

At 13, he's at ease spreading understanding of Tourette's

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When Zachary Fink started at Shrewsbury's Oak Middle School in the fall of 2009, he did what he has always done since being diagnosed with Tourette syndrome at age 8: He spoke before a faculty meeting about the often-misunderstood neurological disorder.

Zack, now 13 and in eighth grade, told his teachers that sometimes they might see him retreating to the hallways when his tics became frequent. He told them that he needed a silent room to read and take tests.



Zachary Fink (center) works with classmates at Oak Middle School in Shrewsbury,... (Adam hunger for the boston globe)

“You have a bunch of motor and vocal tics and you have a very difficult time controlling it,” said Zack, who has also been diagnosed with obsessive-compulsive disorder and attention deficit hyperactivity disorder. “And the longer you try to control it, the harder it gets. It’s very difficult sometimes.”

In the five years since he was diagnosed with Tourette's, Zack has grown comfortable speaking about the disorder in front of a group. So when the school nurse heard that the national Tourette Syndrome Association was looking for youth ambassadors around the country, she suggested that Zack apply. He did, and wrote an essay about his experience with the condition.

Based on his essay, earlier this year Zack was named Massachusetts Youth Ambassador for the Tourette Syndrome Association, and spent three days in Washington, D.C., taking training to educate other students about the disorder. Soon, he will begin speaking at other schools, hoping to dispel myths about Tourette's and make it easier for students diagnosed with the condition.

“Sometimes what I don't like is when people make fun of it, and just pretend they have Tourette's so they can swear or something,” he said. “A lot of people aren't educated, which I also think is important, because they should know what it is.”

Tourette syndrome is a neurological disorder that usually shows up in children and teenagers, and causes involuntary motor and vocal tics. It is not known what causes Tourette's, though medication can help control the symptoms.

Medicine has helped control Zack's tics, but he still can find himself sniffing a lot or breathing heavily. His facial tics include blinking frequently and twitching his head.

When Zach first started showing the involuntary verbal tics of Tourette's, making noises in his classroom, his parents thought he was misbehaving.

“It was very stressful at first because I didn't know how to control it,” he said. “I'd sometimes cry a lot because I didn't know what to do. But I've learned to just overcome it.”

Zack's mother, Barbara Fink, soon began to suspect her son had Tourette's. Before he was diagnosed, the family happened to see the HBO documentary, "I Have Tourette's, but Tourette's Doesn't Have Me." They recognized Zack's tics.

"We all sat down and watched it and we all cried," she said. The early days of her son's diagnosis were especially hard for him, she said.

Medication helped. And so has explaining to his teachers and his peers why he sometimes needs to leave class and spend a few minutes in the hallway.

"I really think he's a brave child," Barbara Fink said.

This is how Zack describes what it is like to have Tourette's: "I say sometimes it's like a balloon or something, and you're pumping air into it, and the air is like the tics. But if the balloon tries to hold it, eventually it's going to have to let some air out. And if it doesn't, the tics are just going to eventually explode and just a ton will happen. So you have to do them regularly."

Zack's Tourette's and other conditions have not limited his school activities. He plays football and has a leading role in the school play. He reached the state competition for National History Day. He was just at districts for choir. He is an honor student.

"He's got that kind of drive about him," said Zack's father, Steven Fink, who went to Washington with him. "He really kind of excels, despite all these problems."

Judit Ungar, president of the Tourette Syndrome Association, said sometimes children laugh at or bully classmates with the disorder. Her group recommends that schools talk about Tourette's so the other students understand why they might have verbal or motor tics.

Ungar met Zack at the national gathering in March, and was impressed with the way he has spoken out about Tourette's at his school, she said.

"Instead of holding back and being scared, he took his strength, which is speaking in public, and went ahead and said, 'I'm going to fight this.'"

Recently, officials at Oak Middle School asked Zack to speak with a younger student who had been diagnosed with Tourette syndrome. She was just starting to learn about what having the condition would mean for her.

"My main theme was, it will get better," Zack said. "Trust me."

Zack has an aide at school, though he has improved so much that he will no longer need one next year as a freshman. "To see what he has to go through, it just amazes me every day," said the aide, Kathleen Harmon.

Zack wants to study law after college. He likes public speaking and feels comfortable in front of a crowd.

"He is not in any way withdrawn," said his father. "He has, over the years, learned to advocate for himself quite well."

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