teach young children about what it means to live with the diagnosis.

“Before, I used to say, ‘Oh, it’s nothing,’ and blow it off, so it’s helped confront rather than avoid it with friends,” he said. “It can be difficult because there’s a time and place to say it in a friendship. My friends have been understanding and accepting. Most of them don’t believe it.”

Johnson is feeling bolder after his D.C. trip because he was there as part of a three-day event organized by the National Tourette Syndrome Association and aimed specifically at teenagers with the disorder.

As one of about 20 youth ambassadors, he learned how to educate others about the syndrome — its symptoms and its misunderstandings. He also met congressmen and their staff from Massachusetts and elsewhere in the country, to encourage them to consider people with Tourette syndrome when voting on legislation such as

Tim Johnson, 17, of Ashland, who has Tourette syndrome returned from a three-day conference on the disorder in Washington, D.C.
Teen a Tourette syndrome ambassador

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special education and workplace protection.

The conference was also a learning process for Johnson because for the first time he was in a room full of people who also had Tourette syndrome and openly acknowledged it as part of their activities together. At first, he said, it was difficult to adjust, "but on the second day, I settled in. It was refreshing because they struggled with the same things I struggled with in school." He said spending time with so many similar people also made him think about how Tourette syndrome is part of who he is. Living with the syndrome has, in general, receded to the back of his mind, he said.

No one meeting Johnson for the first time would realize he has the syndrome, with which he was diagnosed at age 5. He said he concentrates in class, at his job at a local movie theater and elsewhere to control mental tics.

An art and fashion design enthusiast, Johnson said he would like to attend the Fashion Institute of Technology in New York after graduating. He also plays the alto saxophone in the high school's concert band, enjoys music, Broadway shows and traveling, and likes spending time with friends.

Now that he's returned from the National Tourette Syndrome Association's conference, Johnson said he wants to start sharing what he learned with younger children and continue raising awareness of the syndrome at his college campus, wherever that is.

He said it's important to dispel common misconceptions about the syndrome, such as the one that all people diagnosed with it swear uncontrollably.

"I think it will be easier if they (young children) grow up knowing about mental disabilities than learning in high school," Johnson said. "If they learn about it early, they accept it better, rather than it being another thing to make fun of in middle school."

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