



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

P.O. Box 615 • Jericho, NY 11753 • LongIslandTSA@aol.com • www.li-tsa.org • 516-876-6947

## Message from the Chair

I hope that you are all faring well during this unusually cold winter. I have claimed the rocking chair next to the fireplace as my winter evening refuge, where I like to curl up with a good book; winter does have its charms!

We have **two new board members** who have brought new vigor to the chapter's efforts. **Kate Callan** has been making sure our newly (and dramatically) improved Web site remains up-to-date, and has lots of useful information for members. If you haven't had a chance to visit our website lately, I urge you to spend some time navigating around the site. It is much more attractive, user-friendly and useful! The Web site has long been one of our sore spots, and we are so pleased with its transformation thanks to Kate's brother, Thomas Kugler. **Florentina Lazaroaie** has taken on the very important tasks of coordinating volunteers and editing the material that goes into the newsletter. Welcome to our new board members, and THANK YOU!

Our support group has been receiving much praise from participants, parents, young children and teens alike, and that is always heart-warming to hear. We are proud of the help and comfort we can offer member parents, and are pleased to be there for you in this capacity. The stories, struggles, and ideas that we share and generate at the meetings reassure, and help all of us to cope better with our individual day-to-day difficulties. The children love to attend the art therapy support group, and have really bonded into a close-knit group; of course, our TS 'buddies' have been a great help with the children's group, as well. The teens also have a place to share their concerns and just to hang out with other teens for a rap session in their own support group. If you haven't participated yet, please join us in one of the groups! You'll go home feeling refreshed and with a new and more positive outlook.

We had a fabulous year-end event in December. Matt Giordano, who has severe TS, inspired and energized all as he ran a dynamic drum circle. See inside for photos and story! Peggy Coburn has planned several fun social activities for us this winter and spring, and we hope that many of you will join in the fun. See inside for details.

As always, Jane Zwilling of the Education/Advocacy committee has been busy going in to schools to do in-services for faculty and staff, and the Youth Ambassadors have been going into classrooms, all to help make the academic realm a more understanding and comfortable place for our children to be. See inside for more info about how to arrange for a presentation at your child's school.

**Hang in there during these last few winter weeks, and let's all look forward to a bright new spring!**

Warmest regards,  
Lisa Filippi, Ph.D.  
Chair, LI-TSA

## ASK THE O.T.

Q&A to:

SUE GOCHMAN, O.T.

Occupational Therapist

Corresponding Secretary, LI-TSA

**Q:** My child's handwriting is a real problem. Any ideas?

**A:** Illegible handwriting, hand fatigue and homework frustration are common difficulties noted with many children, including those with Tourette Syndrome. Handwriting or graphomotor function is a very complex task and is one of the more intricate fine motor activities we perform, often on a daily basis. Many times the child's thoughts are running faster than their hands can keep up. It becomes very wearisome and a task that is frequently avoided.

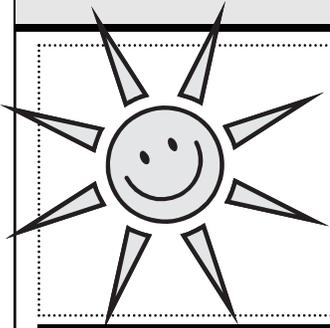
Signs of handwriting difficulty include poor legibility, rushing through work, short responses to essay homework, procrastination, hand fatigue, and, of course, avoidance, with its many warning signs or behaviors that parents observe prior to and during homework time (going to the bathroom, taking a drink of water, sharpening the pencil for the third time, etc.).

Since handwriting is a multi-faceted task, it is important to consider a variety of origins for this difficulty. An Occupational Therapist can be of assistance in this area; however, parents and teachers are often great observers and can begin to isolate the problem areas.

*Things to consider:*

**\*POSTURE** - It is essential that a child's sitting position be appropriate for best writing results. Be sure their feet can touch the floor when sitting. If not, consider a low bench to rest their feet on, a chair with a support beam for foot placement or a smaller desk/chair set. Basically, the body should be able to get to 90 degrees at the hips, knees and feet. The desk/table should be at a height that allows the arms to rest comfortably on the surface (no shoulder hiking or leaning down to reach the desk). Some children benefit from a sitting...

... continued on page 6



### Quote of the month:

*“Sow a thought and you reap an action;  
sow an act and you reap a habit;  
sow a habit and you reap a character;  
sow a character and you reap a destiny.”*

— Anonymous

## 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.

### Latest TS-related Books of Interest:

Against Medical Advice, by James Patterson and Hal Friedman  
*Alphabet Kids - From ADD to Zellweger Syndrome: A Guide to Developmental, Neurobiological and Psychological Disorders for Parents and Professionals*, by Robbie Woliver

### Family Social Activities

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.

## CALL FOR HELP - PLEASE DONATE ITEMS:

Please help support L.I. Tourette Syndrome Association so that we can continue our valuable mission and services to the TS community. We are preparing for an upcoming online auction. We need donations of: cash, services, gift certificates, unique experiences, show and sports tickets “regifted” items, new and slightly used handbags, jewelry, antiques and other prizes. Please be charitable and use your connection and your imagination to help us raise money for our valuable organization. We depend on your help. If interested in donating or being a team event member please contact Sheila at: [sbk915@aol.com](mailto:sbk915@aol.com)

WE ALSO NEED ADDITIONAL CORPORATE SPONSORS: Thank you Otterbourg, Steindler, Houston and Rosen P.C., N.Y. for becoming our first premium online sponsor. They have generously helped jumpstart our exciting LI-TSA auction.

Along with the philanthropic benefit of supporting LI-TSA, our corporate and personal sponsors will be featured for several months on our auction site. This site is capable of linking into YOUR COMPANY WEB SITE. There will also be press releases and advertisement featuring your company. Not only will you feel good but this will give good cause marketing to our supporters. If interested please contact Sheila at: [sbk915@aol.com](mailto:sbk915@aol.com)

Please check out cMarkets BiddingForGood catalogs online at: [www.cmarket.com/auction/BiddingForGood.action](http://www.cmarket.com/auction/BiddingForGood.action) if you are interested in a preview of auctions. We will let you know when we have enough donations to start up our LI-TSA Auction.

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 is out in Nassau and Suffolk presenting in-services and assisting parents with preparing for meetings.

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

Long Island TSA is excited to have participated in a new initiative of National TSA. Lisa Filippi and Jane Zwilling were present at this very successful, well-received, informative presentation.

*Below please see a write-up from National TSA about the program.*

### Librarian Education & Outreach-A New TSA Initiative

On the day before an historic Election Day, November 3, 2008, TSA made its own history of another kind. The organization mounted its first major education and outreach program directed to librarians. An excellent overview presentation on "Living With Tourette Syndrome" was delivered to an eager audience of near 50 librarians affiliated with the county-wide, Nassau Library System, in Uniondale, Nassau County, Long Island, New York. The featured presenter was Kathy Giordano, TSA Education Specialist.

The aim of this program was to fully inform and encourage interest in TS on the part of community librarians. Generously supported by the office of New York State Senator Charles Fuschillo, the program was a great success.

As a parent of three now-adult children with TS, a former educator, a part-time advocate for people with disabilities, and a TSA Education Specialist, Kathy Giordano was very well positioned to share essential information about the disorder and its effects. She augmented her presentation with many personal stories from each of these perspectives.

To further support this unique outreach, information and materials in both print and electronic formats were provided to all in attendance as part of the professional TS Education and Outreach Program Partnership joining the TSA with the US Centers for Disease Control & Prevention (CDC).

In addition to a detailed overview of the condition, its salient symptoms and a discussion of its effects in schools and in the community, much of the focus involved the essential role local librarians can play in the development of children. All in attendance agree that librarians promote inclusion and involvement in library and community life for people with Tourette Syndrome.

## Youth Ambassadors and Buddies

Our Youth Ambassadors are also out in full force.

Lee Gochman, Dara Furhman, Brian Wedeking and Eric Zwilling have all been presenting. Additionally Jen and Amanda Zwilling presented two programs while on Long Island during their winter break. Jen also assisted an up-coming new Youth Ambassador, Patrick Callan do his first presentation. Congratulations Patrick on a job well done!

Please contact us at [LongIslandTSA@aol.com](mailto:LongIslandTSA@aol.com) if you would like a Youth Ambassador Presentation.

Our Buddies have been dedicated to assisting with our monthly Children's Support Group.

If you know of anyone interested in being a Youth Ambassador or Buddy please contact us at [LongIslandTSA@aol.com](mailto:LongIslandTSA@aol.com)



The LONG ISLAND TSA  
is inviting YOU...

We're going BOWLING!

*Please join us:*

Where: Syosset Lanes, 111 Eileen Way,  
Syosset, NY 11791 (516)921-7575

When: Saturday, February 28, 2009 • 3-5pm

What: **Free** to members, includes: shoes,  
pizza, salad and soda!

\$25.00/person for non-members:  
become a member and save!

*Please RSVP by Saturday, February 21, 2009*

*To Peggy: [litsakidsevents@optonline.net](mailto:litsakidsevents@optonline.net)*

Include names and ages of bowlers and let us know if anyone in your family will be attending but NOT bowling.

**Please be prompt, as extra lanes will be forfeited after 3 p.m.**

## Holiday Drum Circle event

by Peggy Coburn

Our chapter hosted an amazing Drum Circle event on Dec. 5. It was led by Matt Giordano of Drum Echoes ([www.drumechoes.org](http://www.drumechoes.org)). Adults and children, alike, were totally engrossed in this experience. Matt was terrific in leading our group of 60 people from age 5 to grandparents, on this little journey where we had never been before! Matt led us through fun and challenging (but not impossible) drumming exercises in ever-more-complex patterns. It felt so communal to all be doing this together, even having to cooperate and trust each other while playing each other's various-sized, hand-held drum pads. The "journey into the rainstorm" was so magical. We closed our eyes, and employed simple techniques to simulate the sounds of gentle rain, intensifying into a major thunderstorm. Next, we were awed by the "heartbeat drum-dance". Matt taught us about primal peoples' use of heartbeat rhythms and stomping throughout time and the world. I could imagine being around a campfire with my tribe ten thousand years ago, barefoot, and even felt "whole" and "connected" doing this in my high heels with our group. Then, a few brave volunteers each held a different-sized drum pad while Matt



LI-TSA 'buddies' with some of our kids at the holiday drum circle party.

demonstrated some drumming.

I have never seen a human's hands move so fast! Afterwards, a woman who was sitting behind me while Matt drummed, told me she saw our backs vibrating during this exhibition! Finally when we were done, Matt – who has TS and emerged from a childhood of particular difficulty – shared bits of his life story. His inspirational words made me feel like the world was ready and waiting for me, so full of hope and encouragement. *The evening was unforgettable.*



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.

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)



## Congratulations and Thank you!

by Lisa Filippi

Congratulations to TSA's first Youth Ambassador, and the Long Island Chapter's own **Jennifer Zwilling** for being honored in the November 24th, 2008 issue of People Magazine with the *Heroes Among Us Award!* People Magazine has a tradition of honoring in each issue ordinary people who do extraordinary things. The magazine has feature articles that highlight, "real people who selflessly open their hearts, offer help and inspire others along the way." Jennifer does all of that every day, through the way she lives her remarkable life, and through her work with National TSA's Youth Ambassador Program, which Jennifer created along with her sister, Amanda, when she was just 14. Jen is now a freshman and a Robertson Scholar at Duke University, where she continues to inspire and shine on. We miss her presence and clear voice of reason at our chapter board meetings dearly, but there is no doubt that, even as a busy college student, she continues to have a great impact on so many. In addition to the actual advocacy she is involved in through her program, the publicity surrounding the many awards she has received has also increased TS awareness around the country tremendously. Bless you, Jen! Jen is still active as head of the TSA Youth Ambassador Program, where she trains other teens to be effective advocates in the classroom for students with TS. Go, girl!

Congratulations to **Lee Gochman** (16) for being recognized in an article in Newsday (12/31/08) as one of four "Do-Gooders" on Long Island! As a trained Youth Ambassador for the Long Island Chapter of TSA, Lee goes into schools where there is a student with TS to educate either the entire student body, or the student's classmates, about what it means to live with Tourette Syndrome. Students with TS have a much better school experience as a result of the awareness and understanding that he is able to generate in the interactive presentation. Lee is a politically savvy dynamo, and a brilliant young man, with wisdom beyond his years. Go for the moon, Lee! You rock!

*On a personal note, may I say how proud I am to know these fine people, and to be a part of this group where I am continually amazed at the power of the heart and spirit to overcome adversity, and overcome it so brilliantly! Thank You.*

Many thanks to Cindi Eilbot for donating sponsorship funds generated as a participant in TEAM TSA at the NYC Marathon on November 2nd. Thank you so much, Cindi! You did a fantastic job! Keep on running!

Thank you to all the Youth Ambassadors of the **Long Island TSA** Chapter who are doing so much to improve the lives of students with TS. Your efforts mean so much, and we trust that the experience is enriching your lives, as well!

Thank you to our army of "**LI-TSA Buddies**" for all their efforts at keeping the younger children entertained! They were especially wonderful at the Drum Circle Event in December, spontaneously initiating games of tag, etc., and

providing just the perfect balance of excitement and calm! The kids were thrilled!

Thank you, always, to the **DeMatteis Center**, in Greenvale, for the use of three rooms every month. Without your generosity, our wonderfully successful support groups could not be! Thank you!

Thanks to Thomas Kugler for the brilliant job he did refurbishing the chapter website! It looks fantastic, and is, finally, so useful! Thank you!

Thank you to **Eric Zwilling** for initiating the "Cans for Kids" Program. Children promote a healthy environment by recycling cans and bottles at home and at school, and donate the proceeds to LI-TSA. Thank you, Eric!

A big **Thank You** to **Anita Filippi-D'Anca** for her tireless effort, and the beautiful work she does putting together our newsletter. She really does a fantastic job. Thank you, Anita!



### LONG ISLAND TOURETTE SYNDROME ASSOCIATION

*launches it's first*

### CANS FOR KIDS CAMPAIGN

Support Long Island TSA and go GREEN!  
for the 2008-2009 school year

It is simple... start collecting cans and bottles in your home, school, clubs, neighborhood, church, temple or wherever...

Return cans and bottles to a recycling center and bring donations to our meetings or send your donations to:

Long Island TSA  
P.O. Box 615 • Jericho, NY 11753

**Any kid CAN participate!**

**Let's support Long Island TSA and be GREEN!**

**We CAN do it!**

Make sure to include Cans for Kids with your name, address, phone number and e-mail when you send in donations.

The top three collectors will receive prizes, which will be awarded at our last meeting of 2008-2009 school year.

June 4th at 7:30 p.m. at the Dematteis Center,  
101 Northern Boulevard, Greenvale, NY

## Ask the O.T. *(cont. from page 1)*

...surface that has slight motion to help maintain posture when sitting still is tough and to keep the alert state at an optimal level. This may be a small seat cushion such as a beach ball blown up with very little air, a large therapy ball in lieu of a chair, or even an old stocking tied around the two front chair legs for children to kick and push against.

**\*GRASP** - There are several "proper" ways to hold a pencil. If a child uses an "awkward" grasp, however is experiencing no fatigue and has adequate legibility – no change is needed. Only change a grasp if it is not functional. It is important that the child supports his forearm on the writing surface (desk). Encourage a grasp that is not too high up on the pencil to achieve this. Some children benefit from an angled board (try a clip board with something to elevate the top to create a slope). Some children benefit from pencil grippers, others find that they get in the way or see them as another mechanic to think about. Experiment. There are many products on the market that address this need, like attachable grippers or readily available pens with cushiony grips. Also consider trying a chunky sized pencil (purchased at an office supply store) vs. a standard sized one. Offer play that includes use of manipulatives (Legos, Tinker Toys, Silly Putty, Jacks, sorting coins into sleeves) so the child gets a chance to use intricate finger motions.

**\*GRASP STRENGTH** - Hand fatigue can be due to weak musculature. It can ALSO be caused when a child is using too much pressure on the pencil. Some children tighten their grasp in an attempt to get increased sensation as to what their hands are doing. It probably won't be enough to say "lighten up" or "use less pressure". Try pens with a spongy grip. Children may need to gain experience with movement that is "graded" in terms of amount of pressure, so they can feel when to change the force and eventually write with lighter pressure. Try games like writing on bubble wrap (without ripping the paper), using a mechanical pencil which breaks if using too much pressure (don't use to the point of frustration), games which require balance and a delicate touch, such as stacking (Jenga), or using a number 3 pencil (writes darker than 2). Writing on vertical surfaces increases arm strength, helps position the wrist and fingers, and helps the visual system. Try blackboards or play with toys which are vertically held (felt boards, etc.)

Also include strengthening play, which will help with fatigue as well as with the sensation of changing pressure. Try squeeze toys, push/pull play, make up games with hinged clothespins, clay, squeezing cookie dough from corner hole in zip lock baggie, etc. Certainly, taking breaks while writing may be in order.

**\*PERCEPTION** - Of course, it is essential to rule out visual impairment. This goes beyond the acuity test done in the pediatrician's office. Visual differences are not always related to acuity and can be difficult for a parent/teacher to recognize. Ask your pediatrician about a referral to a pediatric ophthalmologist. In addition, consider the size of the paper. Some children do better with college rule, others with wide rule. Experiment with these. For those children who tend to avoid the margins when writing and have "drifting" words, try using a black marker to make a double vertical line at the left margin; this helps draw the eye and hand back to position. Spacing and sizing inconsistencies often interfere with legibility. Are the letters the same size? Are they anchored on the line or floating under or above? Is there proper space between words? Help the child recognize their successes (those letters that meet the criteria). The "rules of writing": letters must be the same size, letters must walk on the line, and words can't "hold hands" with other words (spacing between words). Try fun games, when not doing the obligatory homework. These may include: writing letters or forms with fingers in salt on black paper, using a stick in the dirt to make forms, making letters on flat Play Doh or Putty, using foam soap on bathtub wall to make pictures, playing board games with form (Pictionary, Pictureka, I Spy) and use play that involves rhythm (musical instruments). Encourage top to bottom writing when printing.

**\*MOTOR PLANNING AND TOUCH** - Difficulties with motor planning (the ability to plan and sequence steps to accomplish a motor task), as well as touch sensitivities can also interfere with writing. Many children benefit from hand warm-ups. Preparing the hand can be useful, by: shaking them out, rubbing palms together, gently pulling fingers, snapping fingers, squeezing a squishy rubber ball, etc. Also, large motor play involving the hands, like walking on hands, crab walk, pushing heavy laundry basket, carrying in heavy grocery bags are good ways to set-up the body before writing tasks. Take breaks, but not so much to watch TV, rather to MOVE. Think about "revving" up the engine. Use "heavy work" play that challenges the body: jump rope, pogo stick, jumping jacks, rolling, weight lifting, sports, swings, running, etc.

Don't forget about introducing a good computer keyboarding program to help with speed and to reduce frustration. Computers are often the way to go. Many schools now allow homework, essays, and projects to be done on the computer. It can even be written into the IEP!

**Reference catalogs:** Pocket full of therapy (pfot.com), Abilitations.com

**I would love to hear from you. Send me your questions for the next newsletter; contact me, Sue, at [sgochman@optonline.net](mailto:sgochman@optonline.net)**

## 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](mailto: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 one less person to tease or respond negatively to someone else with TS tomorrow!

## THE CONTINUING SAGA OF SHOH

### PART 12

by Lisa Filippi

The saying about not being able to see the forest for the trees keeps popping up in my world these days, so I thought I might speak to this as it relates to my experiences with Shoh. In karate, one has to attack each single opponent fully in response to a multiple opponent attack, but maintain vigilance, remaining prepared to deal with each of the other opponents at any given time, in order to win the battle. In our daily lives, we must pay attention to the successful completion of individual steps in a larger task, in order to successfully meet the ultimate goal of the task. I suspect that getting stuck on the minutiae (the trees), and being unable to focus on the larger goal (the forest) is a common issue with many of our members, especially those with comorbid OCD. Each 'tree' presents a new obstacle that they simply can't get past, or even see beyond, until they are satisfied, and 'satisfied' to them can be totally unreasonable or even ridiculous to everyone else watching. They are unable to see that the trees together make up a forest, which has a whole life and purpose separate from the individual trees. And quite frankly, the forest may not be nearly as important to them as each of the trees. Shoh encounters trees and forests many times a day (frustrating me, his teachers and his aids!), but the forest that I find most troubling is getting ready for school *in time to meet the bus*. Ring a bell, anyone?

First, even with the dog enthusiastically doing his part to cooperate by jumping on Shoh's bed, licking his face and carrying on like he has found a treasure, he still won't get up. He goes to bed at 8:30, so, lack of sleep is not the problem. I suspect that, on top of not feeling terribly enthusiastic about going to school, the medications he takes at night make it harder for him to wake up. So, we finally get him out of bed after 45 minutes of effort. However, even after he is up, he cannot move forward to get through his morning rituals. He takes forever to get into the bathroom, and then he never comes out, stuck on thoughts of something that he can't let go of, or else just zoning out.

Then we move into the kitchen where he dresses (strange place to dress, I know, but otherwise I can't be guiding him while I finish getting lunch and snack ready, and he will go

back to bed). But *first* he has to stare at the clothes for 15 minutes. Even when I put a clock on the table in front of his face, he cannot motivate himself to 'rush'. In fact, it seems that another comorbid issue of my son's version of TS is that the word 'rush' simply cannot be understood; the concept permanently remains alien, and the word just can't become a part of his vocabulary. Maybe the other words in his head just keep chasing it away at the memory gate? At any rate, once the clothes are on, he then just sits at the table staring at his breakfast, or at nothing at all, and again can't move forward. He forgets that the goal is to get ready for school *before* the bus comes, and somehow seems to think that everything starts *when* the bus comes. So, getting up earlier *doesn't* work in our house. He still can't kick into drive until the bus comes. Even if I put a clock in front of him, so that he can see the time passing by as he sits doing nothing; it just doesn't sink in.

Then, once he begins eating, he examines each morsel for imperfections, eating in his fussy, time-consuming, idiosyncratic way, and again cannot consider the time. He eats so very slowly, and as I watch, I grow increasingly agitated because I know that once again, he will not be done before the bus arrives, and will have a hissy fit if I tell him to leave the food and go. Only *then* does he start to direct the food to his mouth in a purposeful way. He simply cannot see the whole picture of a morning routine, and instead labors over each individual task, not thinking about what remains to be done before the bus comes. What can a parent do in this situation? Well, I feel like saying, "I haven't got a clue," but, that would indicate defeat, and I won't have that! So I came up with a tentative plan: I finish all of the breakfast and lunch preparations *before* I wake him up, and, while getting him up and through the changing into clothes phases is still a struggle, I find that at least if we sit down together to eat, he gets through the eating phase a good bit quicker than if left on his own. At least this morning the bus only waited for two minutes, instead of five. Now, if we could get the tooth brushing phase to actually happen every day within that time frame, I would be satisfied ... too often it doesn't happen at all!



### We're going to the movies!!

Is going to the movies something of a challenge for your family because of those darn annoying tics? Well, LI-TSA is planning to arrange for a theater for a night, just for us! Popcorn and all. Sound like fun? We will post the information on our website as soon as it is confirmed, so please check the website for details about this upcoming event (hopefully in April!) and others, as well!

**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

### 2008 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 July of 2009 will meet on the following Fridays: March 6, April 3, May 1, June 5 and July 3

## Chapter General Meeting Friday, March 20, 2009 • 7:30-9 p.m.

Psychologist guest speaker to be announced; in addition, researchers studying TS will come to explain their work and seek out families to participate in their studies. *Come hear how you can help find a treatment/cure for TS!*

DeMatteis Center, 101 Northern Blvd., Greenvale, NY 11548



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### Bowling Social, Saturday, February 28 • 3-5 p.m.

See page 3 for more information.

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### We're going to the movies!

See page 7 for more information.



**THE LONG ISLAND CHAPTER OF THE  
TOURETTE SYNDROME ASSOCIATION  
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