

LI Tourette Association
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MARCH



TOURETTE ASSOCIATION OF AMERICA LONG ISLAND CHAPTER

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longisland.tsa@gmail.com

516-590-7551



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>

LITA IS HEADING TO WASHINGTON D.C.



"March 1 in TAA National Advocacy Day. Please support our National Advocacy Day by utilizing our take action letter ([hyperlink to our take action letter](#)) to ask your Senators and Congressman/Congresswoman to support TAA's Public Policy priorities, including \$2 million in funding for the Centers for Disease Control and

Prevention (CDC) Tourette Syndrome Program.

Please forward the link to your family and friends and ask them to Take Action on National Advocacy Day and support you by taking a few minutes to send letters. The online software is simple and only takes a couple minutes yet has a powerful impact.”

Here it is the link:

<https://secure3.convio.net/taoa/site/Advocacy?cmd=display&page=UserAction&id=129>

Thanks!

Diana Felner
Vice President, Public Policy
Tourette Association of America
P.O. Box 75560
Washington, DC 20013
718.224.2999 ext 202
Mobile 703.966.5551

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?](#)

The logo for 'Save the Date' features the words 'SAVE THE DATE' in a serif font. 'SAVE' and 'DATE' are in a larger, bold font, while 'THE' is smaller and positioned between them. The text is dark brown and set against a light beige background.

**JUNE 9, 2018 - FAMILY FUN DAY - MCKENNA ELEMENTARY,
MASSAPEQUA**



SOCIAL/INFORMAL SUPPORT GROUP

*Join us for a night of bowling on **Friday, April 6th** at Bowlmor, 895 Walt Whitman Road, Melville - 7:00 to 9:30. Adults, young adults, teen and kids are welcome.*

We look forward to seeing everyone there and having a night of fun!

educate



*Thank you to YA Becca Caron for her great presentations at
Canaan Elementary School*

LI YA Rebecca Caron Meets With Representative Peter King

YA Rebecca Caron and her mom Sue Caron, adult member of YA team, had a great meeting with

Representative Pete King on Feb 2nd.

Rep. King has been a long time friend and supporter of not only LI TA, but of TAA and everyone country wide living with Tourette.

Rep King complimented Rebecca for being a confident young woman and assured her he will continue to support the Tourette community.



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.

Diane Diamantis
President

Kelsey Diamantis
Vice President



DOLLARS 4 TIC SCHOLARS

*The Kelsey B. Diamantis TS Scholarship
Family Foundation, Inc.*

Office: 561-487-9526

Cell: 561-212-2684

info@dollars4ticscholars.org

<http://www.dollars4ticscholars.org>

<https://www.facebook.com/dollars4ticscholars>

@Dol4TicScholars

*College Scholarships for Movers & Shakers --
Encouragement for Students with Tourette's Syndrome*

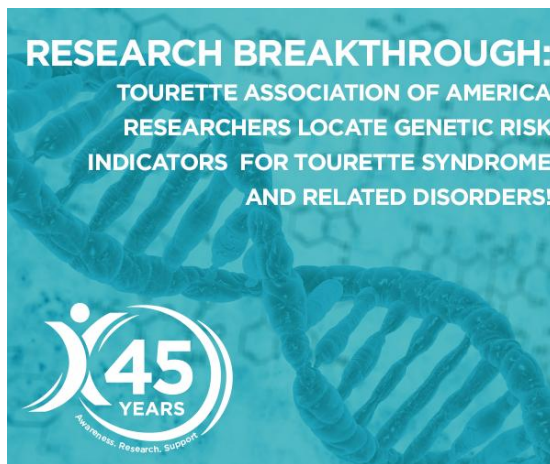
Do you know a student who will enter college in 2018, or a student who is already in college, who has been diagnosed with Tourette Syndrome or Chronic Tic Disorder? Do you know a grad student who has Tourette Syndrome?

The Kelsey B. Diamantis TS Scholarship Family Foundation, Inc., d/b/a Dollars 4 Tic Scholars is happy to report that scholarship applications for Fall 2018 are now live on their website at www.dollars4ticscholars.org/application.

This year Dollars 4 Tic Scholars are very excited to have expanded programs by making a graduate student scholarship available.

Applications will be due by April 15, 2018.

Since 2015, Dollars 4 Tics have awarded 13 college scholarships, and sponsored six children to attend Tourette Syndrome summer camp. They strive to continue to grow to help even more students around the country. Please encourage any students you know to apply, and help spread the word!



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>

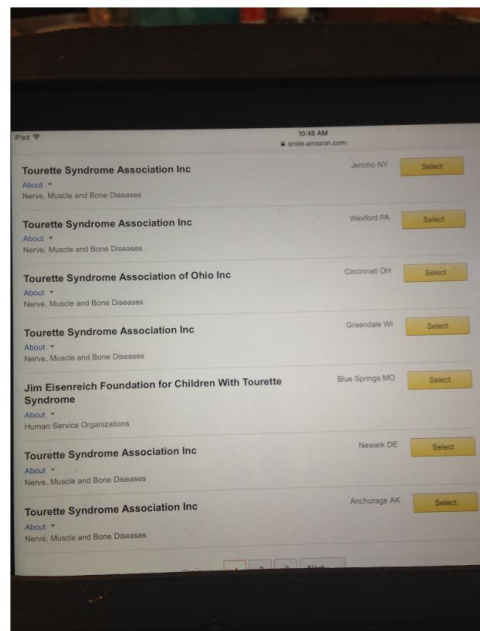


We are excited to announce that LI TA is participating in AmazonSmile!

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](#)

[WEBSITE ADVERTISEMENT](#)

[EMAIL ADVERTISEMENT](#)



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.

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



Please contact us at 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.



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.



REMINDER: NEXT SUPPORT GROUP - FRIDAY, MARCH 9th, BEGINNING AT 7:30 P.M. AT DeMATTEIS CENTER, 101 Northern Blvd, Greenvale, NY. [Click here for directions.](#)

Schedule for 2017-18 school year.

Please note March 2018 date is the 2nd Friday of the month.

NOTE: *SECOND FRIDAY OF THE MONTH

April 6th (moved from April 13th!)

May 4th

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.

