



LI Tourette Association
P.O. Box 615
Jericho, NY 11753
[516-876-6947](tel:516-876-6947)



TOURETTE ASSOCIATION OF AMERICA LONG ISLAND CHAPTER

Home Upcoming Events Services Youth Programs More longisland.tsa@gmail.com 516-590-7551 



Our new and improved website is now live!
Please check it out at: www.longislandtourette.org

Please note and mark your calendars:

The April support Group has changed:
We will be meeting on April 6th (the first Friday in
April) not Friday April 13th...



FOLLOW US ON...

Twitter: <https://twitter.com/LITouretteAssoc>
Instagram: <https://www.instagram.com/litouretteassociation>



Congratulations to our very own Jilly Bliss!

Jillian Bliss, a 2017 Youth Ambassador from Long Island, joined John Quinones on ABC's nationally televised show, "What Would You Do?" this past Friday to educate about Tourette Syndrome and bullying. We could not be more proud of Jilly for her bravery!

We are so touched by every person on the show who demonstrated natural compassion and understanding for those impacted by Tourette.

[Click here](#) to watch the segment.

SAVE THE DATE

NOVEMBER 5th 11:00 A.M. TO 3:00 P.M. - SPECIAL NEEDS FAIR - SACHEM PUBLIC LIBRARY, 150 HOLBROOK ROAD, SACHEM, NY

NOVEMBER 30th - CHAMPIONS FOR CHARITY KICK OFF COCKTAIL PARTY AT LONDON JEWELERS

NOVEMBER 30th - DECEMBER 3rd - CHAMPIONS FOR CHARITY SHOPPING DAYS

DECEMBER 8th - LONG ISLAND TA HOLIDAY PARTY

JUNE 9, 2018 - FAMILY FUN DAY - McKENNA ELEMENTARY, MASSAPEQUA

SAVE THE DATE!

Tuesday, November 28, 2017 is:

#GivingTuesday – a national day of philanthropy.

With the holidays fast approaching, we're about to enter the season of giving.

Perfectly situated between Thanksgiving and the year-end holidays,

#GivingTuesday

is equal parts gratitude and gift-giving.

On November 28th, Long Island Tourette Association is asking friends, followers and families to gather together to support LI TA.

#GivingTuesday is about ordinary people coming together doing extraordinary things – and we can't do it without you.

Every single donation makes a difference so please join us on

#GivingTuesday and make your tax deductible donation to our campaign.

Help us make a difference in the life of someone living on Long Island with Tourette and Tic Disorders.

**To Donate to Long Island Tourette Association
go to our webpage at www.longislandtourette.org and
click on the Donate button at the bottom of the page.
THANK YOU!!!**

Your copy should address 3 key questions: Who am I writing for? (Audience) Why should they care? (Benefit) What do I want them to do here? (Call-to-Action)

Create a great offer by adding words like "free" "personalized" "complimentary" or "customized." A sense of urgency often helps readers take an action, so think about inserting phrases like "for a limited time only" or "only 7 remaining!"

Youth Ambassadors

***We are happy to announce the
2018 TAA Youth Ambassador Training Conference
is being held
Tuesday, February 27 – Thursday, March 1, 2018
at the
Renaissance Arlington Capital View Hotel***

in Arlington, VA.

The application is now available and can be accessed by using this link: www.tourette.org/youth-ambassador.

Please note: TAA is only accepting online applications.

-Long Island TA interviews for applicants will take place on Friday Dec 8th, prior to the Holiday Party, at the DeMatteis Center -

Thank you to our Youth Ambassadors who did an outstanding job presenting to 122 students and 16 staff members in Franklin Square School District!



left to right: YAs Patrick Reilly, Katie Reilly, Eric Sommer, Chris Alessandri, Ben Rabinowitz and Becca Caron



LI TA and every student with TS in NY State needs your help!

Please see the below from the Greater NY State Chapter. Dr. Jane Zwilling and Kate Callan will be attending the meeting in Albany but we need your help!

*Please sign the petition and forward this to family and friends and....
where it says.....*

*Please send your letters to Greater New York State TA.....instead please send your
letters to LI TA at*

**Longisland.tsa@gmail.com (not to Greater NY) as LI TA would like to see your
stories and be able to adequately represent you in Albany.**

*If you can scan a photo of your child (and don't mind us bringing a photo along) that
would be extremely helpful. We have found, advocating on the Hill, that pictures help the
policy makers see our kids as real individuals needing their support.*

Thank you!
LI TA

**Please do not skip by this email. It may be one of the most important emails
you read. We need you to act immediately in support of your loved one,
your friend or yourself who deals with a diagnosis of Tourette Syndrome.**

**This past June, one of our teens in the Greater NY chapter was expelled
from a summer music camp due to coprolalia. It was a traumatic experience
for him and his family, but the story turned out to have an unexpected silver
lining. I'll let his mother, "Sophie," explain:**

After my son, "Malik", was expelled from music camp in June because of coprolalia, I realized that it was going to be really important to get Tourette training set up for his next music camp in July. I called the July camp director and explained what had happened in June. I was nervous, because our school district had fought us tooth and nail on our requests for Tourette education.

But to my amazement, I received a surprise email from Joanne LaCrosse, a high-level special education official at NYSED (New York State Education Department), which runs the July camp. Joanne, the head of Special Education Policy and Professional Development, first congratulated my son on his acceptance into their very competitive

program. Then she explained that upper level leadership of the State Education Department had asked her to assist in providing training on TS, to ensure that Malik would have a positive experience at the camp.

What a breath of fresh air! The training of both staff and campers took place and was extremely helpful. Joanne actually drove out from Albany in person, twice, once to assist with staff training, and another day to assist with peer training! Malik had a wonderful experience at the program, thanks to her support.

In my thank-you letter, which I sent to the Assistant Commissioner for Special Education, Christopher Suriano, I explained how helpful the training had been for Malik's successful experience at the NYSED camp, and asked him to meet with Sue and me, so we could describe the difficulties that many families in New York State have experienced, trying to set up Tourette education at school for our children.

To our delight and surprise, the answer came back that YES! The Assistant Commissioner would meet with us!

We have consulted with, and obtained 100% support, from the four other TAA chapters in NY State, as well as the members of the NYS Medical Centers of Excellence in Tourette Syndrome. Representatives of each chapter, as well as the NYS Centers of Excellence, will be attending the meeting in Albany along with Sophie, her son, and me.

But we need you!

We have developed a petition to send in advance of this meeting. Please click the link at the bottom of the email to view and sign the online petition. I know for a fact that so many students have dealt with the lack of understanding of school personnel and I know how devastating this has been for anyone who has faced it. Kids are teased, bullied and punished for symptoms of a neurodevelopmental disorder that they cannot control. Our goal is to obtain a mandate from NYSED for all schools in NY State who have a student enrolled with TS to provide in-service training on this very complex disorder. We are also requesting peer education, if so desired by the parents, to help kids with TS avoid the teasing and bullying that so many of them experience.

You can view the petition, and add your signature, at the link below. Please feel free to ask other people you know to sign it. Any resident in the State of New York age 13 or over may sign. Don't hesitate to ask neighbors, family members, medical providers, teachers, etc., to sign also. We will post updates on the TAA of Greater NY State website at tsa-gnys.org.

There's plenty of space in the online petition form to let NYSED know about your specific experience and point of view around Tourette education. But if you want to write your thoughts in a letter, you can! Just scan and email your letter to us at tourette.gnys@gmail.com, and we will forward all the letters received in a batch to the Assistant Commissioner, along with the petition.

Please do this now to help all kids from across NY State who are afflicted with Tourette Syndrome to be understood and be able to reach their full potential.

Supported by:

Jane Zwilling and Kate Callan, TAA of Long Island
Helene Walisever and Sharon Hammer, TAA of Hudson Valley
Gary Wainwright, TAA of Rochester and the Finger Lakes Region
Lisa Hazen, TAA of NY City

Click [here](#) to sign the online petition

or
Cut and paste the link below into your browser

<https://goo.gl/forms/BX4RlcqPaFStQfsD2>

*We need to receive all signatures and letters by **Saturday, October 21.***

Thank you!
Susan Conners, President
TAA of Greater NY State

Tourette Association of America National Board Member Visits Long Island

TAA Board Member and Dr. Zwilling



TAA Board Member Steve McCall visited Long Island to discuss the Youth Ambassador Program and a newly forming Diversity committee with Dr. Zwilling



HASSENFELD
CHILDREN'S
HOSPITAL
AT NYU LANGONE

Department of Child and
Adolescent Psychiatry

SYMPOSIUM

Treating Tics and Tourette Disorder: A Conversation with Experts on Innovative Interventions

Tourette syndrome is a chronic neurological disorder that starts in childhood and can continue through adolescence and into adulthood. Its main feature is involuntary tics—sudden twitches, movements, or vocal sounds that occur repeatedly—that can get in the way of everyday activities. Psychiatrists, neurologists, and psychologists work together to diagnose tics and Tourette disorder and to develop a comprehensive care plan for children and adults with the condition.

The Tics, Tourette Disorder, and Trichotillomania Program, or T3 Program, at the Child Study Center is hosting a one-day symposium to showcase multidisciplinary research and clinical application of innovative treatments for tics and Tourette's Disorder at NYU Langone Health.

There will be highlights from other departments—including psychiatry, neurology, and neurosurgery—regarding relevant evidence-based clinical interventions and treatments. This symposium also provides an open dialogue between families of patients, health care professionals, and a panel of experts occurring at the end of the symposium.

Agenda

3:00-3:30 pm | Keynote Address

Deep Brain Stimulation, a New Effective Treatment

Michael H. Pourfar, MD

Assistant Professor, Department of Neurosurgery

3:30-3:50 pm

Understanding Tourette's Disorder throughout the Life Cycle

Scott E. Hirsch, MD

Clinical Associate Professor, Department of Neurology

3:50-4:10 pm

Management of Severe Pediatric Tourette Syndrome Resistant to Drug Treatment

Glenn Hirsch, MD

Vice Chair, Department of Child and Adolescent Psychiatry

4:10-4:30 pm

Clinical Management of Tourette's and tic Disorders

Rebecca Berry, PhD

Clinical Assistant Professor, Department of Child and Adolescent Psychiatry

Aleta Angelosante, PhD

Clinical Assistant Professor, Department of Child and Adolescent Psychiatry

4:30-5:00 pm

Panel Discussion and Q&A

For more information

about this symposium, please [download our flyer](#) or contact:

Rebecca Rialon Berry, PhD

Rebecca.Berry@nyumc.org

[516-358-1808](tel:516-358-1808) Copyright © 2017 Child Study Center at Hassenfeld

Children's Hospital at NYU Langone, All rights reserved.

RESEARCH BREAKTHROUGH:

TOURETTE ASSOCIATION OF AMERICA
RESEARCHERS LOCATE GENETIC RISK
INDICATORS FOR TOURETTE SYNDROME
AND RELATED DISORDERS!



Data Collected from 2,434 Tourette Cases and More than 4,000 Controls Reveal the First Statistically Significant Genetic Risk Factors for Tourette Syndrome.

*The Tourette Association of America is proud to announce that conclusive findings of TAA-funded research investigating highly complex genetic risk indicators for TS and related disorders were published today in the prestigious scientific journal **Neuron**. This major research milestone represents a large-scale collaborative effort involving dozens of clinicians, geneticists and advocacy leaders from around the world, and is the first to identify, with genome-wide significance, two definitive genetic defects underlying the development of Tourette Syndrome and related neurological disorders.*

In the study, scientists from the Tourette Syndrome Association International Consortium for Genetics (TSAICG) analyzed and compared the genes of 2,434 individuals with Tourette Syndrome to 4,093 people without the disorder in order to decipher underlying genetic contributors.

*As reported in **Neuron**, two prominent gene abnormalities have been definitively shown to be present in TS: deletions (or loss of one copy) of the **Neurexin-1 gene (NRXN1)**, and duplications (or an extra copy) of a different gene called **Contactin-6 (CNTN6)**. Approximately one out of every 100 TS cases studied carries one of these copy-number variants, indicating a significant contribution to the genetic architecture of Tourette Syndrome.*

*“The genetic evidence presented in **Neuron** represents a major breakthrough in our understanding of how Tourette develops and who is at increased risk for developing the disorder,” said John Miller, President and CEO of Tourette Association of America. “The Tourette Association of America is enormously proud to have been the facilitating partner for this important discovery by the TSAICG consortium. Today, we are one giant step closer to fulfilling our mission to drive improved quality of life for all who are affected by Tourette and other tic disorders through research, support, and awareness.”*

[Click Here to Read More](#)

The Tourette Association of America
is happy to announce that
CDC Patient Toolkits are now available

These toolkits are full of information and resources to help anyone dealing with the complexities of Tourette Syndrome.

The toolkits can be downloaded through this link:

<https://www.tourette.org/media/Full-Family-Toolkit-rev.pdf>.

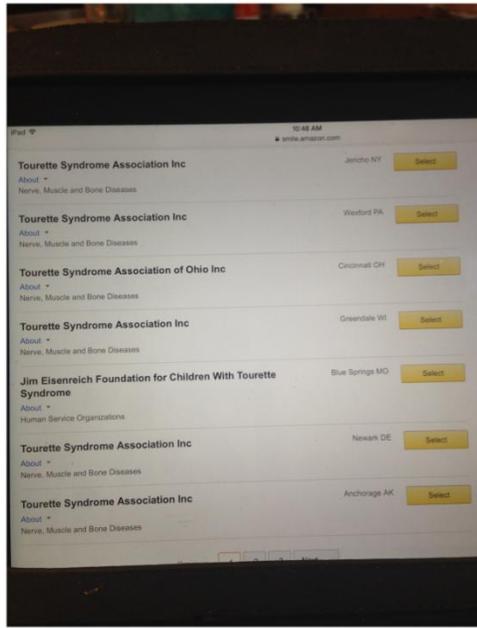


We are excited to announce that LI TA is participating in AmazonSmile!

Please support LI TA each time you shop at Amazon by logging into Amazon through AmazonSmile and selecting:

**"Tourette Syndrome Association" with the Jericho address
(see below image showing our chapter... there are 54 organizations listed for Tourette so please make sure you select the Jericho one!)**

Please remember to log in to "AmazonSmile" before going shopping!



Long Island TA is a member of the NY State Centers of Excellence Consortium, and we are all working towards understanding the needs of the TS community in NY State. Please take the 10-20 minutes to fill out this survey and help us help!

[PLEASE CLICK HERE FOR SURVEY](#)

Thank you!

LI TA

A new research study is being conducted through the University of Rochester Medical Center (URMC) Division of Neurology that is recruiting both adults, and parents of children with Tic Disorders (i.e. Tourette Syndrome, Chronic

Motor Tic Disorder, Chronic Vocal Tic Disorder).

The Principal Investigator is Heather Adams, PhD, a Psychologist in the Division of Child Neurology. The purpose of this study is to learn about the needs (both met and unmet) in the Tic Disorder Community. This study involves completing an online survey, which should take approximately 10-20 minutes to complete. The link to the survey is below.

We would appreciate your voluntary effort in completing the survey. Your input will help us learn how to best serve both adults and children with Tic Disorders.

Click here for survey - <http://bit.ly/2i1TTwy>

If you have any questions, please contact: Alyssa Thatcher, M.S. at [\(585\) 276 – 5966](tel:5852765966) at UPMC Division of Child Neurology

NEEDS ASSESSMENT STUDY DOCUMENTS

RESEARCH STUDY FOR TIC DISORDERS

WEBSITE ADVERTISEMENT

EMAIL ADVERTISEMENT



New clinical research study for Tourette Syndrome- The T-Force Green Study is for children ages 6 to 17. The primary purpose of this study is to determine the effectiveness, safety, and tolerability of an investigational medication for Tourette Syndrome. An investigational medication is not approved by the U.S. Food and Drug Administration. As with any clinical research study, each interested child will be evaluated to determine his or her eligibility. All who qualify will receive the study medication, study-related medical exams, and study-related laboratory tests at no cost.

Compensation for time and travel may also be available.

If you're interested, we've [attached a flyer](#) with more details. You can also visit TForceGreen.com to see if your child may qualify.

The College Board has finally agreed to provide the same accommodations that students are receiving in school.

[Click here for article](#)

TAA will continue to monitor this.

If you continue to have difficulties receiving accommodations, please contact us.

**Youth Ambassadors and our Education/Advocacy Committee
Have Been To Many Schools Already and are Booking
Presentations**



Please contact us at longisland.tsa@gmail.com to schedule Youth Ambassador presentations, in-services for school faculties and/or to have a member of the Education/Advocacy Committee attend any school meeting.



***If you haven't already done so.....or if you aren't
a member already.....***

We hope you will consider becoming a member of our chapter. There are wonderful resources available for members and their families.

We provide:

-Free in-service presentations to schools to educate faculty and staff about Tourette and the best ways to manage Tourette in the classroom.

-Advocates to accompany parents to school meetings (free of charge to members).

-Youth Ambassador presentations which are peer-to-peer presentations that involve experienced and trained teens going into schools to educate students about living with Tourette.

-Collaboration with the Long Island Center for Tourette and Related Disorders- which provides a variety of synthesized services to families living with Tourette.

-Educational events/conferences/workshops presented by a variety of specialists for parents

-(free) social events for members' families living with Tourette.

If you would like to become a member of our chapter please go to our website:

www.longislandtourette.org and join-

The link will take you to the National website; when you join you will become a member of both the National organization and our Chapter.



REMINDER: NEXT SUPPORT GROUP - FRIDAY, October 6th, BEGINNING AT 7:30 P.M. AT DeMATTEIS CENTER, [101 Northern Blvd, Greenvale, NY](#). [Click here for directions.](#)

Schedule for 2017-18 school year.

Please note December 2017 and March 2018 dates are the 2nd Friday of the month.

NOTE: *SECOND FRIDAY OF THE MONTH

Nov 3rd

***Dec 8th - Holiday Party!**

Jan 5th

Feb 2nd

***March 9th**

Apr 6th (moved from April 13th!)

May 4th

June 1st

As usual, siblings of TS kids are invited. The Youth Ambassador (peer education) training program participants will also meet. And as always, our teen Buddies will be available to the children.



Long Island Tourette Association | [Email Us](#) | [Website](#)
