

Tourette Syndrome changing perceptions: Teen pushes for deeper understanding

Young woman pushes for a deeper understanding

7:54 AM, Sep. 13, 2011

Written by

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NEPTUNE — For the two dozen or so resident doctors gathered at Jersey Shore University Medical Center's Brennan Pavilion, it was an opportunity to further their learning in their fields.

For the presenter at the forum — a teenager from East Brunswick — it was possibly the chance of a lifetime: to help educate physicians-in-training about Tourette syndrome, attention deficit disorder



Amanda Silver, 16, has Tourette syndrome. The East Brunswick teen addressed resident doctors at Jersey Shore University Medical Center in Neptune last month, sharing her experience and giving the doctors a patient's perspective.

(ADD) and obsessive compulsive disorder (OCD).

Amanda Silver, 16, who has all three neurological conditions, was the focus of the patient-centered training at the Neptune hospital last month.

The project, launched this year by the Tourette Syndrome Association of New Jersey (TSANJ), is geared toward pediatric and family resident programs throughout the state, inviting adolescent Tourette patients and their parents to address clinicians.

Training sessions also have been conducted at Overlook Medical Center in Summit and Robert Wood Johnson University Hospital in New Brunswick.

"I think the sessions are important because it's better for the doctors to hear it from the person than read it in a book," Amanda said. "You can't get that knowledge from a book, with all the stories

people tell, because every case is different."

During the talk, she described her typical days with Tourette syndrome and the commonly associated disorders of ADD and OCD, how the conditions

affect interactions with her family and peers, "and how doctors treat me and how I interact with them," she said.

"I could tell they were really interested," she said of the residents, "because they were all paying attention."

"We find this in every presentation," added Faith Rice, executive director of the state Tourette Syndrome Association. "It's clear we're striking a chord, that they want to hear directly from the patient."

Amanda's story

Amanda told the physicians her tics — then, repeated blinking of the eyes and humming — began when she was approximately 5 years old.

"My mom and dad realized I couldn't help what I was doing and took me to a doctor," she said.

The doctor attributed the movements and vocalizations to depression. A second physician, Amanda said, diagnosed Tourette syndrome.

She was placed on medications, but one exacerbated the tics and the side effects of others — fainting and excessive weight gain — were deemed unacceptable.

Amanda said her parents, Barbara and David Silver, help her cope with the tics, ADD and OCD.

“At school I hold in the tics, but it gets worse when I get home,” Amanda said.

Her dad described the release of motor and vocal tics as “sort of like a dam bursting.”

“At night I keep throwing my head back or bouncing up and down,” Amanda said, adding that she also cracks the joints in her hands or makes horse sounds. Yet she's often unaware she's experiencing tics until someone asks her to stop.

At times, she's able to calm herself by playing piano.

“Amanda works with a neurologist and realizes she can't extinguish all the tics but can make adaptations so she can function,” Barbara Silver said.

During Amanda's early school years, her mom would begin each term by visiting her teachers to explain the effects of Tourette syndrome, OCD and ADD on her learning. By the time she was in seventh grade, Amanda took over the task as a self-advocate.

“Amanda's a very good student, but sometimes teachers don't realize she still needs accommodations even when she's getting As,” Silver said.

Among her accommodations are writing with a school laptop computer, additional time for taking tests and preferred seating in class. But as a teenager, Amanda doesn't want to be seen as different, Silver said, and her daughter doesn't always seek accommodations.

“I don't want to exclude myself. I want to do everything,” Amanda said.

At East Brunswick High School, where she's a junior, Amanda's working toward certification as a student athletic trainer to be able to treat injured athletes, apply first-aid bandages and treat for shock. In many ways she's a typical teen — except, because of the OCD, her room is clean — her mom said.

Amanda said she hopes sharing her story with others will help them better understand her conditions.

“When I tell my friends about it, I like them to ask questions because I don't want them to have the perception of Tourette as seen in the media,” she said, “Sometimes the media makes fun of it or it's presented as worse than it is.”

Teaching new doctors

“We knew from experience we needed to get to the doctors and therapists before they finished their training to make a difference,” Rice said.

“I would hope,” added Barbara Silver, “it broadens horizons for a lot of doctors already out there, and a new group of doctors, just to be informed about Tourette syndrome not only as a medical condition, but as a way of life for the family.”

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