



**Tourette Association** of America

Long Island Chapter

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



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](http://www.longislandtourette.org)

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*Heartfelt thanks to:*  
**The Alessandri Family-Denise, John, Matt and Chris  
and to  
Beyond Control  
and Their Amazing Music Teacher  
Al Pennachio**



**Beyond Control Directed by music teacher....Al Pennachio  
put on an exceptional performance at  
Memories Bar and Grill in East Williston to raise awareness and  
funds for LI TA!**

**The Alessandri family organized this wonderful event which brought together over 100 individuals who came out to enjoy the outstanding performance of these incredibly talented teens while enjoying great food and raffle prizes!**

**Thank you to Beyond Control Band Members:  
You were all sensational!!!**

*Walter Szczech*

*Justin Harvey*

*Danny Ramirez*

*Marena Ramirez*

*Angelo Nardo*

*Leo Nardo*

*Kaitlyn Dugal*

*Kristina Rossi*

*Wes Morrisey*

*Alexis Diaz*

*Sofia Leiter*

*Chris Alessandri*







*Front of the Class* is a 2008 American drama film based on the book by Brad Cohen, *Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had*, co-authored by Lisa Wysocky.

As depicted in the video below, an educated, understanding school environment means so much!

If you would like a Youth Ambassador presentation and/or in-service to school staff, please contact us at [longisland.tsa@gmail.com](mailto:longisland.tsa@gmail.com)



**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>.

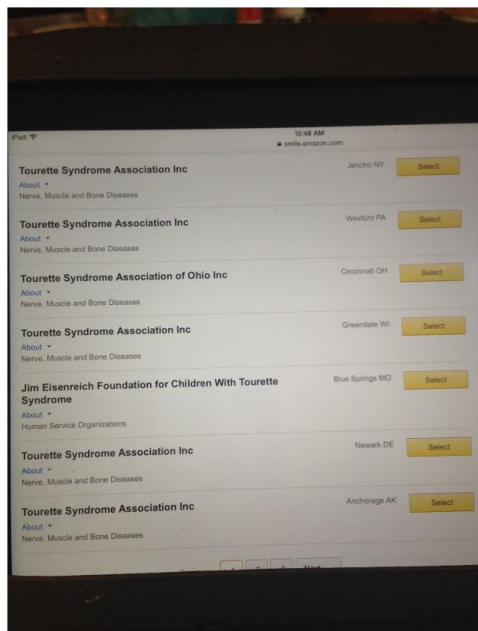


**We are excited to announce that LI TA is participating in AmazonSmile!**

**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!

**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](http://TForceGreen.com) to see if your child may qualify.

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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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**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.

