

# Newsletter OF THE LONG ISLAND CHAPTER OF THE TOURETTE SYNDROME ASSOCIATION

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## Message from the Chair

Hi Folks,

I hope this newsletter finds you all well! Summer is just about over, but we still have a handful of fun days in the sun left. Along with the fun days, there have probably been occasional (frequent?) days of TS not-so-much fun to contend with, as well. Parents may be worse for their wear for having to navigate many more difficult TS/OCD, etc., episodes during summer vacation than during the school year. Thus, although many parents, and kids, of course, will feel some sadness as summer fades away, many others may be quite ready for the summer to end! If your summer, like ours, has been filled with a series of different routines and late mornings, I recommend trying hard now to reestablish a good amount of daily structure. Although most kids seem to do better with that anyway, ours really, really *need* it.

We ended our spring and celebrated the start of summer with our first, very successful and FUN Family Fun Day. If you were there, you KNOW how terrific it was, and if you were not, be sure to make it next year. See inside for more on Family Fun Day, and check out the website for photos of the day (LI-TSA.org).

We continue in our efforts to move towards greener management policies, and in that endeavor, we would eventually like our newsletter to be mostly electronic. Please send us your current e-mail address if you have not done so already.

Regarding back to school season in just a few weeks, please remember that it is critical to your child's success in the coming school year that you meet with as many of this year's teachers and anyone who will be working with your child as early as possible, and preferably even before school starts. Start calling the school the last week of summer vacation to arrange that meeting. Teachers are usually back by then, and available for a meeting. Setting all the pieces in place, and starting on solid footing from day one goes a long way towards achieving success!

Please note that, because of Labor Day and other scheduling conflicts later in the month, there will be no September Support Group. We hope that many of you were able to attend our Back-to-School special meeting on August 28th, which replaced the September meeting. We will begin our regular support group meetings on October 2nd (see inside for support group calendar for the next four months). Hope to see many of you there!

Enjoy the rest of your summer!

Regards,  
Lisa Filippi, Ph.D.  
Chair, LI-TSA

## 5th International Scientific Symposium on Tourette Syndrome a Huge Success!

*This article is from the National TSA Web site: tsa-usa.org.*

The national Tourette Syndrome Association, Inc. brought together 250 delegates and internationally renowned scientists, clinicians and other experts from 17 countries, including Argentina, Belgium, Canada, France, Germany, Iceland, Israel, Japan, South Korea and Spain, to share and discuss the latest research into and treatments for Tourette Syndrome. The Symposium was held in New York City on June 12 and 13, and focused on the advances made since the last Symposium which was held in 2004. Notable hot topics were deep brain stimulation (DBS); the development of animal models for the study of TS; and the use of cognitive behavioral therapy in reducing tics. However, fields as wide and diverse as genetics, neuroimaging, neuropathology, epidemiology and neuroimmunology were all covered during the course of the conference. Presenters conveyed their research findings through platform presentations, small group meetings/workshops and poster displays.

The Symposium was co-chaired by the TSA Scientific Advisory Board co-chairs, Peter J. Hollenbeck, Ph.D., Purdue University; Jonathan Mink, M.D., Ph.D., University of Rochester Medical Center; and John T. Walkup, Johns Hopkins School of Medicine. The program was developed by a Steering Committee chaired by Kevin Black, M.D., Washington University School of Medicine.

TSA was honored to welcome New York City Council Speaker Christine Quinn, who presented opening remarks to the distinguished attendees on Friday, June 12.

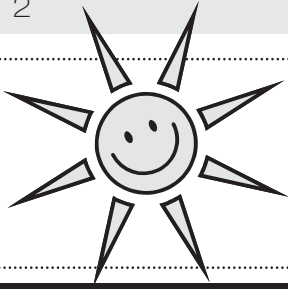
Dr. Black commented on the success of the event and the high level of the material presented. "The quality of the presentations was superb. We heard breaking news..."

*continued on page 6*

## Local Families Came Out to Have Fun While Supporting Long Island TSA

*see pages 4 and 5 for story and more photos*





## Quote of the month:

*“Of all nature’s gifts to the human race, what is sweeter to a parent than their children?”*

— Marcus Tullius Cicero

## Board Members

### EXECUTIVE MEMBERS

**Lisa Filippi, Ph.D., Chair**

**Jane Zwilling, Psy.D., Co-Vice-Chair; Chair, Education/Advocacy Committee**

**Daniel Rabinowitz, Esq., Co-Vice-Chair**

**Rachel Gibbons, Esq., Treasurer; Government Liaison**

**Sue Gochman, OTR, Corresponding Secretary**

**Demetria Marino, Recording Secretary**

**Sheila Kastner, Community Relations**

**Jen Zwilling, Youth Ambassador**

### NON EXECUTIVE MEMBERS

**Peggy Coburn, Chair, Family Activities Committee**

**Kate Callan, Web site Manager**

**Haylee Goldberg, Chair, Local Medical/ Psychological Liaison Committee**

**Florentina Lazaroaic, Volunteer Coordinator, Newsletter Editor**

**Julia Vinsky, MHA, Information Line Facilitator**

### PROFESSIONAL ADVISORY BOARD

ROBERT ARAUJO, PH.D • RUTH D. BRUUN, M.D. • CATHY BUDMAN, M.D.  
HERMAN DAVIDOWICZ, PH.D. • LINDA JACOBS, M.D.

## Congratulations and Thank you!

**Thank You!** The Board would like to thank **Jane Zwilling** and **Kate Callan** for the superb job they did organizing our first **Family Fun Day Fundraising event**. They really went all out investing endless hours in the months preceding the event, to make sure we had sponsors and all the components of a really great day. This was our first major fundraising event, and it was a brilliant success. Thank you both so very much!

Thank you to **Skeery Jones** and the staff of **Z100** for coming to do their thing in the draining heat at Family Fun Day. The children were thrilled, and your presence really gave a charge to the day.

Thank you to **Anita Filippi-D’Anca** for her beautiful and inspired work on both the newsletter and the brochure she designed with **Ilyse Zincone** for Family Fun Day and for being our photographer for our special event!

As always, we are so very grateful to **Julia Vinsky, M.S.W.**, and the **DeMatteis Center of St. Francis Hospital** for the use of three rooms a month where we hold our support group meetings.

**Congratulations!** Congratulations to **Allison Kastner (22)**, who graduated with honors from Lynn University in June. We are all so proud at how well you have succeeded. Best of luck in hotel management in the future!

Congratulations to **Michael J. Marino (15)** who scored 100 on the All-State NYSSMA Snare Drum in May! Way to go Michael! You really do rock!

Congratulations to **Lee Gochman (16)** for appearing in the Long Islander Newspaper with **Congressman Steve Israel** in June regarding his participation in the **TSA Trip to the Hill** and also as a promotional piece for National TS awareness month! You have become a very charismatic and valuable spokesperson for TS, Lee! Way to go!

Thank you to everyone who participated in our **Cans for Kids** green fundraiser, spearheaded by **Eric Zwilling (16)**. Thanks to your efforts, we raised over \$300.00. Certificates were awarded to the top four donors: **1st place: Eric Zwilling, 2nd place: Rachel and Chadd Maddalone, 3rd place: Michelle Collica, 4th place: Patrick Charles**. We hope to continue this community effort to generate funds for LI-TSA, so keep on recycling!

## Family Social Activities

**Coming in October, LI-TSA rock wall climbing party** at Island Rock in Plainview, NY. Visit [www.li-tsa.org](http://www.li-tsa.org) for the details and updated info.

Log onto our Web site at [www.li-tsa.org](http://www.li-tsa.org) and click on events to find out about our up-and-coming events. Please make sure we have your e-mail address so we can send you electronic flyers as new events are planned.

Don't forget our **Information Line** which exists as a helping hand to the community. We return calls promptly and provide medical and professional referrals as well as community resources. We can answer general questions on TS and associated disorders. Call us at (516) 876-6947 or e-mail us at [LongIslandTSA@aol.com](mailto:LongIslandTSA@aol.com).



## EDUCATION AND ADVOCACY COMMITTEE UPDATE

Jane Zwilling, Psy.D., Advocacy Chair

The Education/Advocacy Committee as well as the Youth Ambassadors had a very productive 2008-2009 school year. We are in the process of scheduling for the 2009-2010 school year.

If you would like a presentation in your school please contact or have your school contact us at LongIslandTSA@aol.com. Additionally, please let us know if we can help in any way.

The Americans with Disabilities Act (ADA) has been amended and there are two changes that will significantly impact the ability of children with TS to receive a 504 Plan.

Based on information from the official notice Kathy Giordano, National TSA Advocacy Specialist, wrote the article below. She states "This is the best news since I heard that TS was going to be included under OHI (Other Health Impaired) in IDEA (Individuals with Disabilities Education Act)!"

## Amendment to the Americans with Disabilities Act (ADA) In Effect

by Kathy Giordano

On September 28, 2008 the Americans with Disabilities Amendments Act of 2008 was signed into law and became effective January 1, 2009. The ADA is an anti-discrimination law that ensures that eligible students with disabilities are provided a free and appropriate public education by implementing a 504 Plan that includes accommodations and modifications to specifically assist the student.

This new amendment "emphasizes that the definition of disability should be construed in favor of broad coverage of individuals to the maximum extent permitted by the terms of the ADA and generally shall not require extensive analysis. The effect of these changes is to make it easier for an individual seeking protection under the ADA to establish that he or she has a disability within the meaning of the ADA."

Two items below are addressed in this Amendment that may be helpful for parents of children with TS to be aware of when attempting to have their child found to be eligible for a 504 Plan. It is important that parents know that school personnel may not be aware of these changes and it may be helpful to send this article to the 504 Chairperson when requesting the meeting to determine eligibility or to bring a copy of this article to the 504 meeting.

**1. Episodic and Inconsistent Symptoms** The 2008 Amendment "*clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active.*"

This speaks directly to issues regarding the inconsistency and the waxing and waning of symptoms of TS. Parents may want to be prepared to discuss how specific symptoms experienced by their child "substantially limit a major life activity." Documentation from a doctor, therapist, teacher or an education evaluation may be helpful.

**2. Addition to 'Major Life Activity' List** 2008 Amendment has added "**reading, bending and communicating**" to the list of major life activities.

This can significantly assist parents when preparing to demonstrate the specific 'Major Life Activity' that is impacting their child's life and makes the student eligible for a 504 Plan. As an example, many students with TS have symptoms that interfere with reading and therefore the student would be eligible for a 504 Plan under 'reading.' Additionally, many students have difficulties with verbal (vocal tics) and/or written communication, which would make them eligible for a 504 Plan under 'communicating.'

The ADA Amendments Act is effective as of January 1, 2009. For further information regarding 504 Plans go to: [www.ed.gov/about/offices/list/ocr/504faq.html](http://www.ed.gov/about/offices/list/ocr/504faq.html)

### TS INFO CARDS AVAILABLE FOR MEMBER USE!

Have you ever been out somewhere in public, perhaps in a theater, in a store or on the train, and found that your or your child's tics were drawing unwanted, negative attention? Please feel free to contact the chapter at LongIslandtsa@aol.com if you would like to obtain a box of TS information cards to hand out as a way to handle uncomfortable situations! Hand them out whenever you feel an awkward situation is about to happen, and be an educator at the same time! The person you educate today by giving them an info card, could be one less person to tease or respond negatively to someone else with TS tomorrow!

# FIRST LI-TSA FAMILY FUN

## Local Families Came Out to Have Fun

*Congress has declared May 15th – June*

**LI-TSA held its very first Family Fun Day Fundraising event on May 30th, coinciding with TS Awareness Month.**

On May 30th with blue skies overhead, Jericho High School's track and field became a carnival-like atmosphere for families from all over Long Island. Smiling, excited children enjoyed inflatables, face painting, sand art, craft activities the excitement of Scotty B, Skeery Jones and the Z100 crew, and more.

The first annual Family Fun Day to benefit LI-TSA was a huge success and raised much-needed funds, which will enable us to continue, and to improve, the chapter's services. LI-TSA was touched by the huge turn-out and support from local families who enjoyed a relaxing day where kids could be safe, have fun, play, dance with hula hoops, enjoy refreshments, and win raffle prizes, while also becoming more educated, aware of and sensitized to Tourette Syndrome.

We are so grateful for the support of our sponsors, raffle donors and the help of our volunteers. LI-TSA thanks it's main Sponsors, including **Event Sponsors- Astoria Federal Savings, New York Yankees; Registration Sponsor- One Liberty Properties; Publicity Sponsor- Anton Community Newspapers and The Boulevard**, for their support, as well as the main local sponsors including- **be jeweled now** (inside Venus nails), **Steven J. Boral D.D.S., P.C.**, **Weiss & Luccarelli Orthodontics**, **North Shore University Hospital/LIJ** and **North Shore University/LIJ TSAICG**, **Albert's Pizza**, **Metro 1**, **Operation Fun**, **SOS**, **St Francis Hospital**, **Thomas Kugler Graphic and Web Design** and **Z100**.

Although all of our board members and several chapter members helped in a variety of ways with this event, board members **Jane Zwilling** and **Kate Callan** were the two principal event planners. Their tireless,



**Volunteers with the Z100 crew – Back row:** Amanda Zwilling, Dana Palmieri, Sami Ostrow, Dan from Z100, Scott Freudenthal, Bryan Joachim, Skeery Jones from Z100, Michelle Karen, Lindsay Rawot; **Middle row:** Tracie Mandel, Lee Gochman, Matt Weiss, Jake Freidberg, Lexi D'Esposito, Christine from Z100, Jen Zwilling, Jenna Nevit; **Front row:** Shoshana Rabinowitz and Eric Zwilling



**LI-TSA Youth Ambassadors with Z100 – Back row:** Jen Zwilling, Dan from Z100, Lee Gochman, Skeery Jones; **Middle row:** Ben Rabinowitz, Shoshana Rabinowitz, Patrick Callan, Dara Fuhrman and Christine from Z100; **Front row:** Eric Zwilling

# FN DAY A HUGE SUCCESS!

## in While Supporting Long Island TSA

### 15 Tourette Syndrome Awareness Month



Skeery Jones engages the kids at LI-TSA Family Fun Day



Kristina Callan having fun on the velcro wall



TSA President Judit Unger and LI-TSA board member Kate Callan.

phenomenal efforts were largely responsible for acquiring the major sponsors for this event. We are so very grateful to Jane and Kate for the incredible scale to which they took this event. Thanks are also due to all of the board and chapter members who contributed to the success of this event, as well as all the chapter members who came out with families and friends to share in the fun and support this event.

The event would not have been possible without the **volunteerism** of local High School students. A group of Jericho High School students who volunteer as Buddies for LI-TSA, including Student Coordinator-**Eric Zwilling**, along with **Alexandra D'Esposito, Jake Freidberg, Taylor Katz, Tracie Mandel, Samantha Ostrow** and **Dana Palmieri** assisted in running the event and raising awareness. Other Jericho students, **Scott Freudenthal, Bryan Joachim** and **Matt Weiss** attended a training session to specifically volunteer for the Awareness event.

Long Island Youth Ambassadors, **Dara Furhman** from Plainview Old Bethpage Kennedy High School and **Lee Gochman** from Half Hollow Hills "manned" a Youth Ambassador booth, while **Jen Zwilling, Amanda Zwilling, Eric Zwilling**, and Junior Youth Ambassadors **Shoshana Rabinowitz** from Port Washington and **Patrick Callan** from Locust Valley were available to educate attendees and to answer questions throughout the day from kids and adults.

**Dr. Cathy Budman** and her research assistant **Mia Banakos** from NSUH/LIJ Hospital were also on hand to educate attendees about TS and a current genetic study at NSUH for which they are recruiting subjects.

*This event was such a success that we plan to make the LI-TSA Family Fun Day a yearly event, so please be sure to stop by next year!*

## Important Change to IDEA - Parental Right to Revoke Consent

by Kathy Giordano

New regulations for the federal IDEA became effective December 31, 2008. One of them dramatically impacts how parents can discontinue special education and related services.

Schools are required to contact parents so that they may sign a consent form that gives permission to the child's school to conduct initial evaluations and to provide special education and related services.

Parents have always had the right to withdraw their consent; however schools were able to contest their decision. This amendment requires that the school abide by the parent's written decision to remove their child from special education and will not be able to challenge that decision through either mediation or impartial hearing as they have been able to do in the past.

This new regulation does not require that schools remove references to special education in student's school records. As in the past, parents may request that the records be amended in order to remove inaccurate or misleading information.

It is important to note:

- This does not allow a parent to **selectively** discontinue services. If a parent revokes consent, all special education

services will be discontinued and the child will be a regular education student.

- The child will need to meet all state requirements and no accommodations for state testing will be allowed.
- All the rights and protections that are provided under IDEA (discipline protection, accommodations, and modifications) will no longer apply. This is an important consideration as behaviors that are not subject to disciplinary actions under IDEA would now be responded to in the same manner as a regular education student. The protections that IDEA provides from suspensions and expulsions would no longer apply.
- Consent for evaluation and special education services may be re-initiated by the parent at any time. However, the process will begin as a request for an initial evaluation to determine if the student is eligible for special education services or a 504 Plan.

This change may be helpful for those parents who believe that the services their child is receiving are detrimental and all attempts at having the IEP changed have been unsuccessful.

### 5th International Scientific symposium... continued from front page



New York City Council Speaker Christine Quinn presenting opening remarks.

...on several fronts: a report from the CDC on the first nationwide survey of people diagnosed with TS, an update on the search for genes that cause TS, an fMRI study of how the TS brain's organization develops in adolescence, discussion of animals that have tic-like movements and may help us find new treatments, and compelling results on PANDAS with a very lively discussion of their implications. Much of the meeting was organized to shed light on the results of the recent NIH-funded multi-site controlled study of CBIT (Comprehensive Behavioral Interventions for Tics), presented for the first time at this Symposium. The study results were very compelling and I believe will help bring an important new treatment to the standard care of people with TS. It is not a cure, but it looks to be an important tool for helping manage and reduce symptoms."

The TSA's Early Career Research Award was presented to the TSA grant recipient Nicole Calakos, M.D., Ph.D for her work on synaptic and circuit level insights for TS and OCD using mouse models. Dr. Calakos was also among the 57 scientists who presented posters. Among these, six were scholarship awardees. The scholarships are part of TSA's commitment to encouraging young researchers to focus on pursuits related to TS.

Feedback from attendees was overwhelmingly positive and they stressed how the symposium provided a unique opportunity to hear not only the latest information about TS advances in medicine and treatment, but also to meet other medical and scientific professionals from around the world to share information, ideas and experiences. Attendees are now anxiously awaiting the next TSA symposium and expressed a desire for it to be held sooner than the next meeting which is scheduled to take place 5 years later in 2014.

On Sunday, June 14, the final day of the Symposium was a 'Family Day' when local TS families were invited to hear Dr. James Leckman of the Yale Child Study Center talk about the medical and scientific advances presented at the Symposium. Douglas Woods, Ph.D., also spoke about CBIT (Comprehensive Behavioral Intervention for Tics) and the results of the NIH-funded study.



Symposium co-chair Jonathan Mink, M.D., Ph.D. presents the TSA Early Career Research Award to Nicole Calakos, M.D., Ph.D



Co-Chair Dr. John Walkup with Dr. Kevin Black, Steering Committee Chair.



Dr. James Leckman and Douglas Woods, Ph.D., who presented to local families during the post conference meeting on Sunday.

## The Continuing Saga of Shoh Part 13

by Lisa Filippi

I thought that in this episode I would clear up a fallacy that seems to have taken hold. A friend and LI-TSA member, recalling the previous Shoh pieces I have written, mentioned how impressed she was that I am always so positive and undaunted. She seemed a bit envious at how well I manage to keep everything in perspective. I suppose that from the way I write about living with Shoh, it may seem as though we always manage to sail through our crises unscathed, and even somewhat enriched! Hah! Though I do consider myself a positive, optimistic person, I suppose it is time for a reality check. I certainly do try to end all of our misadventures on a positive note, relating as best I can how we managed to navigate each episode to a positive outcome. But, to borrow one of Obama's favorite lines, "let me be clear," life is not, I repeat emphatically, NOT a basket of roses. Not by a long shot. In fact, right this minute, as I type, Shoh is sulking in the back sunroom because I asked him to leave the house. I was too furious with him, and was afraid I might give in to temptations to pummel him. You see, he just came in to the living room to nonchalantly apologize for putting a hole in the closet door that I just fixed last summer. We spend our summers in Japan with Daddy, and the closet doors are made of layers of thick paper. He said that his tics made him throw the ring that we had just bought him (it was either 'buy' or risk another OCD meltdown in public) into the closet door, where it became lodged within the layers, so that he then had to rip open the door even more to remove it. The hole in the closet door now matches the NEW hole in our bedroom wall (don't even remember how that happened, but it was sometime last week!), which had already matched the older hole in the wall. Anybody else out there have holes in walls that make the house look like a war zone? But, truthfully, Japanese homes and kids with TS just don't work. Oh, the ring? I wish we never got

“ Though I do consider myself a positive, optimistic person, I suppose it is time for a reality check. ... “let me be clear,” life is not, I repeat emphatically, NOT a basket of roses.”

it! His tics keep making him smash his head with it, and he passes many hours of the day stomping around the house uttering furious comments, cursing the darn thing and throwing it about. It is a bulky ring that must really hurt when banged against the head. I tried to buy it from him to end the horror, but he was charging me way more than we had paid for it!

So, you see, I spend a considerable amount of time less than pleased with dear Shoh, and beside myself, to boot. Shoh's psychologist helps us through many difficult times, and even when we are here, in Japan, with Shoh having meltdowns several times a day (TS/OCD/impulsivity plus puberty-related over-the-top irritability?), I find myself thinking of how dear

Dr. T would navigate us through it. It does help. So, please, I hope that I have convinced you that our family struggles just like yours. We have our lovely moments and our tortured moments. However, by writing about some of Shoh's episodes, I seem more able to come to terms with them. At the very least, I am forced to reflect on them, and consider the different potential ways to assure a more promising outcome, for future reference. I also find myself appreciating the depth of Shoh's quandaries just a bit more. As hard as it is for us as parents to live with this disorder in the house, it cannot compare with what our children are going through. In that context, I consider writing these pieces to be very therapeutic, and I am certainly collecting them to present to Shoh in 'book form' when he grows up. ***I urge other parents out there in LI-TSA land to consider writing pieces about your own children for inclusion in our newsletter! Reap the rewards on several levels!***

Dear Tourette Syndrome Association member,  
We are happy to be going **GREEN!** In an attempt to save money and to help our environment, we will be sending out fewer paper mailings. Please help by providing us with your updated e-mail address. We will use this **ONLY** for announcements regarding the Long Island Chapter of the Tourette Syndrome Association functions. This includes our Newsletter, Support Groups, socials... (You may request to be removed at any time). If you think we have your address, but you have not received any e-mails in the past 6 months, please re-submit your e-mail address.

THANKS!

Please send your e-mail addresses to  
**Sue at: [sgochman@optonline.net](mailto:sgochman@optonline.net)**  
ALSO: Please note that our Web site has been updated and is New and Improved! Visit us at: **[www.li-tsa.org](http://www.li-tsa.org)**



Don't miss important chapter announcements between newsletters!  
Register on our chapter's E-mail Notification List! Include family members' names, and age and name of child who has TS. To be included on our list, please e-mail us at LongIslandTSA@aol.com. Thank you.

## CALENDAR OF EVENTS

### 2009 ADULT SUPPORT GROUP • CHILDREN'S SUPPORT GROUP and TEEN SUPPORT GROUP

All meetings begin at 7:30 p.m. and are held at the DeMatteis Center, 101 Northern Blvd., Greenvale, NY 11548, located on the north side of Northern Blvd., just west of Route 107, past the C.W. Post Campus of Long Island University, opposite NYIT.

Support groups through January of 2010 will meet on the following Fridays:  
October 2, November 6 and December 4, January 8 (note: this is second Friday)

\*Due to the 1st Friday falling on Labor Day weekend and scheduling conflicts for other weekends, there will be no September support group meeting.

**We will be holding chapter elections soon, so PLEASE** contact us by e-mail at LongIslandTSA@aol.com if you are interested in running for a position, or would like to nominate someone. The Executive Board positions include: Chair, Vice-Chair (may be multiple Vice-Chairs); Recording Secretary, Corresponding Secretary and Treasurer. Committees for which Chairs will be elected include: Education/Advocacy, Newsletter, Family Activities, Web site, Volunteer, Medical/Psychological Liaison. **Support your chapter by running for an office!**



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