

LI Tourette Association
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TOURETTE ASSOCIATION OF AMERICA LONG ISLAND CHAPTER

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

LONG ISLAND YOUTH AMBASSADORS PARTICIPATED IN TIM HOWARD LEADERSHIP ACADEMY



YAs Jackie Beckhardt, Steven Argenzio and Mary Gregorian

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>.

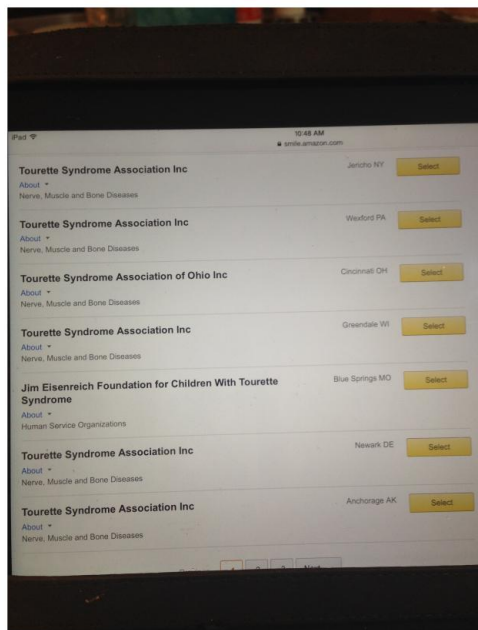


We are excited to announce that LI TA is participating in AmazonSmile!

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 URMC Division of Child Neurology

NEEDS ASSESSMENT STUDY DOCUMENTS

[RESEARCH STUDY FOR TIC DISORDERS](#)

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*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.**



REMINDER: NEXT SUPPORT GROUP - FRIDAY, SEPTEMBER 8th, BEGINNING AT 7:30 P.M. AT DeMATTEIS CENTER, 101 Northern Blvd, Greenvale, NY. [Click here for directions](#). Enjoy the summer vacation and see you at our first meeting of the year. Friday, September 8th!

Schedule for 2017-18 school year.

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

NOTE: *SECOND FRIDAY OF THE MONTH

***Sept 8th**

Oct 6th

Nov 3rd

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

Jan 5th
Feb 2nd
***March 9th**
***Apr 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](#)

