

Tourette's Association selects Marblehead student as youth ambassador



The Tourette Association of America selected Camden Alexander, 13, as one of 33 youth ambassadors from across the country. Alexander, who was diagnosed with Tourette's at 4, head to Washington, D.C. next week for a two-day training, in part, on how to educate the public about Tourette's.
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MARBLEHEAD

Marblehead Veterans Middle School seventh-grader Camden Alexander, 13, lives with Tourette Syndrome, but that isn't stopping him from making a difference--in fact it's inspiring him.

"I hope that I can help others, like me, and spread awareness about what it's like to live with Tourette's syndrome," said Camden. "I'm excited to get the chance to have a formal training on Capitol Hill and make a difference."

According to the Tourette Association of America, one out of every 100 school-aged children in the US has Tourette's syndrome or a related tic disorder. Camden is one of 33 teens from across the country chosen to help educate the public on his condition through the Tourette Association of America's competitive Youth Ambassador Program. The program is designed to "empower youth to improve public speaking skills while spreading awareness and acceptance for Tourette's disorder."

From March 8 to 10, the young Marbleheader will undergo training in Washington, D.C. to learn how to properly speak about the disorder in public settings. The two-day event will be capped off with ambassadors heading to their state's congressional delegation offices to share their stories during the association's annual advocacy day.

He will then return to "educate peers in the Marblehead region about this widely misunderstood neurodevelopmental condition," according to the association.

The formal training comes after years of Camden already having shared his story with peers and even educators. He has even developed a simple explanation for his condition.

"On the inside your bad brain is making your good brain do things it doesn't want to do," he said.

Steve Alexander, Camden's dad, said his son was diagnosed with Tourette Syndrome at four years old when he started, out of the blue, "grunting constantly."

The syndrome also has other side effects. Camden recalled once attending a important dinner party with his dad, asking adults whom they were voting for and the status of their relationships. Asking inappropriate questions is also one of a spectrum of involuntary symptoms can also include repetitive movements and unwanted sounds and behaviors.

Camden said his most severe symptoms included a lack of self control, repeating meaningless expletives and defiant behaviors, by no fault of his own.

His symptoms - with the help of teachers, self-relaxation techniques, hobbies and home interventions - have subsided, but it hasn't always been easy, he said.

His symptoms were most pronounced during his early elementary years. Camden said his first and second grade years were marked by bouts of screaming that sometimes lasted for 30-minute periods, repeating swear words and spitting in front of classmates and teachers.

All of this, Steve Alexander said, "disrupted the decorum of the classroom."

Camden's unintentional behaviors required his parents to move him from a private Montessori school that did not have the resources to meet his educational needs to a public schools where help is mandated.

"Most kids, like Cam, who are diagnosed are empathetic, kind and caring," said Steve Alexander.

What further compounds the frustration is young kids with the disorder know something is wrong inside but lack the vocabulary to explain what's going on, Steve Alexander added. Often the behavior is seen as attention seeking, he said.

Steve Alexander credited the ebb in his son's symptoms to an early diagnosis of the disorder, which led to early intervention by teachers. That early intervention also helped Camden's teachers normalize his condition in the classroom, but that's not always the case, Steve Alexander said.

Camden said he was lucky, he's never experienced bullying from his peers.

"Kids knew me as the friendly kid and then the kid who sometimes had meltdowns," he said with a chuckle.

Camden said his last severe episode, an hours-long repetition of the word OK lasted until his voice went hoarse, was months ago. Lately it's only on occasion that he has sustained periods "where I snap or wiggle my fingers," he said.

Unfortunately, some kids who display symptoms such as Camden's go undiagnosed and can stigmatize them, Camden and Steve Alexander said, as "a brat, rude and attention seeking."

And if classmates' perceptions and misunderstandings go unchecked, symptoms can lead to their bullying and shunning kids with the disorder.

Camden's triumph over the disorder is partly due to his myriad hobbies including his love of skiing and acting. He has performed in "Peter Pan," "Wiley and the Hairy Man," "Midsummer Night's Dream," "Jack and the Beanstalk," "Twinderella" and "The Tempest."

He also plays the piano, violin and guitar.

Steven Alexander said Camden's engagement with music, in particular, helps "focus his brain in way that makes his symptoms fall away."