



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

P.O. Box 615  
Jericho, NY 11753

Volume 1

Number 3

September 2005

## PRESIDENT'S MESSAGE

Message From the Chair

Hello to All Our Wonderful Members!

I hope that all of our families are having a smooth transition into the new school year. Transitions from a less structured, fun-filled summer to the rigorous back-to-school lifestyle can be difficult for many TS children. I hope that you will contact us with any problems that you may have as the school year gets underway. Please be aware that someone from our highly qualified and well-received Advocacy Committee can visit your school and speak with teachers, counselors, etc. if there is a need, and your school may also request an in-service presentation on Tourette.

As you read through the newsletter, you will see that we have a very busy fall calendar planned, so mark your home calendars to be sure not to miss anything. We are delighted to be having Susan Conners visit Long Island again, in October. Also in October, we will have a fundraising event at Bloomingdale's, that will help our chapter and get you off to a great start with holiday shopping. In November, we will have a special viewing of the long-awaited HBO documentary, "I have Tourette's, but Tourette's doesn't have me," with a discussion panel afterwards. The Board is working hard to make all of these events happen, and we can always use volunteers, especially with the Bloomingdale's event. I will be contacting all of our members to say hello, and to see who can help us out.

I also suggest that every member who has a child in school make a special announcement at their school (send a flyer or note through the principal's or school psychologist's office), inviting school personnel to attend the Susan Conners and HBO documentary events. Teachers and other school personnel that regularly interact with TS children have expressed to us their deep appreciation for the opportunity to attend these talks, and often tell us how much their relationship with our children benefits from their having heard Susan speak. I am sure that the HBO documentary will have the same positive impact on our children's school experiences.

Another bit of exciting news is that we finally got our website back in service, and are making modifications as we move forward. Look for this announcement and the website address inside the newsletter.

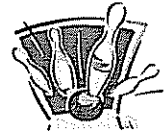
I hope to see all of you at the upcoming events, and will hopefully be speaking with many of you before then. As always, we are here for you, so contact us and tell us what you need. And, please let us know if you would be willing to help out on any of our standing committees (Advocacy, Newsletter, Fundraising, Events). It is a great way to get involved and feel part of the LI-TSA family.

Best wishes to you all,

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

## LI-TSA June Bowling Event for Tourette Awareness Month

On June 11th, LI-TSA held a Bowling Event at the AMF Syosset Bowling Alley in honor of Tourette Syndrome Awareness Month. It was great fun; we had raffle prizes and pizza, and Herbs by Nature sold a delicious variety of herbs and seasonings at the Bowling Alley. We used the opportunity to promote awareness by handing out some brochures and chatting with people from other bowling groups. This was a great trial run and learning experience, but next year we hope that by holding the event not so close to the end of the school year we will be able to attract many more members and their families and friends. Check out our pictures of the event on page 5.



Thanks to Trader Joe's, Plainview Store, for kindly allowing us to publicize our cause and fundraise in your store.

Thanks to Mr. Eric Zwilling and The Community Service Learning Class at The Jericho Middle School, for your remarkable efforts to promote awareness about TS by selling the TSA bracelets at your school.

### Acknowledgments

We wish to thank AMF Syosset for their generous discount, and the following establishments for kindly donating raffle prizes:

*Spa Adriana* (beauty salon and spa), Huntington Village  
*Scissors Salon and Day Spa*, Syosset  
*Vine & Roses*, Huntington Village  
*Ariana Restaurant & Café*, Huntington Village  
*Huntington Business Products*, Huntington Village  
*Village Flowers*, Huntington Village  
*EMagine Toys*, Syosset  
*Spencer and Traci's Boutique*, Woodbury  
*Discovery Toys*, Huntington  
*Herbs by Nature*, Huntington  
*M.J.Bean Toys*, Plainview

## CALENDAR OF EVENTS

### FREE PARENT SUPPORT GROUP for members of the Long Island Chapter of TOURETTE SYNDROME ASSOCIATION

Monthly meetings are held at:

**Western Suffolk Psychological Services, 755 New York Avenue, Suite 200, Huntington, NY 11743**  
(Directions below)

This group is ongoing, with new attendees always welcome. (TSA Membership Forms are available at the meetings). Meeting time is 8:00 - 9:30 p.m. and upcoming meeting dates are as follows:

Friday, October 7, 2005

Friday, November 11, 2005

Friday, December 2, 2005

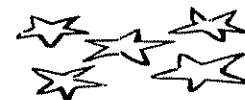
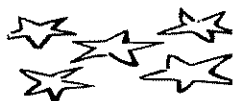
Friday, January 6, 2006

Facilitator: Sue Vitek, L.C.S.W.  
(631) 271-2999

Directions: Western Suffolk Psychological Services at 755 New York Avenue, Huntington, NY. From the east or west, take the Long Island Expressway (I-495) to Exit 49N or the Northern State Parkway to Exit 40N. Proceed north on Route 110 past Jericho Turnpike (Route 25) (Route 110 turns into New York Avenue past Jericho Turnpike). Travel approximately 2.5 miles. We are located one block north of the Big H Shopping Center on the left side of the street. Use the rear (main) parking lot and entrance.

### BACK BY POPULAR DEMAND

### SUSAN CONNERS



Susan Connors, Education Specialist from the National Tourette Syndrome Association, herself a retired teacher who also has Tourette Syndrome, will be speaking at the Reckson Building, 6900 Jericho Turnpike, Syosset on Wednesday, October 26th from 7:30-9:30. Don't miss this opportunity to hear Susan, who through humor and relating to personal experiences, speaks from the heart about the real problems that TS kids have to deal with. She has a wealth of information and creative ideas on how to help TS children and educators have a better school experience. For more information, please email Lisa Filipi at [filnoma2@optonline.net](mailto:filnoma2@optonline.net).



### \*\*\*\*\*HBO SPECIAL\*\*\*\*\*



COME SEE AN ADVANCE SCREENING OF  
"I HAVE TOURETTE, BUT TOURETTE DOESN'T HAVE ME"

LI-TSA will be showing a pre-screening of this new documentary on Wednesday, November 9th from 7:30 to 9:30 to be held at the Reckson Building, 6900 Jericho Turnpike, Syosset. A thoughtful discussion will be held afterward when you will have the opportunity to ask questions from those who have TS, and those who live with it in their families.

#### Directions to Reckson Building.

**From the West:** LIE East to exit 41N (Rt. 106/107). Take to Rt. 25 East (Jericho Tpke. bearing right past the Milleridge Inn) Once on Jericho Tpke. watch for Michael Drive which is the fourth traffic light (you'll see a Chase Manhattan Bank on the corner). Keep going on Jericho Tpke. and make your first right onto the North Shore Atrium parking lot. 6800 is the two story building set back from the road and 6900 is the four story building adjacent to Jericho Tpke. GO TO 6900. Enter the building from the rear. The Theatre Room is on the ground level.

**From the East:** LIE West to Seaford Oyster Bay Expressway North (135). Follow to end - Jericho Tpke. West. Follow past Syosset Hospital (on your right) past Home Depot. Go under railroad bridge then down hill. first office building on the left (4 story) past Caracalla Restaurant.

## Mom, I Wish I Had Been Born Knowing Everything I Need To Know (The School Experience)

by: Sue Vitek, CSW

This title is a quote which I heard frequently. As the mother of a now grown son with TS+, I am familiar with the gut wrenching feeling caused by a hard day at school. Parents share the hurt and frustration encountered by their children and, of course, want to FIX THINGS. How desperately we wish we could control events, so that our children do not suffer! If only we could prevent humiliation and sadness. I believe any parent would join in that wish, but unfortunately, struggles cannot be avoided.

As a retired teacher, I am in the position of seeing multiple angles of school issues. I'd like to take a stab at offering some thoughts about the potential for team work in the school setting. Please remember that my premise is that we cannot remove all negative experiences in school, or in any other aspect of our children's lives. However, a sensitivity to all views can raise the odds in favor of students.

Benefits are gained from relating to others' perspectives. Once, I remember receiving from a mother, on the first day of school, a brief written introduction to her TS child. Not only did this provide helpful information, it also immediately opened lines of communication. Early in my teaching career, a week or so into the new term, a parent wrote a note, telling me her child had ADHD, and included a short article about the disorder. These approaches went a long way toward creating a partnership.

In contrast, it feels very different if a parent assumes that a teacher has previously read and absorbed the records of all his/her new students, or expects a teacher to know just what approaches do or do not work with a particular child, based on a diagnosis the child has received. Instead, overtures like the two described above, indicate a parent's awareness that the teacher may or may not know about a disorder, and, in addition, a wish to share information in a helpful way. A positive beginning is desirable for all.

When possible, it is wise to schedule a fall meeting of parents (and/or the student's therapist) and as many of the student's teachers as can be arranged. A common understanding can thus be established. An initial agreement about realistic goals can forestall later confusion. (Provision for such a gathering might be included in an IEP or 504 Plan.)

Another suggestion is to set up a format which facilitates an ongoing exchange of information between parent and teacher. A mutually agreed upon plan for regular contact should be put in place as early in the year as possible. A brief note back and forth, on a daily or weekly basis, might be established. For example, every Thursday, the teacher would know to look for a sentence or two from Mom or Dad written in a spiral assignment book, which always stays fastened in the rings of the loose leaf. Thursday afternoon parents would know to

look for a short response from the special education, inclusion, or regular teacher. Such a system could prevent minor problems from growing into major ones, and equally as important, it removes negativity as the cause for parent-teacher notes. Frequently, a note from the teacher is seen as bad news by both the child and the parent. (For older students, the guidance counselor could act as the conduit for weekly or biweekly phone contact between parent and teacher(s).)

Even under the best of circumstances, academic study includes pressure. Teachers feel the demands of the changing curriculum and the required NY State Tests. Parents deal with the expectations of the school to make sure their children are present and prepared each day. Youngsters are recipients of pressure from both parents and school, not to mention all the normal "growing pains." If any type of learning difference and/or behavior difference is added to the mix, a young person's life can be overwhelming.

Therefore, it must be the role of parent(s) and teacher(s) and other school personnel to strike a balance, in the best interests of the child. If learning is to occur, the child needs to put forth effort. Teachers need to keep in mind, however, that a peaceful home is a priority, and that parents may not be able to insist that all assignments be completed at home, especially if their number is increased because work not finished in school is sent home. Similarly, parents need to remember that if a student is "excused" from completing work, there are apt to be gaps in learning. It is a responsible teacher who worries about these gaps and tries to keep them to a minimum. The adults must be careful to avoid a power struggle, in which the child is caught in the middle. This is another reason why ongoing communication is wise.

However, open lines of communication which are argumentative are counter-productive. There is no place in this picture for blame. When things are not going well, impatience most assuredly will not make them better. On the contrary, patience is a requirement because for our children, progress often will be slower than we (or they!) would like. Problem-solving is an important skill which can be modeled for students and through their involvement, can become a learning opportunity.

It should be a given that people do the best they can, yet mistakes will occur because perfection is an unrealistic goal. Parents, students and teachers should make every effort to deal with each day cooperatively, always keeping the focus forward. There needs to be mutual respect among all concerned parties.

Appropriately, the school's goal is education. Another important goal is for youngsters not to perceive education as a negative experience. Student effort is necessary and all effort must be acknowledged, or motivation

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## The Continuing Saga of Shoh in Saga (Japan)

by: Lisa Filipi, Ph.D.

Last time I spoke of Shoh as a newborn. In this episode I will discuss some of his issues through the age of three.

As soon as he got big enough to hold things in his tiny hands, he decided he didn't like holding things. He preferred throwing them. Rice bowls, coffee mugs, etc., literally became flying saucers. The dishes and cups we went through reduced after meal dishwashing time considerably. Even when we gave him plastic, he went for everyone else's place settings. I guess he liked the crashing sound; perhaps he could relate to it? Anyway, this behavior was attributed to "attention-getting" displays. We did have three older children, "Littles", I like to call them, but, I assure you, the littlest Little was already getting ALL of the attention, and the bigger Littles, in fact, were being neglected. Nevertheless, human beings can come to consider almost any situation "normal", and so we got so used to Shoh's antics in our family, that we forgot how unusual he was until relatives in America commented on it. My twin sister was particularly put off when one and a half year old Shoh took down a side table, along with the vase that was sitting on it, a prized wedding gift was returned to sand. She was convinced he was possessed by the devil.

Shoh was not without his charms, and so we decided to keep him. He was terrific at gesturing and miming; it became his very appealing and creative way of communicating. Shoh could communicate brilliantly the video he wanted to watch by acting out a very brief scene that captured an essence we could identify immediately. He was still so young (two, three), that we again failed to associate it with a neurobiological issue, in this case causing a language delay; just a preference, even a talent, it seemed.

The teachers at his day care center mentioned that they thought his learning both Japanese and English might be hindering him, but I, in my infinite wisdom, claimed otherwise, on the basis that my older three children had had no problems with language, despite having had constant exposure to both at home; in fact, they excelled in Japanese.

Nevertheless, something was odd, at least. He would categorize his vocabulary, and use words sparingly. For example he knew the names of each fruit when asked

to choose from among several, but seemed to have trouble retrieving the specific names from his head. Equipped with great problem solving and compensation skills, Shoh effectively simplified the number of words he had to retrieve by putting things into categories, and calling all things in each category by the one he liked best: Drinks were all called "juice"; all of our four cats were called "Cairo", fruits were all called "mikan" (Japanese for tangerine); all colors were "red". Thus, for a time, we suspected that he might be lazy and color-blind.

More on this exciting age bracket in the next issue!



### 2005 Mentoring Brunch

Join the NYC Chapter of TSA at the The Players Club in Gramercy Park, Manhattan and listen as five accomplished adults with Tourette Syndrome discuss their lives and careers and answer your questions. Enjoy a delicious brunch as well.

**WHEN:** Saturday, November 12, 2005

**WHERE:** The Players Club, 16 Gramercy Park South, (East 20th Street, between Park Avenue South & 3rd Avenue), Manhattan

**TIME:** 12 noon - 3:00 PM

**COST:** Free!

**RSVP:** 646-202-9683 or [chapter@tsa.nyc.org](mailto:chapter@tsa.nyc.org)



### COMPUTER WEBSITE

The Long Island Tourette's Association has a new website servicing Nassau and Suffolk Counties and can be accessed at [www.li-tsa.org](http://www.li-tsa.org). We urge everyone to take a look around and see all the information now available including web resources and books to read. We will be adding and updating information to the website as time goes on. If you have any suggestions or items you would like to see on the website please email Demetria at [dmarino5@optonline.net](mailto:dmarino5@optonline.net).



Managing the display table

Pictures from our recent bowling event

**EVERYONE HAVING FUN!!!!**



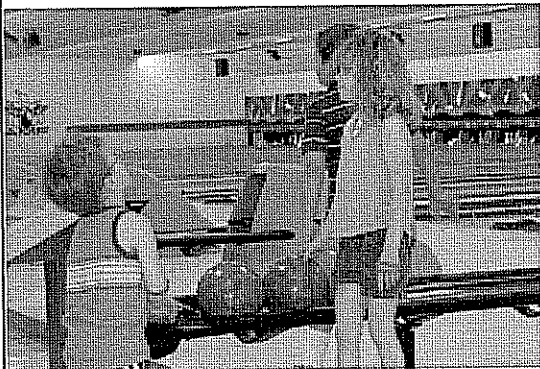
President Lisa Filippi and friends

**MARK YOUR CALENDARS**

Wednesday, October 26th - Night with Sue Conners

Thursday, October 27th - Holiday Shopping Day

Wednesday, November 9th - Pre-screening of HBO Special



What's my score? Yeah, I'm winning!!!

See page 2 for details on these events

Please be a spare, please be a spare.....!!



**YOUR SUPPORT CAN MAKE A DIFFERENCE  
JOIN US ON OCTOBER 27, 2005  
HELP MAKE OUR SHOPPING BENEFIT A SUCCESS!**

It's never too early to start your holiday shopping. Now you can save 15 to 20 percent at Bloomingdales and help the Tourette Syndrome Association continue to search for a cure and provide programs for people living with TS and their families.

National TSA and the TSA Long Island Chapter have joined together to participate in the Bloomingdales Shopping Benefit, scheduled for Thursday, October 27, 2005. The event benefits both the Chapter and National TSA.

The one-day event begins at 10 a.m. and ends at 10 p.m. The participating stores include the Roosevelt Field Bloomingdales and Furniture Gallery and the Walt Whitman Bloomingdales.

If you cannot shop on October 27th don't worry the pre-sale begins on October 20th and ends on October 26th. You can come into the store early and beat the crowds, then you will have seven days after October 27th to pick up your merchandise.

You can save money while helping TSA earn money by purchasing a ticket for \$10. TSA keeps all of your \$10 ticket donation, but we need you to also visit the store. On the day of the event, please come to the store and turn in the bottom stub, the top portion is for you to keep and use for all your purchases. Even if you do not spend a penny at Bloomingdales, the store will give TSA \$5 for your ticket stub. If we have more than 75 people come into the store, Bloomingdales will give us a split of funds raised by Bloomingdales, which is estimated to be between \$10,000 and \$20,000.

Your presence alone will earn TSA money. And if you shop you will receive at least 15 percent off virtually everything in the store, even sale items. The only exclusions are cosmetics and fragrances. Buy one ticket or buy tickets for your friends or family. If you own a business, reward your employees by purchasing a ticket for each employee.

Tickets can be purchased by credit card or check and the tickets will be mailed directly to you. For more information, please email Michelle Staley at michelle.staley@tsa-usa.org or call her directly at 718-224-2999 ext. 256 or you can email Sheila Kastner at sbk915@aol.com.

(cont. from page 3)

will be lost. Learning styles differ, and parents are the experts on their children, so they can shed light on strategies for teaching them. There is much potential for combining efforts to achieve the best possible results. Parents and school staff can work together toward making the school experience a flexible working arrangement in which progress can be maximized, while keeping vital self-esteem intact.

### Interesting Web Sites and Articles

Here are some websites and articles to check out. Hope its informative.

Gifted children with ADHD at [www.uniquelygifted.org](http://www.uniquelygifted.org)

Les mess organizing cards for kids at [lesismore.net](http://lesismore.net)

See the 151 Positive Characteristics of people with ADD at [www.addcoach4u.com/positivesofadd.html](http://www.addcoach4u.com/positivesofadd.html)

ADD Advice for Adults with ADHD at [health.groups.yahoo.com/group/ADD\\_Advice](http://health.groups.yahoo.com/group/ADD_Advice)

Advocating for Your Pre-school Child at [www.nclid.org/LDInfoZone/InfoZone\\_FactSheet\\_Advocate\\_Preschool.cfm](http://www.nclid.org/LDInfoZone/InfoZone_FactSheet_Advocate_Preschool.cfm)

Advocating for your School-Age Child at [www.nclid.org/LDInfoZone/InfoZone\\_FactSheet\\_Advocate\\_SchoolAged.cfm](http://www.nclid.org/LDInfoZone/InfoZone_FactSheet_Advocate_SchoolAged.cfm)

Being your own Advocate for Teens and Adults at [www.nclid.org/LDInfoZone/InfoZone\\_FactSheet\\_SelfAdvocacy\\_Teens.cfm](http://www.nclid.org/LDInfoZone/InfoZone_FactSheet_SelfAdvocacy_Teens.cfm)

Welcome to Success Consciousness Website - containing Articles, ebooks, guidance, quotes and ezine about self improvement, happiness, success and positive thinking at [www.successconsciousness.com/index.htm](http://www.successconsciousness.com/index.htm)



Don't forget our **Info-Hot 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.

#### Board Members

*Lisa Filippi, Chair*

*Jane Zwilling, Vice-Chair*

*Josephine Carini, Treasurer*

*Sheila Kastner, Chair-Fundraising*

*Jennifer Zwilling, Youth Ambassador*

*Demetria Marino, Secretary & Editor-In-Chief*



## Education and Advocacy Committee Update

As the 2005-2006 school year begins, the Education and Advocacy Committee is gearing back up for in-services for this school year. Several are already scheduled. However, as we plan to reach even more schools during the 2005-2006 school year we ask that if you, or anyone that you know, would like committee members to come into a school or support a parent and youngster please be in touch with us. We are especially interested in expanding our services in Suffolk County.

Additionally, Jen Zwilling, the Chair of our Student Advocacy Committee is still very busy with her efforts to bring awareness. In April 2006, at the TSA National Conference in Washington, DC Jen will be training youngsters from other TS Chapters to be Youth Ambassadors and to do presentations in their own communities.

We are hoping to see everyone at our October meeting when our Mentor Sue Connors will be addressing Long Island.

We also hope to see everyone at the HBO screening.

As always we will keep you up-dated! We ask that you please do the same. Please let us know how and where we can be of help. And.....we are still looking for members who are willing and available to help us in our efforts. Please contact us at 516-876-6947.

We hope to hear from you. Thank you,

**Jane Zwilling, Psy.D., Chair**  
Advocacy Committee

**Jen Zwilling, Chair**  
Student Advocacy Committee

#### PROFESSIONAL ADVISORY BOARD

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