



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

P.O. Box 615
Jericho, NY 11753

Volume 1

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January-February 2005

PRESIDENT'S MESSAGE

Happy New Year! We hope that 2005 brings you health, wealth and happiness and, maybe, a cure for Tourette Syndrome.

Last year was an exciting one for our chapter. The Long Island Chapter, was once the very first of National's regional affiliates. We were involved in everything Tourette – and then we weren't. In 2004, we returned to the position of servicing our membership.

We presented weekly workshops to the staff at many Long Island Schools, educating them on how best to work with our kids. We have seven in-services alone scheduled for the month of January. Fantastic!

In 2004, our chapter experienced a marked increase in adult support group attendance. On the first Friday night of the month, we get together and talk about our experiences, our issues and our feelings. Everyone feels better afterwards.

We have developed a hotline that constantly works to deliver referrals and answers to callers in need. Thirty years of Tourette experience. All for the asking.

We look forward to 2005 with great excitement! This will be an important year for us. Our group of volunteers has worked feverishly, just to inch our way to grow this chapter – and we did it well!

We need you: join our newsletter committee, our school advocacy committee, our social event committee or any other committee that fits. Make us an offer.

We're on the move. Please join us.

Sincerely,
Arthur Zuckerman
President

This is the first Newsletter from the Long Island Chapter in a long while. We hope that it will help those who are dealing with Tourette Syndrome (TS) on a daily basis, either as a sufferer of TS or a parent of a TS child. The newsletter will contain a message from our President, articles from individuals within our organization, as well as a calendar of upcoming meetings/workshops and events that are open to all. Please feel free to join us in making this **your** Newsletter. To do so we need volunteers to help write articles or give suggestions. You can submit them directly to Demetria Marino at dmarino5@optonline.net or call her at 516-679-8055.

We are in need of volunteers who are interested in helping us out. Join our Social Events Committee, Fundraising Committee, or any other committee. We need your help to keep this Chapter running. If interested, please contact us at the address or phone number below. Please help us out!

LONG ISLAND CHAPTER OF TOURETTE SYNDROME ASSOCIATION

P.O. Box 615
Jericho, NY 11753

516-876-6947

Board Members

Arthur Zuckerman, President
Bernadette Smilovic, Vice President
Jane Zwilling, Vice President
Josephine Carini, Treasurer
Lisa Filippi, Secretary
Demetria Marino, Editor-In-Chief

CALENDAR OF EVENTS

KIDS GROUP NOW FORMING

Support/Education Group for Young People Ages 10-12 who have been diagnosed with ADD, Tourette Syndrome, Obsessive Compulsive Disorder, Asperger's...

Seven Sessions - Mondays from 5:00 - 6:30 p.m. held at Western Suffolk Psychological Services; 755 New York Avenue, Suite 200, Huntington, NY 11743

Group begins Monday, January 31st
The cost per session is \$35.00

For further information, contact facilitator; Sue Vitek MA, MSW, LCSW-R - at (631) 271-2999

PARENT SUPPORT GROUP MEETINGS

This group is intended to assist parents with understanding and handling the situations presented by children who have TS, ADD, ADHD, OCD, or PDD.

This is an open group. Please feel free to join us anytime. Meetings are free and are held at Western Suffolk Psychological Services, 755 New York Avenue, Suite 200, Huntington, NY 11743

Meetings held on Friday evenings at 7:30 to 9:00 p.m.

Upcoming Dates are:

- February 11
- March 11
- April 15
- May 13
- June 10

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

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, February 4th
- Friday, March 4th

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 SEPTA Meeting

When: February 9, 2005

Time: 8:00 p.m.

Where: Southwoods Junior HS (in Library), 99 Pell Lane, Syosset, NY

Speaker: Susan Connors



Come see Susan Connors, a long time leader with the National Tourettes Syndrome Association and a TS sufferer herself speak about her work within the Syosset School District and SEPTA. It will be an interesting night for all.

Directions: Take Seaford Oyster Bay North to end. Take Jericho Turnpike East (25E) toward Woodbury. Turn right onto Jericho Turnpike and go about 3/4 of mile and turn left onto Southwoods Road. Go 1.3 miles and then turn left onto Chelsea Drive. Go .3 miles and then turn left onto Wilshire Drive and then left onto Pell Lane. You will see Southwood Junior HS.



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.

Education and Advocacy Committee Update

The Education and Advocacy Committee is currently being Co-Chaired by Bernadette Smilovic and Jane Zwilling, Psy.D. Additionally, Jen Zwilling is Chairing the Student Advocacy Committee.

As a follow-up to the November 2004 Long Island Educators' Conference conducted by National, the Long Island Chapter completed their long awaited mailing to all the school districts in Nassau County. This was to inform the school districts of our existence and our role.

The Committee is dedicated to presenting in-service workshops for school staff and faculties and is also available for consultations to school personnel and to parents.

There was an overwhelming positive response to the mailing and as a result many in-services are currently being presented and scheduled.

Additionally, the committee has been responding to parents' requests for information and is helping parents to advocate for their children at IEP and other team meetings at schools.

Jen Zwilling and Amanda Zwilling have designed a peer presentation and have been traveling not only to schools on Long Island, but to other states as well. Their mission is to educate peers and to help children with TS learn to advocate for themselves. The program has been approved by National and there are plans to train other teens. We will keep you up-dated!

If any one is interested in being trained to be an advocate and is willing to, or able to, be available to present at school districts, please contact us at 516-876-6947.

We hope to hear from you soon.

Thank you,
Bernadette Smilovic
Jane Zwilling, Psy.D.
Co-Chairs
Advocacy Committee

NEXT GENERAL MEETING

The next General Meeting of the Long Island Chapter of TS will be held on February 16th from 8:00 p.m. to 9:30 p.m. at 6900 Jericho Turnpike, Syosset, NY (West of Seaford Oyster Bay) in the offices of Sagemark Consulting - one flight up. As this is a rebirth of the LI Chapter and we are just at the starting gate, we wish to invite everyone to come down to this meeting. Meet other members, ask questions, help us out, speak out or just get general information on TS. Children young and old are also invited. We will be hosting a small "get together" for them to meet and play some games. See you there!

The Start of a Tourette Adventure

by: Lisi Filippi

My husband and I first suspected that our eight year-old son, Shoh, had Tourette Syndrome (TS) after a search on the internet about various tic disorders. Then, all the pieces of the enigmatic puzzle that had characterized Shoh since his birth began to fall into place. Although we are both biologists by profession, we failed to make a connection between the vocal and motor tics we had been noticing for the past year, and the intense and impulsive behavioral issues he had been displaying from birth, his delayed language skills, and his poor memory and recall ability. In fact, when we first brought him to a neurologist with our suspicions of TS, we were given a list of eleven co-morbid factors that may be associated with the disorder. As we scanned the list, we were stunned to note that our son presented with ten of the eleven! We consoled ourselves by noting that at least the last issue on the list, sleep problems, had not been problematic for us since he was two. Hah! From that night on, Shoh awoke like clockwork at 2:00 am, wide-eyed and bushy-tailed, ready to start the day. It usually took until 5:00 to get him back to sleep, at which time I had to get up; that very fun period thankfully resolved itself after about five months. So, until now, the tics, while noticeable, have not caused as much concern as the troublesome co-morbid issues.

However, the tics are changing of late, as will happen with TS, and are causing Shoh much concern, not because he is self-conscious about them, but because of their disruptive effect on his activities. Now that he can articulate his feelings with us, in amazing detail, he talks about "good" and "bad" tics. The good tics are cute little twirls, hops, mild facial contortions, sounds, etc. The "bad" tics cause him great frustration because they interfere with his tasks, both at school (he will scribble on an assignment he had just put great effort into) and at play (he will feel compelled to continually knock over the pieces of a game he is trying to play). Of course these self-defeating acts cause him great frustration, and make it hard for him to stay on task. The harder he tries to control himself, the worse the tic gets, until he just gives up. Although it is heartbreaking to see our son fighting with himself during these episodes, we can only make him feel loved, good tics and bad, and try to help him recognize the patterns and figure out practical ways to deal with them together. I suspect that we, like all families dealing with TS, are on a life-long journey that will be an adventure, because one can not quite anticipate what will come up next, but must always be prepared. Like all adventures, we know that flexibility and adaptability will be critical to management of our son's Tourette's. And, we are sure that with a loving, supportive and accepting family and school environment, this adventure will be a success story.



TEACHERS SHOULD KNOW ABOUT THIS BOOK . . .

QUIT IT

by Marcia Byalick

This book has been mentioned before in TSA newsletters, & I was excited when I first heard about it. Not only is the novel appealing and validating for youngsters with TS, but it is a valuable educational tool for non-TS folks as well. I wish it had been around before I retired from teaching sixth graders in middle school!

For years, trade books have been used in school reading programs. Titles are selected to blend the reading curriculum with that of other subject areas, or to familiarize students with topics of human interest. In my reading classes I have covered adoption, autism, dealing with a gravely ill relative, and even death of a classmate, among others. As the mom of a TS son, I am aware of a need for understanding, so you can be sure that if this book had been available, it would have been part of my curriculum!

I am even more aware of the need for education about TS now, however, since I've become a social worker, specializing in assisting TS sufferers and their families. This disorder, and Obsessive Compulsive Disorder, which often accompanies it, are much more common than most people realize. With increased research and knowledge, diagnoses can be made at early ages, which facilitates adjustment to living with a disorder. However, there is such concern about sharing the diagnosis with friends, the school staff, even relatives! If you can't share it, how can you adjust to it? The shame that is so often felt, becomes an additional difficulty.

This writer believes Quit It should be part of every intermediate reading program. Since everyone will encounter people with TS during their lives, familiarity with the impact the disorder has on its victims will be beneficial. Understanding leads to acceptance, and often someone who is "different" loses out on opportunities, which would have been available had their difference been commonly understood, rather than a source of curiosity.

Sue Vitek, L.C.S.W.