



Tourette Association of America

Long Island Chapter

**LI Tourette Association
P.O. Box 615
Jericho, NY 11753
516-876-6947**



*Hope you're enjoying the summer!
See you at our next Support Group*
**FRIDAY, September 7th, BEGINNING AT 7:30 P.M.
AT DeMATTEIS CENTER, 101 Northern Blvd,
Greenvale, NY.
[Click here for directions.](#)
See you there!**



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



FOLLOW US ON...

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

NEED HELP DEALING WITH SCHOOL ISSUES AND YOUR CHILD

Kathy Giordano (TAA Education Specialist) has supplied us with two education links, that addresses some common challenges when dealing with schools.

If Parent Disagrees with School Evaluation

[Independent Educational Evaluations \(IEEs\): What You Need to Know](#)

The Teacher is Not Following IEP: What Can I Do

[The Teacher Isn't Following My Child's IEP. What Can I Do?](#)



SAVE THE DATE - SUNDAY, SEPTEMBER 8, 2018

LI TA extends heartfelt appreciation to:

The Rising Stars, Long Island Student-Internship Council
American Diversity Forum
for generously sponsoring

JUMP & SHOUT WITH TOURETTE-SKYDIVE
Sunday September 8, 2018
10 am-3 pm
LONG ISLAND SKYDIVE
133 Dawn Drive
Shirley, NY 11967

The Rising Stars' goal is to raise money to create a TV commercial or Public Service Announcement (PSA) to help educate ALL Long Islanders about Tourette

To learn about the exciting event and to join the Rising Stars, Randy Jackson from Zebra, Everest and others on September 8th

Please go to:

https://www.gofundme.com/jump-amp-shout?pc=em_co_shareflow_m&rcid=r01-152874145226-e05afd55d7224e95

*Thank you-
LI TA*

educate

**Heartfelt Appreciation to the Presenters Jen Zwilling, Founder of
the YA Program, and Jane Zwilling, Psy.D!
The 2018 CDC funded YA Training in San Antonio was a Huge
Success!
TAA Now Has 22 New YAs, and LI TA Has an Amazing New YA!**



***Long Island's very own Jen Zwilling, Founder of
the TAA YA Program training another group of
amazing new Youth Ambassadors.***



Welcome new LI TA YA Joseph Cortez



Jen and Jane Zwilling, Psy.D with the 22 newly trained 2018 San antonio YAs



Welcome to new LI TA YA team Joseph and his mom Leigh Cortez



We would like to take this opportunity to share information about a new Tourette Syndrome research program that may be of interest to you. In the ARTISTS program, doctors are evaluating the efficacy, safety, and tolerability of TEV-50717 in children and adolescents with Tourette syndrome.

TEV-50717 is an investigational medication. Investigational medications are not approved by the U.S Food and Drug Administration.

To pre-qualify for the ARTISTS 1 and ARTISTS 2 studies, patients must:

- Be 6 to 16 years of age
- Exhibit tics or have been diagnosed with tics and / or Tourette syndrome
- Have a caregiver willing to comply with all study-related procedures
- Not have a diagnosis of bipolar disorder or psychosis, including schizophrenia

All eligible participants will receive either TEV-50717 or placebo (inactive substance), study-related medical exams, and study related laboratory tests at no cost. In addition, participants may be reimbursed for study-related travel.

After the end of the study, all participants who complete the ARTISTS 1 and ARTISTS 2 study may have the opportunity to enroll in a year-long study, if eligible, in which all participants receive TEV-50717.

For more information, please visit www.artiststudyts.com to learn more and see if your child may qualify.

Behavior Therapy Institute (BTI) Comprehensive Behavioral Intervention for Tics (CBIT) Training

This training is open to the nursing profession, as well as social workers, psychologists, medical doctors, speech pathologists, occupational therapists and all other licensed healthcare providers who will treat individuals with Tourette Syndrome and tic disorders using CBIT.

[Please click here for flyer and information.](#)

October 6 – 7, 2018

2018 TOURETTE SYNDROME SYMPOSIUM

Tourette Syndrome Across the Lifespan: What you Need to Know
Saturday, October 20, 2018 8:30 a.m. - 1:00 p.m.
[Click here for flyer](#)



We recently learned of a new clinical research study for Tourette Syndrome. The T-Force Gold Study is for children ages 6 to 17 who have a diagnosis of Tourette Syndrome. The primary purpose of this research 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. Like with any clinical research study, each interested child will be evaluated to determine his or her eligibility to participate in the research study. All who qualify will receive the investigational medication or placebo (inactive substance), study-related medical exams, and study-related laboratory tests at no cost. It is our understanding that compensation for time and travel may also be available.

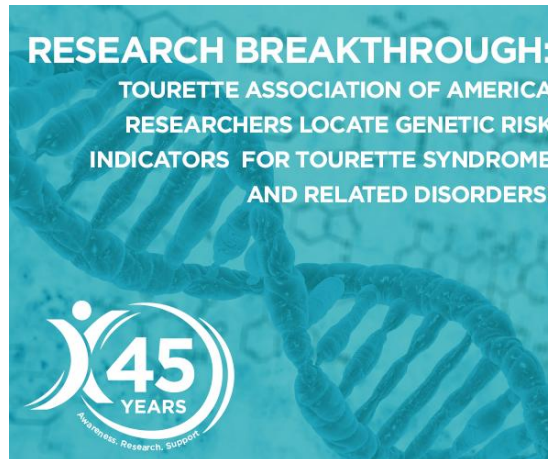
If you're interested, you can visit T-Force Gold.com to learn more and to see if your child may qualify.



LI TA member, 13 year old Sarah Scileppi is making *Candles for a Cause-Wick Away Tics*

Candles are \$10 which Sarah is generously donating to LI TA!

If you would like to order candles, please contact us at LongIsland.tsa@gmail.com and we will get your order to Sarah.



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>.

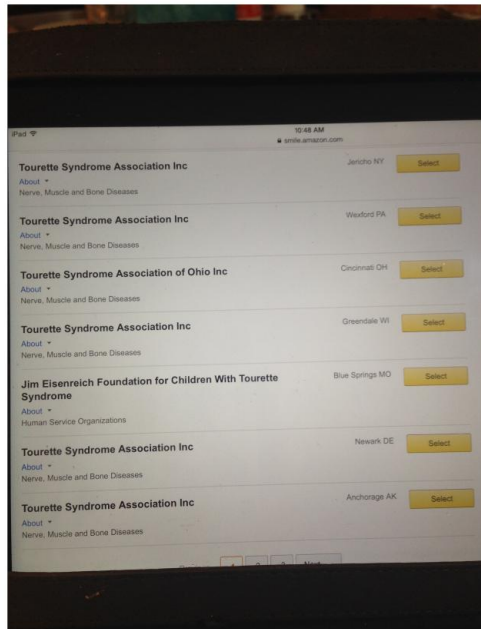


We are excited to announce that LI TA is participating in AmazonSmile!

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!



Message from Taylor working with the T-Force Gold Research Study

My name is Taylor and I work with the T-Force Gold Research Study for children and adolescents with Tourette syndrome. You may have heard of the study as we're partners with the TAA and have attended several national events including the National Education and Advocacy Conference and several Team Tourette events.

I'm reaching out because there is at least one research site in your area that is very interested in partnering with your local chapter in order to raise awareness for the T-Force Gold Study. The study is enrolling children and adolescents ages 6–17 diagnosed with Tourette syndrome. The goal of this research study is to determine the effectiveness, safety, and tolerability of an investigational medication for Tourette syndrome. The website is TForceGold.com if you would like to learn more and see which research sites are in your area.

Please email me at tkaiser@gopraxis.com or call 716-249-5047 if you are interested and don't hesitate to reach out with questions.

*Thanks for your consideration!
Taylor*

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
are Booking Presentations**



Please contact us at info@longislandtourette.org 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.



**Become A
Member**

**[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.



We are on summer break and will see all in September. Hope everyone has a safe and happy summer!

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

2018-2019 Support Groups

October 5
November 8
December 7 (Holiday Party)
January 4, 2019
February 1
March 1
April 5
May 3
June 7

