

**LI Tourette Association  
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TOURETTE ASSOCIATION OF AMERICA LONG ISLAND CHAPTER

[Home](#) [Upcoming Events](#) [Services](#) [Youth Programs](#) [More](#) [longisland.tsa@gmail.com](mailto:longisland.tsa@gmail.com) 516-590-7551 



Our new and improved website is now live!  
Please check it out at: [www.longislandtourette.org](http://www.longislandtourette.org)

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**FOLLOW US ON...**

**Twitter:** <https://twitter.com/LITouretteAssoc>

**Instagram:** <https://www.instagram.com/litouretteassociation>

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## **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?\*\*](#)

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# Family FUN Day

**We are once again having the Family Fun Day (FFD) Challenge!**

Please let us know by this Friday support Group meeting if you are participating so we can get your name in the brochure and on signs!

**If you raise at least \$150 by the June Support Group meeting, which is on June 1st, you will receive:**

- 10 free entries to FFD!**
- Your name on our "FFD Challenge Participant Sign" at the event**
- Your name in the FFD brochure**

**Some of you have already begun and have set up Gofundme pages!  
Thank you for doing this!**

**Social media has been very successful in raising funds quickly for so many causes. Last year one of our Youth Ambassadors raised over \$2,000 on his GoFundMe page. If you are comfortable in setting one up, it is a wonderful way to support Tourette Awareness and to raise funds specifically for our 2018 Family Fun Day Event.**

**If you are not comfortable raising money on gofundme, any fundraisers are great.**

**We've had:  
Lemonade sales  
Bake sales  
Candle sales**

**Anything you can think of will be terrific!**

**Remember that FFD is the only major fund-raiser that Long Island Tourette Association does each year. Money raised support all that we do including (but not limited to): Support Groups (rooms and Leaders in the kids' and teen rooms); socials; educational conferences and**

programs; supporting YAs going to DC; educational materials distributed to physicians, schools and families; guest speakers; and supporting the Long Island Tourette Center.

Your participation in this Challenge will be extremely appreciated and extremely helpful!

Anyone, can participate so if you have any friends or family who would like to participate, please forward this and please include them!

Please let us know if you have any questions! Thank you for your support and taking on our FFD challenge !

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## SAVE THE DATE

For our kick-off event with Wit & Whim  
on Saturday, June 2, 2018 from 12 noon - 3 pm  
[6 Carlton Avenue](#)  
[Port Washington, NY](#)

Refreshments will be served...come out and bring your friends and family!

wit&whim is generously collaborating with LI TA for the entire month of June. They will be donating a percentage of the proceeds to LI TA. Please see flyer below and go to their [Website](#) to see their fabulous merchandise!

Hope to see you there on Saturday, June 2nd!



# Tourette Kick Off Flyer

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

**Tourette Association of America**  
Long Island Chapter

**FAMILY FUN DAY**

**SATURDAY, JUNE 9, 2018**  
**1:00 PM - 5:00 PM**  
**RAIN OR SHINE**  
**McKenna Elementary School**  
**210 Spruce Street, Massapequa Park, NY 11762**

**CHILDREN \$15.00 ADULTS NO FEE**  
**FREE T-SHIRT (while supplies last)**  
MUSIC • CARNIVAL GAMES • 3 STORY HIGH SLIDE • CARICATURE ARTIST • PHOTO BOOTH  
GAGA PIT • GIANT OBSTACLE COURSE • RAFFLES • ARTS AND CRAFTS • FACE PAINTING  
TIE-DYEING • FOOD AND BEVERAGES FOR PURCHASE AND MUCH MORE...  
Your time and support will make a difference.  
All proceeds will go directly to the Long Island Tourette Association.  
For More Information Go To: [www.longislandtourette.org](http://www.longislandtourette.org)

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**educate**



We have some exciting news to share about the Youth Ambassador Program. Like last year, TAA will be hosting a second Youth Ambassador Training from **July 13-14, 2018 at the Grand Hyatt San Antonio in San Antonio, Texas**. The CDC has again agreed to fund this second YA Training. We are encouraging all teens that are qualified to apply.

Applications are currently being accepted, please visit [www.tourette.org/youth-ambassador](http://www.tourette.org/youth-ambassador). **The application deadline is June 1.**

Please note there are a few differences in the CDC-sponsored YA Training compared to the traditional YA Training in Arlington, VA:

- **There will be no Chapter-funded YAs as TAA, through the CDC grant, will cover the costs for all YAs.**
- National will forward YA applications to the corresponding Chapter or Support Group.
- An internal committee at National **TAA will select applicants.**

#### *Training Requirements*

- Youth must be between the ages of 12 and 17.
- A parent/ guardian must attend the training with the Youth Ambassador.

#### *Costs*

The CDC will cover the costs of the San Antonio YA training. The following are covered

- Hotel accommodations for the night of Friday, July 13 for the YA team (additional nights at the team's personal expense).
- Transportation (e.g. airfare, train ticket, mileage reimbursement) up to \$700 total per YA team (teen and parent/guardian).
- Transportation to the Meet & Greet at The Cherrity Bar.
- Training-sponsored meals for YA team.
- Training program materials.

At attendee's own expense (Costs NOT covered by the Tourette Association):

- Hotel charges for any nights that are part of an extended stay.

Please feel free to reach out if you have any questions.

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*Thank you to our amazing Youth Ambassadors who had a very busy month educating and raising awareness!*



*YAs Gabe, Giovanni, Olivia, Patrick Steven and Victoria presented to the Rising Stars, a youth group of the Long Island Diversity Forum.*

**YAs Blaise, Chris, Charlotte and Mary participated on a panel with Dr. Budman and Dr. Zwilling educating 2nd Year Psychiatry residents at Zucker Hillside Hospital.**



*Thank you to YA's Ari, Derek, Giovanni, Sam and Charlotte for Educating Another Class of Nursing Students at Adelphi!*



*Thank you to YAs Charlotte, Chris, Derek, Emily, and Steven for another amazing presentation to a group of Adelphi Nursing Students!*



*Amazing Presentation to Adelphi Nursing Students. Thank you YAs Charlotte, Giovanni, Rebecca, and Steven!*





*LI TAA's very own Rebecca Caron along with fellow Youth Ambassadors Steven Argenzio, Charlotte Cheshire and Giovanni Kubanick were featured in "12 Making a Difference"*



**Link to video on Channel 12:**

<http://longisland.news12.com/clip/14305396/12-making-a-difference-tourette-association-of-america>

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**Thank you to all who came to our bowling social!! It was a great night, filled with fun and laughter!**

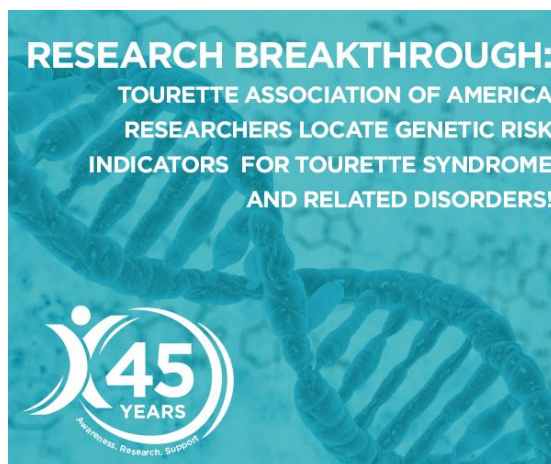




## LI TA member, 13 year old Sarah Scileppi is making *Candles for a Cause-Wick Away Tics*

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](mailto: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>

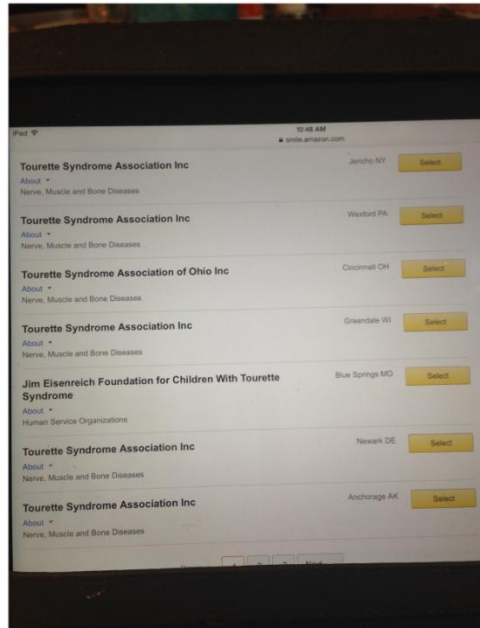


**We are excited to announce that LI TA is participating in AmazonSmile!**

**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!



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 at URMIC Division of Child Neurology

## NEEDS ASSESSMENT STUDY DOCUMENTS

### [RESEARCH STUDY FOR TIC DISORDERS](#)

### [WEBSITE ADVERTISEMENT](#)

### [EMAIL ADVERTISEMENT](#)



#### **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](http://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](mailto: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*

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**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.**

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**Youth Ambassadors and our Education/Advocacy Committee  
are Booking Presentations**



*Please contact us at [longisland.tsa@gmail.com](mailto: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.*

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**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](http://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, May 4th, BEGINNING AT 7:30 P.M. AT DeMATTEIS CENTER, 101 Northern Blvd, Greenvale, NY. [Click here for directions.](#)**

**Schedule for 2017-18 school year.**

**NOTE: \*SECOND FRIDAY OF THE MONTH**

*June 1st*

*June 9th Family Fun Day!*

**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](#)