

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

FAMILY FUN DAY 2017 JUNE 10, 2017



It's that time of the year again and we have begun planning our exciting 2017 Family Fun Day Event!

Our raffle prizes have been amazing year after year, and have represented a considerable share of the funds raised at Family Fun Day. That has been accomplished through the efforts of volunteers and donations!

We could use everyone's help in gathering items for our raffles baskets, so if you would like to donate or solicit raffle prizes for our baskets,

we would love gift cards from your favorite shops/vendors, restaurants, movie tickets, & *basket fillers, (*specifically requesting WIRED Ribbon & Colored Shred*),and/or gift items to fill our baskets.

Attached are FFD forms for your info and use. Please plan on bringing them to 5/5 support meeting for collection. If you can't make the meeting, but have something you would like to donate, please contact us at LI-TAA longisland.tsa@gmail.com and we will arrange for a pick-up.

~SAVE THE DATE~"2017 Family Fun Day"

TO BENEFIT

Long Island Tourette Association of America

Saturday June 10, 2017 (Rain or Shine) 1:00-5:00 PM

McKenna Elementary School

210 Spruce Street, Massapequa park, NY 11762

Admission Fee: \$15 PER CHILD INCLUDES ENTRY& T-SHIRT (While Supplies Last)No fee for adults

Please join us for a family day of fun - music, crafts, face

painting, inflatables, caricature artist, photo booth, gaga pit, carnival games, tie-dyeing & so much more...

Refreshments available for purchase. The cost is only \$15.00 for children (no fee for adults) and all proceeds go directly to the Tourette Association of Long Island.

Your support will go far to help all those whose lives are impacted by Tourette .Join us and make a difference!

FOR MORE INFORMATION GO TO

www.longislandtourette.org

****Click for documents:**

[2017 FFD Flyer](#), [Cover Letter](#) and [Sponsorship Form](#)

**Please email/distribute to family, friends and community!
Thank you!**

*****IF YOU WOULD LIKE TO HAVE A SNEAK PEAK OF A FEW OF OUR WONDERFUL RAFFLE BASKETS -**

[CLICK HERE!](#)

FAMILY FUN DAY 2017 - PLEASE VOLUNTEER

June 10, 2017

It takes many people to put together our annual Family Fun Day and we are asking all our members to consider volunteering for 2017. If you would like to help out, please email us your name, contact number and email address so we can put you on our list. Someone will contact you soon. Thank you.

Download information on FFD 2017 below:

[2017 FFD Flyer](#)

[2017 FFD Letter](#)

[2017 FFD Sponsorship Form](#)

Join us in the 2017 FFD Challenge!

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

If you raise at least \$150 by the June Support Group meeting, which is on June 2nd, 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 \$1700 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 2017 Family Fun Day Event.

Remember that FFD is the only major fund-raiser that Long Island Tourette Association does each year. Monies 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!

Heartfelt Thank You to Dr. Sony Khemlani-Patel

Sony Khemlani-Patel, Ph.D, licensed clinical psychologist specializing in the treatment and research of obsessive compulsive related, anxiety, and mood disorders at the Bio Behavioral Institute in Great Neck, NY presented an extremely well received informative talk to a packed house at our April Support Group meeting.

Dr. Khemlani left us with excellent suggestions and strategies.



Long Island YA Ben Rabinowitz Visits with Northern Ireland Tourette Alliance Youth Representatives



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>

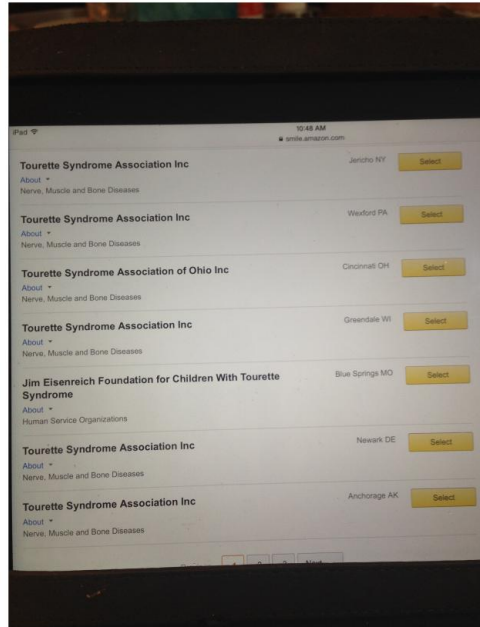


We are excited to announce that LI TA is participating in AmazonSmile!

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!

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 URMC Division of Child Neurology



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.



In Service Presentations

In-service presentations took place at the following schools:

April 4th - Oquenock Elementary School - West Islip School District

April-Education/Advocacy Committee members participated in 4 school meetings in April.



Tourette Syndrome Camp Organization
Chicago, Illinois 60640
[\(773\) 465-7536](tel:7734657536) or E-mail:scott63@prodigy.net

Invites Long Island TA children to attend

Since 1994, Tourette Syndrome Camp Association has run a week long summer camp in Northern Illinois for Children with Tourette Syndrome and Associated Disorders. The first seven years the program was run through the Illinois Chapter. In 2002, the Tourette Syndrome Camping Organization was founded to continue running the camp program and to offer other children programming. One of those programs was running a children's program at the National Tourette Association Conference

The 2017 summer camp program, Tourette Syndrome Camp USA, will be from Sunday, June 25, 2017 until Saturday July 1, 2017 at YMCA Camp Duncan Near Fox Lake, Illinois (35 miles North of Chicago). The cost is \$637. Financial aid is available. This will be the 24th consecutive summer program. Tourette Syndrome Camp USA is the longest running

camp of its kind in the world. In 2016 campers attended from 9 different states.

Information concerning the summer camp and registration as well as information regarding other programs can be found at www.tourettecamp.com.



REMINDER: NEXT SUPPORT GROUP - FRIDAY, MAY 5, BEGINNING AT 7:30 P.M. AT DeMATTEIS CENTER, 101 Northern Blvd, Greenvale, NY. [Click here for directions](#). See you there!

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.

Please mark your calendar for all future Support Group Dates:

- **June 2**

