



New Jersey Center for Tourette Syndrome
AND ASSOCIATED DISORDERS

*Collaborative Partnerships
for the Tourette Syndrome Community*

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NJCTS Peer Advocates deliver rousing medical education message to Yale University doctors

Teenagers Grace Hawruk, Tommy Licato and Tess Kowalski were portraits of confidence as they discussed how their lives and those of their families have been affected by Tourette Syndrome

NEW HAVEN, Conn. – Between them, teenagers Grace Hawruk, Tommy Licato and Tess Kowalski have delivered more than a dozen presentations on behalf of the New Jersey Center for Tourette Syndrome & Associated Disorders (NJCTS). They’ve spoken to students, teachers, doctors and residents about what it’s like to live with TS – an inherited, misdiagnosed, misunderstood neurological disorder that affects 1 in 100 kids.

But prior to October 8, each of their presentations had taken place at hospitals across New Jersey. On this particular Tuesday, however, the trio was invited to speak at one of America’s leading institutions of higher learning – Yale University. Their talk about Patient-Centered Medical Education at the Yale Child Study Center not only was well-received by the nearly 120 faculty and trainees of the Yale School of Medicine, it was lauded and encouraged to be replicated – nationwide.

“In an academic clinical research center – one that is the birthplace of much of the important work into the causes and treatment of TS over the past 40 years – it was very important for clinicians and researchers to hear from the teenagers themselves,” said Dr. Robert King, a Professor of Child Psychiatry at the Yale Child Study Center and a key partner of NJCTS. “There is a lot of excitement here about the thought of the NJCTS Patient-Centered Medical Education program being used as a model with children and families affected by other clinical disorders.”



Photo by NJCTS

From left, NJCTS Peer Advocates Tommy Licato, 14, Grace Hawruk, 17, and Tess Kowalski, 14, prepare to speak to faculty and trainees at the Yale School of Medicine on October 8.

Patient-Centered Medical Education is a unique education program that provides doctors and physicians in training an opportunity to hear directly from adolescents/young adults with Tourette Syndrome and their families. It fosters an understanding of the perspectives, stresses and needs of families living with TS and associated disorders such as OCD, ADHD and anxiety.

Tommy Licato, 14, has done six Patient-Centered Medical Education trainings, and his experience and resulting confidence was clearly on display as he highlighted how answering doctors' questions make him feel like what he's been through – all of his experiences, even the most negative ones – are important and worthy of discussion.

“The most frequent comment I get from doing Patient-Centered Medical Education is that doctors always read about Tourette Syndrome in textbooks, but that hearing from patients in person is a treat and very helpful,” said Licato, a freshman at South Plainfield High School. “And if I can help someone be diagnosed sooner through talking to doctors, somehow, everything I have gone through will become worth it.”

Most of Tess Kowalski's experience has been derived from speaking at schools and hospitals in Central Jersey. Educating doctors has been an “amazing” experience for her, too.

“TS has really changed my life,” said Kowalski, 14, a Plainsboro resident whose father, Tim, also spoke to the Yale audience about the parent perspective of having an adolescent with Tourette. “Even though my tics are painful and stressful, and people stare at me all the time, I'm now this confident girl who can speak in front of people and tell them I have TS without being shy or cowering in front of them. It's amazing.”

Grace Hawruk, meanwhile, is intent on showing that TS has not and never will slow her down. At 17, Hawruk has been a part of the Patient-Centered Medical Education program for two years, is captain of her high school tennis team and has become quite good at suppressing her tics. Diagnosed with TS at age 8, Hawruk had a simple yet powerful message for the faculty and trainees:

“Telling my story is rewarding because I get to teach people and know that I'm bringing everyone one step closer to tolerance and understanding,” said Hawruk, a senior at De Paul Catholic High School who hails from Butler and was introduced to NJCTS after nominating one of her teachers for an Educator of the Year Award in 2011.



Photo by NJCTS

From left, Dr. Stuart Green of Overlook Medical Center; NJCTS Education Outreach Coordinator Melissa Fowler; NJCTS Peer Advocates Tommy Licato, Grace Hawruk and Tess Kowalski; and Tim Kowalski present Patient-Centered Medical Education to nearly 120 faculty and trainees at the Yale School of Medicine on October 8.

“I have a lot of memorable moments because of TS,” Hawruk added.” At past grand rounds, I’ve gotten a standing ovation from the doctors. It was shocking to see how my words moved doctors. So I’m grateful to have TS. Without it, I would not be me.”

Dr. Stuart Green, Associate Director of the Family Medicine Training Program at Overlook Medical Center in Summit, N.J., and NJCTS Education Outreach Coordinator Melissa Fowler also were part of the presentation, one that Dr. Green believes could finally signal the start of advancing medical education not only in the Tourette Syndrome community, but in the medical community as a whole.

Dr. Green, who develops patient-led medical education programs at Overlook, was the catalyst behind the creation of the NJCTS program and firmly believes that “patients and the community-based organizations which support them have powerful lessons to teach us all. Patient educators and advocates should have an active presence and strong voice in every aspect of medical education and health care.”

Added Fowler, who trains each participant before they speak at a Patient-Centered Medical Education presentation: “There are still too many educational and medical professionals who say that they have no idea what is involved with Tourette Syndrome. So it’s a really exciting thing to be a part of a program that is changing that. The hope is that we can see this model have some implications to be expanded beyond Tourette Syndrome.”

Since its inception in 2010, the Patient-Centered Medical Education program has been presented by NJCTS at more than 15 hospitals in New Jersey.

“It is the goal of the New Jersey Center for Tourette Syndrome & Associated Disorders, through the Patient-Centered Medical Education program, to bring each doctor and resident to a level of understanding about TS so that each of the 1 in 100 kids affected by the neurological disorder can be properly diagnosed, treated and someday cured,” NJCTS Executive Director Faith W. Rice said.

For more information about the Patient-Centered Medical Education program, or to schedule it at your location, please call 908-575-7350 or visit www.njcts.org.



Photo by NJCTS

Dr. Stuart Green of Overlook Medical Center helped the New Jersey Center for Tourette Syndrome & Associated Disorders develop its Patient-Centered Medical Education program.

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