



New Jersey Center for Tourette Syndrome  
AND ASSOCIATED DISORDERS

*Collaborative Partnerships  
for the Tourette Syndrome Community*

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## **NJCTS Youth Advocate Tess Kowalski taking awareness efforts around New Jersey, to Washington D.C. in 2013**

*13-year-old encourages students, educators and families to consider their experiences with Tourette Syndrome and use them to help advocate for others and themselves in a positive way*

EDISON, N.J. – Since joining the New Jersey Center for Tourette Syndrome & Associated Disorders (NJCTS) as a Youth Advocate more than 18 months ago, 13-year-old Tess Kowalski has been busy traveling all over the Garden State – and even outside of it, as her home-school schedule allows – to spread the message that kids with TS are no different than anyone else; they just happen to face different, often difficult challenges.

One of Kowalski’s most recent appearances was May 23 at the Dare To Dream Student Leadership Conference at Middlesex County College. Kowalski teamed with Montclair State University student Katie Delaney, NJCTS Youth Advocates Dylan Teator and Tommy Licato, NJCTS Education Outreach Coordinator Melissa Fowler and NJCTS Medical Outreach Coordinator Jamye Shelton Pelosi to educate attendees about the importance of considering how their experiences and stories with a disability might be used to help them advocate for others and themselves in a positive way.



**Photo courtesy of the Hawruk Family**

**Youth Advocates Tess Kowalski, right, and Grace Hawruk during their March 19-21 trip to the National Tourette Syndrome Youth Ambassador Conference in Washington D.C.**

Kowalski told the scores of attendees that their stories can be used to empower others and as a tool for change and a way to generate greater understanding.

“Something that is so special about the Dare to Dream Conference is that every kid, teen and adult can really connect with every speaker because we're all going through something hard – something that we struggle with – which sets us apart from ‘normal’ kids,” she said.

“But then again, no person is truly normal. So when we all are there together, everyone feels comfortable and relaxed, and they can just sit back, cheer on the speakers and truly relate to them,” Kowalski added.



Photo by NJCTS

**Youth Advocates Tess Kowalski, center, Dylan Teator, left, and Tommy Licato talk Tourette on behalf of the New Jersey Center for Tourette Syndrome at the Dare To Dream Student Leadership Conference on May 23 at Middlesex County College in Edison.**

Back in March, Kowalski sojourned with her father, Tim, to Washington, D.C., for the annual National Tourette Syndrome Youth Ambassador Conference. The three-day event presents Youth Advocates such as Kowalski and [fellow New Jersey Youth Ambassador Grace Hawruk](#) with training on how to better speak publicly about TS and advocate not just for themselves, but for all individuals living with Tourette.

Tim Kowalski believes his daughter was well-prepared to speak to the Dare To Dream Conference attendees following her training March 19-21 in Washington.

“Taking part in this year’s Youth Ambassador training with Tess, and meeting families affected by TS who came from all over the country, was inspiring,” Tim Kowalski said. “I was certainly the ‘proud father’ as I watched my 13-year-old daughter explain the importance of funding for TS education, research and advocacy to congressional staff members. She and Grace did a terrific job relating what it’s like to live with TS and why we need to do more to help others dealing with this disorder, often without support and surrounded by people who simply don’t understand Tourette.”

During the trip to Washington, the Kowalskis met with representatives from the offices of Congressman Rush Holt (D-NJ12), Senator Robert Menendez (D-NJ) and the late Senator Frank Lautenberg (D-NJ). Their visit to Senator Menendez’s office on March 20 was especially timely, as that very morning the Senator had just reintroduced the [Collaborative Academic Research Efforts for Tourette Syndrome Act of 2013](#) to the Senate.

“The Youth Ambassador training was very helpful and meaningful to me,” said Tess Kowalski, who also spoke to children and families affected by TS at NJCTS’ 9<sup>th</sup> annual Family Retreat Weekend on June 7-9 at YMCA Camp Bernie. “I got many great ideas for improving my presentations, and I met some really wonderful people. I was thrilled to be a part of this program. This experience is something I will never forget.”

More information about the Youth Advocate and Youth Ambassador programs, the Dare To Dream Conference and the Family Retreat Weekend are available by calling 908-575-7350 or by visiting [www.njcts.org](http://www.njcts.org), the [Teens4TS blog](#) or the [TSParentsOnline blog](#).

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