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Mansfield middle school student living with Tourette's syndrome taking message to Congress



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Brendan Robinson and his sister Olivia are shown at the Qualters Middle School in Mansfield. They both have Tourette's syndrome. Brendan will be making a trip to Washington D.C.

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BY RICK FOSTER SUN CHRONICLE STAFF

MANSFIELD - Qualters Middle School student Brendan Robinson has Tourette's syndrome, but it doesn't define him.

The 12-year-old is a good student and a talented musician who plays oboe and picked up playing piano on his own.

And this month, he goes to Washington to meet with senators and congressmen as part of an effort to raise awareness about the widely misunderstood hereditary condition that produces involuntary facial tics and inappropriate vocal outbursts in many people with the condition.

"It can be hard sometimes, but you have to stay positive and realize you're going to have good days and bad days," said Robinson, whose two younger sisters, ages 4 and 9, have also been diagnosed with Tourette's.

Robinson, a former charter school student who was diagnosed about a year ago, said his symptoms were initially hard for classmates and teachers to comprehend. But he also received some strong support.

"Brendan learned who his friends are," said his father, Michael.

Tourette's syndrome is among a spectrum of hereditary, childhood-originating neurological conditions referred to as tic disorders, according to the Tourette Association of America.

The disorder is characterized by uncontrollable movements and or sounds, including head bobbing and arm jerking. Other complications, like attention deficit disorder, often develop in Tourette's cases.

From March 8 to 10, Brendan will serve as one of 47 youth ambassadors selected to participate in the Tourette Association's Youth Advocacy Day, which will include training and a chance to share their stories with members of Congress.

Brendan said he expects to visit with U.S. Sens. Edward Markey and Elizabeth Warren, as well as U.S. Rep. Joseph Kennedy III.

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

Brendan's father Michael says raising awareness about Tourette can benefit sufferers and their families by educating the public and promoting understanding and acceptance of people like his son.

He hopes it will also lead to greater support for medical research into Tourette, which can be treated but as yet has no cure.

Brendan said he felt inspired and supported last year when a young Tourette ambassador came to speak at his school. After he returns from Washington, the Mansfield student will get to fill a similar role, and will be available to speak to schools, clubs and community organizations.

