



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

P.O. Box 615  
Jericho, NY 11753

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## PRESIDENT'S MESSAGE

Message From the Chair

Hello LITSA members! Allow me to introduce myself. My name is Lisa Filippi, and I am proud to be the new Chair of our Chapter, taking on the role after Arthur Zuckerman, who effectively pulled the chapter back together. We extend our heartfelt thanks to Arthur and Evelyn Zuckerman for their devotion to this Chapter, and for their faith in me.

I am the mother of four children, ranging in age from eight to 22. My eight year-old son Shoh, who you will gradually come to know by the stories I have and will continue to relate in our newsletter, has Tourette. In my second full time job, I work as a faculty member at Hofstra University, where I teach a variety of biology courses including Human Biology, Ecology, Evolution and Biodiversity, Animal Behavior, Science and Culture and the Biology of Stress (a topic on which I carry out ongoing and extensive personal research!).

We have a brilliant and eager Board of Directors, and each member has remarkable talents that will be great assets to our Chapter. Our Vice Chair and Co-chair of the Education/Advocacy committee, Jane Zwilling, has a Ph.D. in psychology, is a certified school psychologist and has a private practice. Jane has wide experience with the ins and outs of navigating the school system. Our Treasurer, Josephine Carini, brings her expertise as an experienced administrative assistant in the world of Finance. Our Board and General Meetings are held in the comfortable and conveniently located Reckson Building in Syosset, thanks to Josephine's husband, Joe, whose offices are also located there. Our Secretary and Editor-in-Chief of the Newsletter, Demetria Marino, works as an office manager of a law firm, and has expertise in preparing newsletters, and brochures, etc. Demetria is also finishing a degree in Political Science. The Chair of our Fundraising Committee, Sheila Kastner is working in public relations and is finishing her degree in Philanthropy, Fundraising and Development. Our youngest member is Jennifer Zwilling, who is our Youth Ambassador. Jen is really a star, and I have introduced her at length in a separate article in this newsletter (see page 3). We are all chomping at the bit, and raring to go, a talented and great group of people.

In mid-April, I had the exhilarating experience of attending my first Chapter leadership meeting in Washington, D.C. We had a trip to the Hill (Capitol Hill, that is), where we each went to speak with local representatives and senators from our states about the issues children and adults with TS deal with on a daily basis; we discussed legislation we hope they will support that could greatly benefit people with TS in many aspects of their lives. I felt like I was contributing to the business of government, and the sense of empowerment that left me with was profound. We can't complain if we are not willing to act; I acted, with fervor, and I feel it will make a small difference.

By meeting and exchanging thoughts and experiences with representatives from many other chapters, I came home with lots of ideas for activities and events that I am sure we could easily arrange for our chapter, as well. Let's go for it!

I also learned a lot about the status quo in other states, and realized how lucky we are here in N.Y. Schools will work with kids if they have the information they need, and our remarkable and energetic Education/Advocacy Committee of two has been doing a heroic job of going into schools and doing presentations that are well-received and contribute significantly to the schools' understanding of the issues involved with TS. They are making a BIG difference here on Long Island, particularly in Nassau County, and need help to be able to do the same in Suffolk County. Please find out how you can help.

We have a lot to do to get this chapter active again, and we can only do it with commitment and volunteerism from chapter members. We want to provide services for our members, but the Board members can not do everything alone, so I would like to ask those of you who were active before, as well as those of you who may never have been active, to step up to the plate now, and contribute to the success of our chapter. Many members perhaps lose interest in actively participating in our organization once their needs have been met, and they are no longer in a difficult time. However, you are all probably aware that the symptoms of TS wax and wane naturally, and as children develop the difficulties they experience will constantly change. One can never be free of TS, and the member who remains an active participant in our chapter will always be in a position of empowerment and readiness should difficult times come again.

We already have a facilitated parent support group once a month (see calendar of events), and are considering having a facilitated children's social skills/support group. These are free services to members. If you would like your child to have such services, please let us know and we will make it happen. If there is widespread interest, perhaps we can arrange to have the parent support group and the children's group on the same night, and that would increase attendance at both meetings. Please tell us of your needs.

We would like to have socials a few times a year, perhaps a bowling league or something similar, fishing trips, hikes in the woods, hopefully in a few age groups, and for adults. In order to arrange these, we need people of like mind who are willing to volunteer a bit of time to help organize them. Please offer to help.

We have a paid membership in excess of 200; let us hear from you. Be an active participant in your chapter. Be involved, and feel the energy. Work with us, and you will see how your chapter can work for you. I look forward to hearing from each and every one of you.

Lisa Filippi, Ph.D.

Chair, LITSA - Filinoma2@optonline.net

## 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, June 3, 2005

Summer Break - start up Fall, 2005

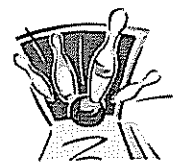
Facilitator: Sue Vitek, L.C.S.W.

(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.

### UPCOMING EVENT

### BOWLING FOR AWARENESS MONTH!



In recognition of Tourette Syndrome Awareness Month, LITSA will hold a bowling event at the AMF Syosset Bowling Center (111 Eileen Way, Syosset - just off Jericho Turnpike) on Saturday, June 11th from 11:00 a.m. to 1:00 p.m. Discovery Toys and E-magine Toys will supply raffle prizes, and Discovery Toys will also have a booth selling their innovative toys. A percentage of their profits will be donated to the LI chapter of Tourette. Parents are encouraged to accompany their children and all are welcome. To further enhance awareness, children are encouraged to find sponsors who will donate funds as they see fit for the child's two hours of bowling. For raffle tickets and further information, please contact Lisa at 516-496-0793. Look forward to seeing everyone there!



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.

## Introducing the LITSA Youth Ambassador

I am very pleased and proud to introduce our newest asset and member of the board, Jennifer Zwilling, who, through her great efforts to aid the mission of LITSA, has earned the prestigious title of Youth Ambassador. This remarkable young lady is the 14 year-old daughter of our Vice Chair, Jane Zwilling. Jennifer is still but a freshman in high school, and yet her academic and civic achievements at this early stage in her life are outstanding, and speak highly to her future as a young woman of great and special promise.

Jennifer displays an invaluable trait that is uncommon in a youth of her young age. She has a drive to be involved and make an important difference in the lives of others. During the past three years, Jennifer has volunteered hundreds of hours of her time to both the National and Long Island Chapters of TSA. Her mission has been to educate peers about Tourette Syndrome.

Jennifer and her sister, Amanda, have initiated a peer education program that is sanctioned by the National Tourette Syndrome Association. Jen and Amanda go into schools to speak to children about Tourette Syndrome, and the need for children to be accepting of all types of individual differences. Jen came up with this idea after observing an in-service for teachers on Tourette. She immediately recognized that in order to minimize the teasing and ostracizing experienced by children with Tourette, not only the teachers but also the classmates of children living with Tourette needed to be educated about the true nature of the disorder.

Jen has already been to a number of schools both here on Long Island and in Westchester, and has even been invited to schools as far away as Virginia. However, she feels very strongly that she wants to accomplish a major goal here at home, on Long Island. That goal is to enlighten her generation about Tourette; she hopes that lessening the stigma will result in a greater understanding and acceptance of people with this widely misunderstood disorder.

When Jen visits a school, not only do the students learn a great deal but the teachers and support staff at the schools also find the information to be invaluable. Even counselors and psychologists who believed they had a basic understanding of the disorder find they have learned much from her presentations. The feedback is always positive: Jennifer is a natural orator, and has a flair for getting her points across while captivating the student's and teacher's/staff's attention. The end result is always the same, a better understanding and acceptance of individual differences.

In April of 2004, Jen spoke at a Congressional briefing moderated by Margaret Bush. Jen has faith in our government, and hopes that Congress and the Senate will allocate funds to support the mission to educate teachers, students, doctors and the general population about Tourette.

Jennifer believes that even educating and helping one person at a time can lead to great progress. She was inspired by an eight year-old boy with Tourette Syndrome. The boy approached her after a visit to his school and said, "Thank you for coming here to make my life better." Isn't that what it is all about?

Another passion of Jennifer's is photography, and she spends many hours of her free time with camera in hand, expressing herself through this artistic avenue, as well. We at LITSA are both proud and thrilled to have her with us, and look forward to seeing how she will use all of her many talents to further support our mission.

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

## A Tourette Adventure: The Prequel

In our last newsletter, I wrote about the period just after our son's diagnosis. In this issue, I would like to tell you about our gem as a tot, the pre-TS diagnosed period. Looking back, I can easily hate myself for the aggravation and anger I felt at the time, but a deeper part of me knows that there was no way to really know that my son had diagnosable neurobiological issues, when modern society has come to focus so much on parenting effects on children. Our four children were all born in Japan, I had been living there for 15 years before Shoh was born, and so was not well informed of the newly established spectrum of children's neurobiological disabilities that had been emerging over the years.

He was number four for me, but the first child of my second husband, and it was difficult for him to understand at first that Shoh was truly .....hmmmmm, shall we say.....unusual? We are behavioral ecologists, and think in terms of normal ranges of variation in behavior that occur along a spectrum. When genes and/or the environment change, the expression of traits will change. There were many causes that could have contributed to his being different from the older three children. Along with new genetic input, the family structure was different. Dad was attentive and present, there were three much older siblings, the youngest of which was ten years older than Shoh, and the older three were each separated by two years. Thus, Shoh was almost an only child in terms of a family playmate who was close in age, possibly spoiled by having the equivalent of four or five adults present to pamper him, and that is a major difference. Finally, Mom, even though it was the same me, was really different, because I was working full time. I had been in Graduate School when the third child was still very little (they were all quite young), but it was not a full time job, and I was certainly a stay-home-mom when they were all babies.

Thus, my husband insisted that Shoh's constant screaming and inability to be calmed were within the "normal" range. I, a thrice experienced mom, however, suspected that something was amiss when he started screaming before his whole body had passed out of mine at his birth, and never stopped screaming for three months. The only difference between him and the rest of the kids at that point had been a pregnant and stressed working mom (but, never undermine the impact stress can have on a child in the womb) and the genes. He hadn't yet experienced the family structure "Some babies are criers," the doctor said. Do obstetricians ever do follow-ups on the babies they deliver, I wonder, especially the "criers"? Even his pediatrician was unconcerned. Shoh cried all day and all night, even when he was nursing; he rarely slept, and we had to hold him constantly to keep the volume of his crying reduced to a level

that would be less likely to drive the rest of us insane.

We were clearly housebound for a long while. He cried so much that we could not tolerate to be in the car with him, and so I couldn't even go to a grocery store. My mother also came to help out for three weeks. So, for a time, it was my husband, my mother, our tall 12 year-old son and myself taking turns holding, rocking and attempting to quell the storm. We could reduce his fury from an F-4 tornado to a bad hurricane, but still had no calm in the family. My mother was convinced something was very wrong, having raised four children herself, including my colicky older sister, and insisted we ignore the assurances of the obstetrician and pediatrician that all was fine and have him examined at a big hospital. Colic, we were told after a battery of tests of his physical state, very bad colic.

I felt awful that my mother's first visit to Japan would see her confined to our home, and decided to venture out on a motor trip to Arita, a town just an hour away that was very famous for its pottery. We strapped the wailing Shoh into his car seat, and set out. We nearly went mad with the incessant background roar (an MRI is less invasive), and had to stop every fifteen minutes, get him out of the seat and walk him a bit because we feared for his sanity. After my mother left, I just had to get to a grocery store every few days and so ventured out, knowing full well that the foreign woman with the wailing baby was likely to draw unwanted attention. You see, in Japan, a new baby is left at home alone, asleep, when mom has to run to the store, and is rarely seen out. Bringing a small baby out is considered selfish and imprudent. Having been raised in America, I simply refused to do that. The anticipated comments came, and when asked in a condescending tone whether we were late for naptime, I replied tersely that he wasn't sleepy, but that he just liked to cry. If they only knew!

Does this scenario sound familiar to anyone out there? I suspect it may not be too uncommon for families living with Tourette. To be sure, many people with Tourette have no symptoms other than motor and vocal tics, which can clearly be distressing, but for those of us lucky enough to be dealing with complex comorbid issues, the tics, even when they are fairly pronounced, can actually be a non-issue in light of all the other struggles. Stay tuned for the continuing saga of Shoh, from Saga (his birthplace in Japan) in our next newsletter.

**Lisa Filippi**

P.S. If anyone else would like to share stories like this about their TS loved ones, please feel free to submit them to our Editor in Chief @dmarino5@optonline! We can't have Shoh hogging the limelight!

## Education and Advocacy Committee Update

As the 2004-2005 school year is coming to an end, the Education and Advocacy Committee is winding down on in-services for this school year. However, we are already in the planning stages for reaching even more schools in the coming 2005-2006 school year. 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.

Additionally, Jen Zwilling, the Chair of our Student Advocacy Committee is still very busy with her efforts to bring awareness. In March, Jen traveled to Washington DC with 4 other National TS Youth Ambassadors and spoke to Senators, Congressman and their staffers both individually and at a Congressional Briefing on Capitol Hill moderated by Margaret Bush. The Youth Ambassadors were very well received by a most supportive and encouraging audience. Jen asked the group to include TS under OHI (Other Health Impaired) in the IDEA (Individuals with Disabilities Education Act) and to continue supporting TSA by providing funding to educate physicians, school faculties and the general public. Congresswomen Nita Lowey told Jen to keep coming back and to keep on speaking up because the staffers and the Senators and Congressmen really do listen when people come and speak.

Jen has a full calendar this month as well. Jen will be speaking in Westchester (they tend to borrow her from Long Island sometimes) twice in May. She will be visiting a school and speaking at their Health Fair. She is also going to be a panel member at City Hall in Mt. Vernon where she will be reaching out to community leaders to educate them.

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,

**Bernadette Smilovic**

**Jane Zwilling, Psy.D.**

Co-Chairs

Advocacy Committee

## **Board Members**

*Lisa Filippi, Chair*

*Jane Zwilling, Vice-Chair*

*Bernadette Smilovic, Co-Chair*

*Josephine Carini, Treasurer*

*Sheila Kastner, Chair-Fundraising*

*Jennifer Zwilling, Youth Ambassador*

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



## THE SPECIAL EDUCATION MUCKRAKER

Folks - The NYS Education Department is going to "audit" how NYS school districts, BOCES and State-approved private schools spend IDEA money! They're only doing so under very, very serious federal pressure, but . . . every little bit helps. And whether they do it well is something only time will tell. But . . . for starters . . .

The NYS Ed. Dept.'s Audit Office just put, for the first time, a place on its web site for people to report fraud, waste and abuse. The Special Education Muckrakers think you should take advantage of this new and exciting option. What are the kinds of things you can report to the NYS Education Department's Audit Office? The list is almost unlimited. Think Roslyn. Think "no show" employees and administrators. Think special ed funds being spent for non-special ed things. What are the kinds of things you can report regarding IDEA (special education)?

### **Waste:**

Schools, districts and BOCES (including the NYC DOE's District 75) using programs and methodologies of remediation and instruction for kids w/disabilities which are not research-validated and which are ineffective.

### **Fraud:**

Schools, districts and BOCES not providing related services as per students' IEP's.

Schools, districts and BOCES billing Medicaid for related services on kids' IEP's which were not really provided.

Schools, districts and BOCES writing up "evaluation" reports although no evaluations were really done.

Schools, districts and BOCES - and CSE's - creating phony IEP paperwork to show that there were CSE meetings when there really were no CSE meetings.

Folks forging signatures on IEP's.

Schools, districts and BOCES billing Medicaid for "targeted case management" services, including monthly contacts with parents to help them access more Medicaid services their kids may need.

Schools, districts and BOCES not reporting kids who dropped out or were pushed out of school and then keeping the kids on their enrollment lists so they can get State and federal money for them although they're not really attending school.

### **Abuse:**

Schools, districts and BOCES using time out rooms based on building-wide behavior/time out room policies instead of doing individual FBA's and BIP's which parents have been involved in developing, and to which parents have specifically agreed in advance.

VESID Regional Associates pretending to investigate parents' complaints when, in fact, they've just taken school folks' words as to what really went on.

The list of things you can file a complaint about is just too long to put in one article.

If you'd like, you can e-mail a copy of your complaint to NYSED's Audit Office regarding fraud, waste or abuse, and especially IDEA-related fraud, waste or abuse, to The Special Education Muckrakers, at: [editor@specialeducationmuckraker.com](mailto:editor@specialeducationmuckraker.com). We'll keep everything completely confidential and try to follow up to make sure that your fraud, waste or abuse complaint is handled properly.

Submit your fraud, waste or abuse complaints to:

Email: [oas@mail.nysed.gov](mailto:oas@mail.nysed.gov)

Fax: (518) 473-0259

Phone: (518) 473-4516

Write to: New York State Education Department

Office of Audit Services

89 Washington Avenue

Room 524 EB

Albany, NY 12242

Dee Alpert, Publisher

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