Collaborative Partnerships for the Tourette Syndrome Community

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## Teenagers help Jersey Shore Medical Center resident physicians better understand Tourette Syndrome

Amanda Silvers, 17, and Grace Hawruk, 16, describe their experiences with TS and address questions about diagnosis, treatment, quality of life and obtaining a driver's license

NEPTUNE – The New Jersey Center for Tourette Syndrome & Associated Disorders (NJCTS) on August 30 made the Pediatric Resident Program at Jersey Shore Medical Center a stop on its yearlong, statewide tour for its Patient-Centered Medical Education (PCME) program. Teenagers Amanda Silvers, 17, of East Brunswick and Grace Hawruk, 16, of Butler, joined NJCTS Medical Outreach Coordinator Laura Taylor for the training, at which Silvers and Hawruk described their experience with Tourette Syndrome at school, at home and in their communities.

Attending doctors, physicians and residents learned the basics about TS, an often misdiagnosed, misunderstood, inherited neurological disorder that affects 1 in 100 children. They also absorbed information that they never before had heard about TS, considering that – by their own admission – the majority of their educational experience with Tourette came in the form of brief exposure in medical school.

Silvers and Hawruk took turns presenting information that focused on the experience of initial diagnosis, on quality of life and on encounters with physicians and the health-care system. The goal of the PCME program is to help resident physicians enhance their understanding of the perspectives, stresses and needs of patients with neurological disorders such as TS – and their families – to



Photo by NJCTS

Grace Hawruk, 16, left, and Amanda Silvers, 17, address a group of resident physicians at Jersey Shore Medical Center as part of the New Jersey Center for Tourette Syndrome & Associated Disorders' Patient-Centered Medical Education program.

improve interpersonal and communication skill in patient encounters.

Even if people know what Tourette Syndrome is, they cannot even begin to understand what it truly is and what life is like for people who have it," said Silvers, who was joined at the presentation by her mother, Barbara. Hawruk had her parents, Kelly and Rick, at her side. "It (the PCME program) provides physicians the opportunity to take my personal feedback and advice to create an improved doctor-patient connection."

The resident physicians asked several questions, including ones about diagnosis and treatment. But the most curious question was addressed to both girls – if having Tourette Syndrome will impede them from getting their driver's licenses over the next year. Silvers relayed how she is nervous about driving because of her eye-blinking tic, but is looking forward to driving in the future.

"The doctors have benefited from this opportunity by grasping a deeper understanding of what life is like from the patient's point of view and what kind of treatments work best," said Silvers, a senior at East Brunswick High School. "They were entirely focused on the presentation from the beginning. Who knew that two young girls could capture the attention of a room full of professionals?"

NJCTS works with hospitals throughout New Jersey and the greater New York and Philadelphia areas to present these trainings. Over the past 18 months, the Center has facilitated trainings twice at Jersey Shore Medical Center, as well as Goryeb Children's Hospital in Morristown, Saint Peter's University Hospital in New Brunswick and Robert Wood Johnson University Hospital in New Brunswick. The next PCME trainings will take place on October 24 at Newark Beth Israel Medical Center in Newark and on November 7 at Cooper University Hospital in Camden. More information about the PCME program is available by calling 908-575-7350 or by visiting <a href="https://www.njcts.org">www.njcts.org</a>.

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New Jersey Center for Tourette Syndrome and Associated Disorders, Inc. Collaborative partnerships for the TS community.