



New Jersey Center for Tourette Syndrome
AND ASSOCIATED DISORDERS

*Collaborative Partnerships
for the Tourette Syndrome Community*

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NJCTS Family Retreat Weekend "Where The GreatS Gather," since 2004

The 11th annual event took place June 12-14 at YMCA Camp Bernie, with families from across New Jersey connecting through fun activities and educational workshops

Port Murray, NJ – Families from across the state affected by Tourette Syndrome (TS) and its associated disorders joined in a fun-filled weekend at YMCA Camp Bernie in Port Murray, NJ. Now in its 11th year, NJCTS Family Retreat weekend allows children and their families to meet others with TS, learn more about their diagnosis, and engage with peer mentors in a fun, safe environment.

This year's Family Retreat Weekend was held June 12-14. It was a huge success thanks to the generous support of sponsors, including the Mendez and Cohen families, Shoprite of Flemington, Costco Wholesale, Trader Joes, Wegman's, and Jersey Mike's of Flemington, as well as the many volunteers and camp staff.

Following closely on the heels of June 4, Tourette Syndrome Awareness Day and the *Team Up with Tim Howard* event, families came to the Retreat Weekend energized and with a sense of pride. On June 4, NJCTS officially launched The GreatS—a powerful, worldwide anti-stigma and TS awareness campaign. The Regen family kicked off the weekend by presenting NJCTS Executive Director Faith Rice with a sign that soon became the mantra for the weekend, "Camp Bernie: Where the GreatS Gather."

Nearly 200 people traveled from far and wide and many families return year after year. "This is our 9th year at Family Retreat Weekend," said Tim Kowalski who attended with his wife and two daughters, "but it feels just as great as our first year." More than half of the families in attendance this year were first-timers.

"'Tic Camp' as we so fondly call it has been an annual trip for us for 11 years now and the highlight of our summer," said Andy and Donna Friedrich. "Our son has gone from an 11 year old camper to a 22 year old mentor and enjoys coming back every year to work with and encourage other kids with TS. We also enjoy meeting with other parents to encourage them as they tread the waters of having children with TS."



Sam and Sydney Regen present a hand-made sign to NJCTS Executive Director Faith Rice at the 2015 Family Retreat Weekend

Families had many opportunities to bond and share their stories while participating in Camp Bernie's activities, including swimming, basketball, wall climbing, archery, arts & crafts, tie dye, yoga, and so much more. Two of the biggest hits at the Family Retreat Weekend were the Friday night campfire and Saturday night's Talent Show led by DJ Harry Hubert.



Kids and parents also participated in the educational portion of the weekend, attending powerful workshops and round-table discussions. The Youth Mentor Panel was facilitated by LCSW Gayle Forman and led by approximately a dozen NJCTS Youth Advocates. Kids from the audience as young as 6 years old asked their most burning questions of the panelists who all live with a Tourette Syndrome diagnosis, sparking lively and candid discussion. Parents were invited to join the second mentor panel facilitated by Leadership

Academy Director Melissa Fowler and led by a second group of Youth Advocates. Parents, kids with TS, and their siblings asked panelists about their experiences transitioning to college and getting a job, about how to speak to educators about TS, and how they deal with driving—the ever-popular question.

"This past weekend was an amazing milestone for our family. It was so special to be around other families dealing with TS," said Lonny Kramer. "My kids flourished and felt free to roam around in the safety of camp. The panels were especially great. My son enjoyed asking questions of the older kids and hearing what they had to say. He really looks up to the teenagers."



The Parent Round Table provided the opportunity for parents more experienced with TS to share their stories of struggle and success with parents of newly-diagnosed children. Parents who live in areas with limited resources and understanding of TS said they gained hope and courage to take back with them. After the round table, several parents connected with NJCTS Education Outreach Coordinator Gina Maria Jones to arrange in-service presentations at their children's schools.

Families were introduced to some of the NJCTS research projects while at Family Retreat Weekend. Dr. Robert King from TIC Genetics (Tourette International Collaborative Genetics Study) interviewed families interested in participating in the National Institute of Health NJCTS Genetics Sharing Program. They also had the opportunity to speak with representatives from the NJCTS Tourette Syndrome Clinic at Rutgers University Graduate School of Applied and Professional Psychology including Director Daniela Colognori Ragas PsyD, post-doctoral fellow Janis Autera, and doctoral student Julia Brillante.

Family Retreat Weekend is an important weekend for families affected by Tourette Syndrome to learn more about the diagnosis and, most importantly, to know that they are not alone and that services are available. "For us it is a way to gain further knowledge



and offer support to our son with TS, said Z and Anna Nowacki. "It is also a way for us to gain support in our journey. It is a nice way to connect with families we have met in the past in a relaxed atmosphere while allowing our children to be who they are, while not worrying that they will be judged or critiqued."

For more information about the Family Retreat Weekend, please call NJCTS at 908-575-7350 or visit www.njcts.org.



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*NJ Center for Tourette Syndrome and Associated Disorders, Inc.
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