Volume 4 Number 4 Fall 2008

(X) Cousletter 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

Hello Good Folks.

Summer is over, and while the end to the relatively calm and carefree season is sad, this ending also brings with it the promise of a new and exciting year at school. I hope that all our parent members were able to get sufficiently recharged over the summer break, and that your children have started the new school year on a positive note!

Transitioning back to school after summer, and especially to a new school, can be very difficult challenges for our children. Please look inside for a very useful piece by our Treasurer/Government Relations Liaison, Rachel Gibbons, which provides some good ideas on how you can make a big difference in easing this transition, for both your child *and* the school personnel. Happy teachers and staff, who feel they are on top of their game and working effectively with your child will probably be reflected in a happier child.

The three simultaneous monthly support group meetings have resumed, and we look forward to seeing you there. Everyone seems to get recharged at these sessions, and, in particular, parents of newly diagnosed children really seem to go home feeling so much more positive about the future than when they arrived. We are there to help, so please join us. We also plan to have our general meeting at the end of October, with a guest speaker. Please see inside for details.

Great news! A professional Web site designer, Tom Luger, has graciously offered to revamp our web site, and we are thrilled that this long overdue effort is finally underway. We will send an e-mail blast when this has been done, but in the meantime, you can check the current website for important dates and information (li-tsa.org).

Remember that we are here for you, so let us know if we can be of help. Our small army of Youth Ambassadors, and our Education/Advocacy committee members will do their best to educate faculty, staff and peers about TS, to make the school experience for our members (children and parents!) as pleasant and rich as possible.

I hope to see some of you at our next meeting!

Sincerely,

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

ASK THE O.T.

O&A to:

SUE GOCHMAN, O.T.
Occupational Therapist
Corresponding Secretary, LI-TSA

Occupational Therapy: what's it all about?

A: Technically, occupational therapy (OT) is defined by the American Occupational Therapy Association executive board (1976) as:

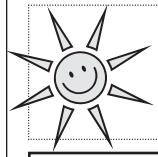
"The therapeutic use of work, self-care, and play activities to increase development and prevent disability. It may include adaptation of task or environment to achieve maximum independence and to enhance the quality of life."

Wow, so many words and so many areas to cover. Occupational therapists address a wide variety of function and skills.

The focus of OT is to improve one's "occupation", or the way in which we occupy our time, on a daily basis. The main targeted areas include self-care, work and leisure. The goal is to increase function and independence in these areas, through meaningful activities. Many occupational therapists specialize in working with children. The occupation of childhood is to develop the skills necessary to become functional and independent adults. A main setting for a child's "work" is school, although home life and social activities are all areas where dysfunction may appear.

For many children with Tourette Syndrome (TS) an OT is "just what the doctor ordered!"

An occupational therapist is trained to evaluate and treat sensory processing differences. Children with TS often have an over-responsive reaction to sensory inputs. This may include strong sensitivity to touch inputs: clothing labels, various textures and difficulty with their overall interpretation of touch. In the same way, other sensations may be hard to "make sense of", for example bright lights, loud noises, food smells, etc. These children may appear to be very particular in their tolerance to specific experiences. Children with sensory processing differences may shy away from social activities due to sensory "overload". In addition, social experiences that require adequate listening, co- ...



Quote of the month:

Our lives are not determined by what happens to us but by how we react to what happens, not by what life brings to us, but by the attitude we bring to life.

A positive attitude causes a chain reaction of positive thoughts, events, and outcomes. It is a catalyst, a spark that creates extraordinary results.**

- Colin Powel

Family Social Activities

Log onto our Web site at 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.

Child Member Poet

Little Sister

Annoying and disruptive Little sister I'm already tired



Alex Lazaroaie, Haiku

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

Kate Callan-Secretary, Web site Manager Florentina Lazaroaic, Secretary, Newsletter Coordinator Sheila Kastner, Community Relations

Jen Zwilling, Youth Ambassador

NON EXECUTIVE MEMBERS

Peggy Coburn, Chair, Family Activities Committee

Haylee Goldberg, Chair, Local Medical/Psychological Liaison
Committee

LATEST PUBLISHED MEDICAL RESEARCH

C.R. Cook, J. Blacher (2007) Evidence-Based Psychosocial Treatments for Tic Disorders. Clinical Psychology: Science and Practice Volume 14, Issue 3, Pages 252-267.

S.W. Chang, J. Piacentini, J.T. Walkup (2007) Behavioral Treatment of Tourette Syndrome: Past, Present, and Future. Clinical Psychology: Science and Practice Volume 14, Issue 3, Pages 268-273.

M.E. Franklin, M.B. Himle (2007) Evidence-Based Psychosocial Treatments for Tic Disorders: Theoretical and Treatment Implications. *Clinical Psychology: Science and Practice* Volume 14, Issue 3, Pages 274-278. M.E. Franklin, M.B. Himle (2007) Barriers to Dissemination: Exploring the Criticisms of Behavior Therapy for Tics. *Clinical Psychology: Science and Practice* Volume 14, Issue 3, Pages 279-282.

Brief Summary: This series of studies reported in the above four papers concludes that behavioral programs and procedures can effectively reduce the symptoms of tic disorders.

J. C. Möller, B. Tackenberg, M. Heinzel-Gutenbrunner, R. Burmester, W. H. Oertel, O. Bandmann and K. R. Müller-Vahl (2008) Immunophenotyping in Tourette syndrome – a pilot study *European Journal of Neurology*, Volume 15 Issue 7, Pages 749 - 753 Published Online: 15 May 2008 © 2008 European Federation of Neurological Societies

Brief Summary: Preliminary data indicate that TS may be associated with an increased peripheral immune activity

C. Kenney, MD; S.H. Kuo, MD; and J. Jiminez-Shahed, MD (2008) Tourette Syndrome.

American Family Physician. 77(5):651-658, 659-660. Copyright © 2008 American Academy of Family Physicians.

Brief Summary: Very current, detailed description of the diagnostic and differential diagnostic criteria, symptoms, causes, comorbid issues and drug treatments of choice.

PROFESSIONAL ADVISORY BOARD

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

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.**



EDUCATION AND ADVOCACY COMMITTEE UPDATE

by Jane Zwilling, Psy.D., Advocacy Chair

The Education/Advocacy Committee once again worked through the summer and had successful presentations. Jane and Jennifer Zwilling educated over 100 Speech and Language Therapists at the Long Island Speech and Hearing Conference. They also accompanied Dr. Bruun, Michelle and Herb Karen to a Rotary Club meeting in West Hampton and had the opportunity to educate business leaders from the area.

The first in-service of the school year was presented to Commack HS staff and we are in the process of scheduling for the 2008-2009 school year.

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

Below, please find valuable information from Kathy Giordano, National TSA Advocacy Specialist, re: Assistive Technology, Assistive Technology and the IEP, and SAT Accommodations. "Assistive Technology" and "Assistive Technology and the IEP" are processes, both of which are funded by the Federal Office for Special Education Programs. Below is the link to where these and other articles regarding AT can be found: www.fctd.info/resources/AT_IEP.php.

Typically Assistive Technology evaluations for students with TS are in relation to dysgraphia (difficulty getting thoughts from the brain to the paper) and processing difficulties. It is very important that people who administer the evaluations have knowledge about TS. It is also important that writing evaluations be lengthy, complex, involve a topic that is not a favorite of the student and administered at a time of the day when symptoms are typically at their worst.

There are many types of technology that can assist students with TS ... access to a computer, word processor for taking notes, calculator, spell check, voice activated programs, math computer programs, etc. Some schools will not provide these accommodations without an AT evaluation.

Youth Ambassadors and Buddies

Our Youth Ambassadors are also beginning to schedule for this year so please contact us or have your school contact us at LongIslandTSA@aol.com if you would like a Youth Ambassador Presentation.

Each and everyone of our *Buddies* returned to buddy-up and help out at the September Support Group meeting run by Ivy Belzer and we are looking forward to a great year with all of them. Our *Buddies* will also be helping out with our Cans for Kids Campaign!

If you know of anyone interested in being a Youth Ambassador or Buddy please contact us at LongIslandTSA@aol.com.

APPLYING FOR ACCOMMODATIONS ON STANDARDIZED TESTS

by Susan Conners, M. Ed., Education Specialist, TSA

TSA is aware that many students with TS who are applying for accommodations on standardized tests such as the SAT, PSAT, AP Exams, Graduate Record Exams, etc. are being denied these accommodations despite the fact that they have existing IEP's or 504 Plans.

As you apply for these accommodations, we urge you to follow the following very important steps:

- Go to the ETS Web site www.ets.org or if you are specifically looking for information regarding College Boards, go to www.collegeboard.com/ssd/student/index.html.
 Both sites provide specific information as to what a student needs for eligibility and to obtain the needed accommodations.
- 2. Obtain letters of support from the treating physician, the treating psychologist, anyone who has tested your child (OT, Speech Therapist, etc.) and appropriate school personnel. These letters need to be very specific. They need to state first and foremost the diagnoses and secondly the specific tics/obsessions and how they interfere with the testing process. If your child has dysgraphia (writing deficits), be very specific about the deficit and how it interferes. If your child also has ADHD, be sure that this is also addressed in the letters that you obtain. If your child has been diagnosed with a specific learning disability, be sure to include documentation of that disability. We have included some examples below that you may wish to share with the treating physician, psychologist, etc., so that they will better understand how specific these letters must be.
- 3. Be sure to have the letters submitted include what specific vocal tics the student has and indicate how they may interfere with the performance of other students. This is usually helpful in obtaining testing in a separate location.
- 4. Include a copy of the student's IEP/504 Plan testing accommodations that he/she already receives for tests taken in the school setting.
- 5. Do not assume that the people making the decisions to grant accommodations are knowledgeable about TS. Include a copy of the TSA Fact Sheet which you can find at http://tsa-usa.org/imaganw/Fact_Sheet.pdf that explains what TS is.
- 6. TSA Education Specialist, Susan Conners, has written a letter of support, which can be included in your packet. Please go to http://tsa-usa.org/imaganw/SATLetterSupport.pdf to view/download/print this letter.

News and Information

Welcome!

We are pleased to announce that we have two new psychologists facilitating the teen group. **Dr. Gil Tippy, PsyD**, is a Clinical Psychologist, and is the Clinical Director and one of the Founders of the Rebecca School, in NYC. Rebecca School is one of the largest schools in the world for children with Neurodevelopmental Disorders of Relating and Communicating. The school utilizes the Developmental, Individual Difference, Relationship Based (DIR) model, developed by Dr. Stanley Greenspan and Dr. Serena Wieder. Dr. Tippy also has a Clinical Practice on Long Island.

Alla Sheynkin, MS, ED., is a DIR, Floortime Specialist at the Rebecca School. She shares a Clinical Practice with Dr. Tippy providing DIR, Floortime Services to a wide range of children with Neurodevelopmental Disorders.

Dr. Tippy and Ms. Sheynkin come to us with a wealth of experience running group sessions, and we anticipate that this dynamic duo will work very well with our complex mixture of teens.

Support Team TSA,Help Spread TS Awareness, and Generate Chapter Revenue!

Support TEAM TSA athlete Cindi Eilbot as she runs the New York City Marathon for the Long Island Chapter of TSA on November 2nd. TEAM TSA members participate in athletic events to benefit more than their own health. With every step they help the national Tourette Syndrome Association get ONE LAP CLOSER TO A CURE.

Donations generated by TEAM TSA members fund research and provide education programs, awareness activities and other services for people living with TS and their families.

Cindi's goal is to spread TS awareness, and generate revenue for national TSA and our chapter. The Long Island Chapter will receive 30% of all donations to TSA if she reaches her goal of \$2500.00. Access the url below to find out more about this event, and make your donation for this very worthy cause. Spread the word about Cindi's goal to promote TS awareness, and support your chapter! www.active.com/donate/08nyc/08nyc/CEilbot

News from the NYC Chapter: Upcoming Mentoring Brunch! Hear the stories of four successful people living with Tourette Syndrome.

The next Mentoring Brunch is scheduled for Sunday, November 16, 12 p.m. to 3 p.m. It is open to curent TSA members, free of charge. If you plan to attend this event, please RSVP by calling the NYC chapter at (646) 202-9683, or send an e-mail to chapter@tsa-nyc.org.

Location and Details: 1050 Restaurant • 735 Tenth Avenue (at 50th Street)

Tourette Syndrome Survey

Dear TSA Friend,

Dr. Douglas Woods and colleagues from the University of Wisconsin - Milwaukee, along with several members from our national TSA Medical Advisory Board, have embarked on an important and extensive data-collecting project designed to provide information about the impact of tics on the lives of those with Tourette Syndrome (TS). If we succeed in having as many people as possible participating, responses to this very worthwhile project will allow TSA and the treating community to learn much more about a very broad range of issues relevant to having and coping with TS. Undoubtedly, this information will help us better serve our TS community's needs.

Internet based, the survey responses are submitted anonymously, and strict confidentiality is assured. Only those who reside in the U.S. are eligible to participate. It is estimated that the Adult survey (for those above 18 years of age) will take about an hour to complete.

The Child survey (for those between 10 and 17 years of age) consists of 2 parts: one part for a parent/legal guardian, and one part for the child to fill out. Each part should take about 45 minutes to complete (total time 90 minutes). Only children between the ages of 10-17 are asked to fill out the child portion. If the child with TS is younger than 10, only the parent/legal guardian portion should be completed.

To participate in the Adult survey go to: www.surveymonkey.com/s.aspx?sm=X_2bx_2b8RocCCBAKzsphe791g_3d_3d To participate in the Child survey go to: www.surveymonkey.com/s.aspx?sm=dsaJRuMnG2qQTJybvb_2fYLw_3d_3d:

This study has been approved by the UWM IRB for a one year period. • IRB Protocol Number: 08.243

MESSAGE FROM THE MEDICAL/ PSYCHOLOGICAL LIAISON COMMITTEE

Hi Everybody,

Anyone who would be willing to leave newsletters and/or literature in a Practitioner's office, please contact me at hayleeg@verizon.net and I will get the materials to you. There is no extra effort involved; just drop the materials off on a regular visit. It's a great opportunity to spread a little TS awareness with practitioners and with patients/clients.

Thank you!

Haylee Goldberg Chair, Medical/Psychological Liaison Committee

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

...operative play skills and appropriate body language may be overwhelming.

OTs are also trained to address motor challenges. Children may present with poor coordination resulting in an inability to hop or skip, awkward running and an overall avoidance of motor activities. Difficulties may also include poor fine or precision control needed for life tasks such as fastening small buttons, tying shoes, or opening wrapped foods. Children with TS often report distress with managing the mechanics of handwriting. Handwriting concerns including writing illegibly, poor note taking skills, hand fatigue and overall dread of doing homework are frequently reported. In addition, difficulty manipulating small objects, appearing clumsy, poor scissor cutting skills and poor speed and dexterity is often noted.

Self-care skills are also areas of function where an OT may be helpful. This includes dressing, grooming, sleeping, and the use of utensils. Children may be messy eaters or dress with clothing reversed. They may have problems settling into a calm, sleepy state at night, with problems rousing for school or weekend activities in the morning.

OTs help children with organizational and perceptual difficulties. This includes the necessary planning skills for setting up homework, copying written work from the blackboard as well as inattention, distractibility, and poor ability to follow through with instructions.

OTs are generally creative in their approach to working with children and finding the best way to address a delay or difficulty. If you suspect that your child may benefit from the services of an occupational therapist you should speak with your pediatrician as well as contact the school for an evaluation. Be specific in what you are observing at home and what difficulties are being observed at school. It is important that our children have the best tools in their bag to face the day's expectations. OTs can help!

Thank you and Congratulations!

As always, we wish to thank Julia Vinsky, Sr. Concetta, and the staff at the DeMatteis Center of Saint Francis Hospital in Greenvale for so generously providing us with rooms for our support group meetings each month, and for our general meeting. The DeMatteis Center is conveniently situated on a beautiful campus, and serves as a major community resource, specializing in outreach and other essential community services, that serve so many so well. Thank you!

Congratulations to board member Sheila Kastner for being recognized by Long Island Business News (LIBN) as a 2008 Health Care Hero in the catagory of Volunteerism! She was recognized for her volunteer affiliations with Huntington Hospital, Island Harvest and LI-TSA. Volunteerism makes the world go round, and we are so lucky to have Sheila on board!

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



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

Easing Transition to New School: Prepare a One Page Personal Summary

By Rachel Gibbons

Last June our daughter graduated from her small and familiar elementary school, where she was one of only 65 fifth graders. This fall she began middle school – and became one of approximately 400 sixth graders! As summer wore on my husband and I watched as her anxiety about the new school mounted and we brainstormed to find ways to make the transition as easy as possible. I turned to the copious notes I have jotted down at various TS and special education related conferences and meetings. I hit the jackpot when I came upon advice given by Sue Conners, TSA national education specialist, at a presentation I attended a couple of years ago that specifically touched upon the dreaded topic of middle school.

At the top of Sue's list of recommendations was the creation of a simple one page summary (see template below) which included the child's name, grade, and core teachers along with a quick description of the child's disabilities, strengths, weaknesses and IEP accommodations. She recommended that this summary be distributed to all of a child's teachers as well as to other staff and faculty who would come into contact with the student. Although all of Shoshana's teachers are theoretically expected to read her IEP, I know that I can hardly get through it, and she's my kid! I figured that a "one pager" might be just the ticket to easing her transition to a new school.

I soon realized that this summary could accomplish something that an IEP never could: I could give the new teachers a snapshot of my child, including the qualities that make her a great person. We gave the new teachers a preview of Shoshana's wonderful personality – which helped to make a positive impression. Our daughter is not just a list of IDEA accommodations and test results – she's an awesome kid. I drafted a one page "snapshot" sticking with the information that Sue recommended. A couple of days before classes started we distributed Shoshana's summary to her core classroom teachers and her "house" office. The reaction was overwhelmingly positive! The assistant to the vice-principal asked if she could photocopy the summary and send it to the nurse as well as additional faculty and staff.

The day before classes began we had a full team meeting attended by Shoshana's teachers, the school psychologist and aide. Each and every one appreciated our handout. The gym teacher (who has hundreds of new students every year) told my husband that she wished that every parent of every special ed student would prepare a similar summary. We highly recommend it and I have included a sample summary for other parents to use as a template.

Sample summary

Confidential Student Information – Summary – September 1, 2008

Jane Doe, age 11

Main Street Middle School Green House – Ms. C and Ms. F

Classified: OHI (Other Health Impaired)

Diagnosis: Tourette Syndrome, (characterized by ______)

Anxiety Disorder, ADHD, Obsessive Compulsive

Disorder and Peanut Allergy.

Strengths: Intelligent, adorable, funny, sensitive, creative, self-aware

and brave. Excels in history and science.

Appears neuro-typical.

Weaknesses: Socially immature, easily distractible and frustrated,

easily fatigued, anxious, physically weak, heat intolerant.

Difficulties with math. Appears neuro-typical.

Accommodations: MANY (please see IEP for full list)

Full time aide (TA)

Adapted physical education

Counseling

Physical therapy

Positive reinforcement plan

Breaks as needed

Preferential seating (by the door, in front of class, please)

Refocusing and redirection

Flexible scheduling (*will need to leave class early

to get to next class)

Additional time to complete tasks

Copy class notes

Modified Homework

Testing Accommodations

For further information call parents:

Mom and Dad

(516) 555-8245

(516) 555-0524

Mom@optonline.net

Dad@optonline.net

THE CONTINUING SAGA OF SHOH

PART 11, The Worst Case Scenario Specialist

by Lisa Filippi

The cry of, "INCOMING!" warns me that an "inappropriate touching" tic is heading my way. I raise my arms to cover myself, just in time to intercept Shoh's hands. I find myself thinking, "hey, at least there was a warning," because there was a time when there was no warning, and even now, sometimes there isn't. I heard the "INCOMING" cry pretty often this summer. We also heard, "lock all windows, lock all doors," so he doesn't open the car door and jump out while we are moving, or the windows so he doesn't throw his most prized possessions out of them while we are moving, "could you move my glass?" so he doesn't deliberately knock it over during meal time, "hold my hand" so he doesn't run into traffic or jump off

a train platform, "take away the knife" at meal time so he doesn't stab himself or anyone else with it. The poor kid really struggles with a variety of tics that can be collectively categorized as self-sabotaging tics. Essentially, his OCD causes him to imagine and focus on the worst possible thing that could take place in any given situation. An individual with typical OCD would then have ritualized behaviors to avoid those outcomes at all costs. For many kids that have TS and OCD, the tics make him actually do the devastating thing he just imagined. To make him feel less devastated by these tics, and give him a sense that there might even be a value to them, we have affectionately endowed him with the prestigious title of Worst Case Scenario Specialist (WCS; aren't TV shows with an acronym all the rage these days?). We tell him that his WCSS skills would be very useful to him should he choose to work for the CIA when he grows up. He could preemptively diffuse possibly dangerous situations before they had a chance to play out! He decided this could be a good thing, and, after thinking on it a bit, qualified his opinion by adding that they should never give him a gun. "Come out with your hands up!" "BANG." No, having the gun would definitely not work... All humor aside, these catch-phrases that Shoh has come up with are brilliant examples of his problem-solving skills; he is essentially modifying his environment so the worst case scenario won't occur. We are very proud of his abilities to do this, and let him know that,



Shoh is ready for the CIA.

often. With all the manifestations of his TS that he deals with on a daily basis, problem-solving skills might be his most valuable attributes as he moves forward into a more independent life.

Of course, the tics still often come out before the warning. At least once a day, and usually several times a day, there is a major spill to clean up at meal or snack time. Well, let's face it, he has to come in contact with that glass of milk or bowl of cereal at some point if he is to actually ingest it, and we frequently have at least as much to wipe up as gets in his mouth. Never a dull moment at our dining table. Many times a day we also hear cries of "STUPID TICS!" from the family room, as he increasingly gets frustrated and angry because his tics make him push the

wrong buttons on his Wii controller, causing him to die, vet again, and the same "STUPID TICS!" from the bathroom. You can fill in the disasters that happen in there. He has a long way to go, but he has come so far already! He manages to cover on/off buttons on the computer and Nintendo DS, so he won't shut down the machines as he tries to use them. All around our home one can find these little signs that Shoh is on the premises, premises that he is very used to. We worry that as he encounters new situations in his increasingly sophisticated world, especially now that he is in middle school, new WCS tics may emerge before he has devised a means to preempt them. This is a real worry, but worrying about it is probably not an effective use of time. Shoh has to be the one to be vigilant, especially when he is away from experienced and perceptive family members. And, there will be slip-ups, but hopefully not major ones. We try to maintain a sense of humor, praise him for all his inventiveness at problem-solving, and encourage him to be vigilant about it when he encounters new situations. Hopefully, the rewards he gets from acting in socially acceptable and safe ways will serve as motivation to do even better, because, we can't always be with him, and, tics or not, HE is the one in the situations. HE has to be the one to find ways to redirect, intercept and somehow thwart those tics if he wants to have a social life outside of his home. You can do it, Shoh! The CIA is waiting for you!

TS INFO CARDS AVAILABLE FOR MEMBER USE!

Have you ever been out somewhere in public, perhaps in a theater, in a store or on the train, and found that your or your child's tics were drawing unwanted, negative attention? Please feel free to contact the chapter at LongIslandtsa@aol.com if you would like to obtain a box of TS information cards to hand out as a way to handle uncomfortable situation! 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!

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. <u>PLEASE NOTE:</u> for the teen group only, the November support meeting will meet on Friday the 14th instead of the 7th.

Friday, November 7, 2008 Friday, December 5, 2008 Friday, January 9, 2009 Friday, February 6, 2009

Chapter General Meeting • Thursday, October 30 • 7:30-9 p.m.

Guest Speaker: RACHAEL GIBBONS, ESQ., speaking on TS and Education Law. DeMatteis Center, 101 Northern Blvd., Greenvale, NY 11548 (Same building, corrected address.)

PLEASE HELP US Long Island TSA has been working tirelessly to keep in pace with the needs of the community we serve. This community includes children and adults with Tourette Syndrome (and accompanying co-morbid disorders such as OCD, ADD, ADHD, LD). We have been working with teachers and medical professionals to give them the knowledge to better understand our children. The appreciation of our time and resources among the community of educators and professionals has been overwhelming. It is truly a win-win! We also have a monthly parent support group and an art therapy session with the children. The Youth Ambassador program was initially started by our own Jen Zwilling, 18 years old of Long Island. She has trained over 100 young adults to date in an effort to educate people all over about the facts vs. fiction of TS. In addition to continuing ongoing programs we would like to establish new programs to help continue our mission. Your support of LI-TSA will continue to help us raise awareness through our programs. To continue to serve tomorrow we must reach out for your help today. HOW TO HELP: We are a 501(c)3 tax deductible not-for-profit organization. PLEASE SEND DONATIONS TO OUR ADDRESS BELOW.



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