

Tourette Syndrome Association of New Jersey, Inc.

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TSANJ Newsletter

Newsletter Date:
Third Quarter 2003

The Mission of TSANJ is to support the needs of families with TS, to advocate for individuals with TS and to educate the public and professionals on TS. TSANJ was reorganized in 1994 to better meet those objectives.

Check the TSANJ website often for additions to this calendar.

TSANJ Calendar

Tim Howard—Making A Difference

Tim Howard, former All-Star Goalkeeper for the New York/New Jersey MetroStars of Major League Soccer and Board Member of Tourette Syndrome Association of New Jersey (TSANJ), will carry his personal message of support for people with TS to the citizens of Great Britain. The 24 year old native of North Brunswick, New Jersey has just completed a transfer of his playing rights from the New Jersey team to Manchester United, the premier franchise in European soccer where he stands to become the starting goalkeeper on the world's number one team.

Prior to the 2001 MetroStars season, the then 22-year old Howard revealed publicly for the first time that he was diagnosed with Tourette Syndrome at age 11. With that announcement, he made it his personal goal to help spread awareness about TS, and to work with children who have been diagnosed with the disorder. He has accomplished this as a TSANJ spokesman, Board member, and volunteer. His frankness, visibility, and support enables children to see his success and thereby establish goals for their future as productive and worthwhile members of society. Among the highlights of his efforts was his annual hosting of over 200 child members of TSANJ and their parents at a game at Giants Stadium followed by a two hour question and answer session on growing up with and successfully dealing with TS.

Howard received Major League Soccer's Humanitarian of the Year award in 2001 in recognition of his work with New Jersey kids diagnosed with Tourette. With his guidance, the MetroStars will continue to support TSANJ's programs of awareness, education and family support across New Jersey. In addition, the MetroStars have framed Howard's goal keeper gloves and presented them to TSANJ for use as an auction item to raise money to support children's programs across the state.

Tim remains committed to Tourette Syndrome Association of New Jersey and will continue to serve as a Board member.

Obsessive Compulsive Mtg. Robert Wood Johnson 108A Sept 8 7pm

Kids Support Group Planning Meeting Sept 9 7pm

TSANJ Board of Directors Meeting Sept 10 7pm

Family Support Group - JFK Hosp Neuroscience Center Sept 11 7pm

Family Support Awareness Day Garden State Exhibition Center Sept 12 & 13 All Day

Making Special Education Understandable for Parents & Advocates 732-246-2525 Sept 20 All Day

TS Families Working with the School Nyack Hospital Sept 20 10am

Adult Support Group Robert Wood Johnson Hospital Sept 21 1pm

TSANJ ANNOUNCES 2003 EDUCATOR OF THE YEAR

TSANJ has announced that John Lamela, Guidance Counselor at East Brunswick High School, East Brunswick, New Jersey, has been selected as the 2003 TSANJ Educator of the Year.

The award will be presented annually to a New Jersey public or private school educator who has made a significant contribution to the education and well-being of a student with Tourette Syndrome. The nomination is made by both the family of the student and school administration. The honor is given to an educator who has made a significant difference in the life of a child with Tourette Syndrome.

Mr. Lamela was nominated by the family of East Brunswick High School senior Marisa Lenger. "Mr. Lamela went to the greatest of lengths to understand the issues that Marisa had to deal with every day," stated Marisa's mom, Sandy. Marisa's Tourette Syndrome manifested itself in a severe tic disorder which made her school years even more difficult than they normally are for a teenage girl. Compounding her difficulty, many teachers were unable to take the time to help address her issues, causing her to lose productivity and increase her classroom problems.

Of Mr. Lamela, Marisa stated, "He is so full of life and passion, and most of all respect; respect for kids who most other people just see as students, not individuals."

"He stands up for the rights of all students with a strength of character, wisdom, and love that radiates wherever he goes. He made high school a place of enjoyment - he made my life a time of enjoyment," she concluded.

In a very moving acceptance of the award, Mr. Lamela stated that it was of the greatest importance to create awareness of TS among educators so that teachers can recognize TS and create an environment where all students succeed.



The annual Educator of the Year Award is funded through the generosity of TSANJ supporters. Individuals interested in supporting the scholarship should forward their contribution to Tourette Syndrome Association of New Jersey, Inc., 26 West High Street, Somerville, NJ 08876. Checks should note that the contribution is to be made to the Educator of the Year fund.

Marisa Lenger Presents Educator of the Year Award to John Lamela at May 8th TSANJ Annual Dinner

TSANJ Calendar

Family Support Group Somerset Medical	Sept 22 7pm
Adult Support Group Valley Hospital Ridgewood	Oct 7 7pm
Family Support Group Valley Hospital Doctors Cafeteria	Oct 8 7pm
TSANJ Board of Directors Meeting	Oct 8 7pm
Family Support Group West Jersey Hospital Voorhees	Oct 13 7pm
TS Medical Conference Children's Specialized Hospital	Oct 17 9am
TS Kids Support Group Halloween Party - Location TBA	Oct 19 1pm
Educators Workshop TS & Related Disorders Ocean County College	Oct 20 TBA
OCD Biological Basis and Pharmacotherapy Treatment, Somerset Marriot	Oct 26 All Day
NJEA Teachers Convention Atlantic City	Nov 6 & 7 All Day
TSANJ Board of Directors Meeting	Nov 12

United Way

TSANJ Calendar

This month the United Way campaign is kicking off across New Jersey and across the nation. This is an easy way for you, your friends and family to direct much needed donations to TSANJ's programs of family support, education and advocacy.

We need your financial help to continue our programs for the thousands of New Jersey families living with TS. When you receive your United Way pledge card at work, use the space provided to designate: Tourette Syndrome Association of New Jersey, 26 W. High St, Somerville, NJ 08876. And please ask your friends and family to do the same. Thanks for helping us to help you!

Employee Charitable Campaign

For those state employees contributing to the Employee Charitable Campaign, please use code # 6563 to designate TSANJ as the recipient of your pledge.

NY Marathon

Jean Driscoll, seven-time Boston Marathon winner and Olympic wheelchair athlete gives some words of encouragement to Tom Blundetto at the TSANJ annual dinner. Tom, who coordinates TSANJ's adult support group, will run the NY Marathon on Nov 2 to raise money for the TSANJ Childrens Scholarship Fund. Your pledge in support of Tom and the Scholarship Fund would be greatly appreciated.



Family Support Group JFK Hospital Neuroscience Institute	Nov 13 7pm
Adult Support Group Robert Wood Johnson Hospital, New Brunswick	Nov 16 1pm
Family Support Group Somerset Medical Ctr. Somerville	Nov 24 7pm
Family Support Group West Jersey Hospital Voorhees	Dec 1 7pm
Adult Support Group Valley Hospital Ridgewood	Dec 9 7pm
Family Support Group Valley Hospital Doctor's Cafeteria, Ridgewood	Dec 10 7pm
TSANJ Board of Directors Meeting	Dec 10 7pm

NY Marathon - November 2, 2003 - In support of the TSANJ Children's Scholarship Fund

I pledge \$ _____ for Tom Blundetto and the TSANJ Scholarship Fund. Thanks for letting me help create awareness of TS and support our children.

Name _____

Address _____

Phone _____

Please return this form with your check made payable to: TSANJ Childrens Scholarship Fund

Opportunities to Help

NJEA Teachers Convention Atlantic City Nov 6 & 7

Nov 6 & 7— We need volunteers to man the Tourette Syndrome booth & distribute literature to educators. This is the largest gathering of educators in the US with an estimated attendance of about 75,000 people. Being part of the convention is a great experience. Call us today to volunteer.

Support Groups

Volunteers are needed to coordinate hospitals Tourette Syndrome Family Support Groups in Mountainside, Atlantic city and Manahawkin. We'll train you!

Newsletter Editor

We need writers and Editors to help with the TSANJ newsletter. Right now it gets published only when time allows. We'd really like to get it out quarterly.

Holidays Are Coming!

TSANJ member Beth Rappoport invites everyone to visit her website <invitationery.invitations.com> between Sept 1 and Dec 31 to order holiday cards. 20% of all business placed on this site during that timeframe will be donated to TSANJ. Thanks, Beth.

Barnes & Noble Cares

We have been invited to man a gift wrapping table at the Bridgewater Barnes & Noble. Barnes & Noble will provide wrapping supplies, we supply "Volunteers" and all proceeds are donated to TSANJ. Here are the dates: Nov 28, Nov 29, Dec 5 & 6, Dec 12 & 13, Dec 19 & 20, Dec 22 & 23. Please volunteer to get in the holiday spirit and wrap gifts at the store on these dates. It should be a lot of fun and an excellent fundraiser. Come on out and help. Call 908 575 7350 for additional information.

Home Schooling Anyone?

Do you home school your TS child? Several NJ families have inquired about forming a network of families who conduct home schooling for their children to share ideas and exchange strategies. Let us know if you'd like to be included in the this group.

12th Annual NJ School Health Conference - October 8

Volunteers from Edison and surrounding areas are needed to man a table at the above conference to be held at the Victorian Manor, 2883 Woodbridge Ave, Edison, NJ. We will need you onsite from 7:00 am until 1:00 pm to answer questions and distribute literature on TS. This conference is attended by school nurses, doctors and other professionals. It's a great place for TSANJ to create awareness and educate these professionals. Hope you can help - call us today.

PathMark Contributes to TSANJ

TSANJ is currently participating in a terrific, painless fundraising opportunity! It involves no work, no solicitation and no extra donations on your part. All you need to do is shop at any PathMark Store. When you do your grocery shopping and use your PathMark Advantage Card (that little card dangling off your key ring!) PathMark will donate 1% of your spending directly to TSANJ. To register for this program, print out, complete and mail the form downloadable from our website <TSANJ.org> under "TSANJ Fundraising". This form must be snail-mailed to the address indicated. Many thanks. Happy shopping!

Rutgers University/TSANJ TS Partnership

Social Skills Workshops for kids with TS are now forming at the Rutgers University TS Clinic. Call 732 445 7795 to register. Children are grouped according to age and sex. Here's what one of the workshop "graduates" had to say:

"I am a fourth grade girl who has TS. I am 9. My name is Jackie. I feel special that I have TS. My friends know about my TS and they think I am the same as them. When I tic I just tell myself to calm down and it helps. The Tourettes Clinic at Rutgers is very helpful. I was in

a group with two other girls who had TS too. They were the same age as me. There were three girls who were in charge of the group named Courtney and Renna. They didn't have TS. They taught us tricks to make us not get so upset when we tic. We also played a lot of fun games and made projects. We made a book that had all our projects in it and at the end we got to keep our projects. If you have TS just call up the TS clinic at Rutgers and they will help a lot. TS rocks!" - By Jackie

TSANJ Kids Support Group Halloween Party

Fun, Friends, Snacks, Games and Goblins

Wear a costume or just decorate your face - this goes for parents too!

Sunday October 19 from 1:00 to 4:00 pm

The exact location has not yet been determined; sounds silly, but we didn't want to hold up this newsletter! We expect it will be in the New Brunswick area. Sign up today and we will get back to you with location, directions and any additional information required. For those families who have attended our prior kids gatherings, you know how much fun this event is for the whole family. For those who have not yet attended, come on out and join us for the afternoon and wear your sneakers so you can join in.



YES, our family will attend _____.

YES, our family will attend and volunteer to help that day _____.

YES, our family will attend and we'd like to help plan the event _____.

NAME: _____

ADDRESS: _____

PHONE: _____ EMAIL: _____

**** KIDS NAMES, AGES AND HOBBIES ****

Return this form by October 10 to: TSANJ, 26 W. High St, Somerville, NJ 08876 or fax it to us at: 908 575 8699

TS Medical Symposium

The Tourette Syndrome Association of New Jersey is pleased that we have been asked to partner with Children's Specialized Hospital on their 19th Annual Medical Symposium. This is a full day conference with continuing education credits being awarded by the Medical Society of New Jersey, the American Speech-Language-Hearing Association, the NJ Board of Education and the Association of Schools & Agencies for the Handicapped. NJ State Board of Social Work Examiners continuing education credits are pending. Parents of children with TS and all others with an interest in knowing more about Tourette Syndrome are invited to attend. You will be receiving a registration brochure in the mail shortly. For scholarships to the conference, please contact TSANJ at 908 575 7350.

Children's Specialized Hospital — 19th Annual Symposium

Tourette Syndrome: Pediatric Perspectives

Friday, October 17, 2003

**Children's Specialized Hospital
150 New Providence Road
Mountainside, New Jersey**

Children's Specialized Hospital is the largest comprehensive, pediatric rehabilitation hospital in the United States. Children's provides a wide array of medical, developmental, educational, and rehabilitative services for infants, children, adolescents and young adults.

Cathy L. Budman, M.D.

Associate Professor of Psychiatry and Neurology, New York University School of Medicine

Associate Attending in Psychiatry, North Shore University Hospital, Manhasset, NY

Member National TSA Medical Advisory Board

Topic: Clinical Management of Tourette Syndrome and Comorbid Psychiatric Disorders

Susan A. Conners, M.Ed.

TS Education Specialist

International Speaker and Educator

Topic: Tourette Syndrome in the Classroom

Bonnie R. Cimring, Psy.D.

Licensed Psychologist specializing in impulse control disorders, anxiety disorders, social skills interventions and Tourette Syndrome in children and adolescents.

Topic: Tourette Syndrome: At home interventions

J. Paul Hieble, Ph.D.

Research Director, GlaxoSmithKline Pharmaceuticals

Topic: Tourette Syndrome Pharmacology - Research and Future Directions

IEP WISH LIST - Beverly Bowser - SPAN "The Bridge" Spring/Summer 2003

I have a strategy that I use to try to have my daughter come out a winner with every IEP. I call it my "Wish List" for the upcoming school year.

I try to start the list around February. I look at what is working, what isn't working, items that are required and items that might be beneficial. Examples are: one-on-one aide, bold lined paper, weighted vest. After the list is drawn up, I then look at each item on the list and I write down why it would be beneficial for my daughter and if it is a code issue, I include the area in

the code that pertains to it. Some examples are:

one-on-one aid: my child needs constant redirection and directions re-stated

bold lined paper: my child has a visual problem and is unable to see the lines on regular paper

weighted vest: my child needs help with focusing.

When all this is done, I send a copy of the wish list, and the reasons why, to my case manager so that we can discuss the items and see how to

incorporate them into the program designed for my daughter. I have done this the last couple of years; it has been well received by my daughter's case manager, has helped speed up the IEP process, and has been extremely successful for me as I have gotten the majority of the items I have requested.

Remember, you know your child best and can judge what will be beneficial to your child. You are a part of the IEP TEAM. And there is no "I" or "THEY" in "TEAM".

SPECIAL EDUCATION TERMS

Special Education and the IDEA: Over twenty years ago Congress guaranteed children with physical and mental disabilities a "free and appropriate public education." In 1990 the law was renamed the Individuals with Disabilities Education Act, or IDEA. This is the law people usually have in mind when they talk about special education.

Individualized Education Program (IEP): A detailed plan describing a child's educational goals and objectives and the services the school will provide to help a child reach goals and learn the general curriculum.

IEP Team: The group of people who work to develop the IEP. By law, the IEP team includes parents, a regular

teacher (if the child takes or may be able to take regular classes), a special education teacher or special service provider, a school district representative, a person knowledgeable about evaluation, others invited by the parents or school district and, in some cases, the student.

Inclusion: The practice of placing students with disabilities in regular classrooms with needed supports and services.

Initial Evaluation: The first time a child is tested to see if he or she is eligible to receive special education services.

Independent Evaluation: Testing done by someone who doesn't work

for the school system.

Least Restrictive Environment (LRE): If possible, children with disabilities should be taught with children who do not have disabilities in a setting that is as much like a regular classroom as possible. Schools may place children with disabilities in separate classrooms or schools only when supports and services are not enough to help the child learn in a regular education classroom.

Transition Plan: Once a student turns 14, the IEP must include a transition plan, describing how the school will prepare the student for life after high school, such as college, employment or independent living. The student has a right to be

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Support Group Highlights

October 8 - Valley Hospital - Ridgewood

"Understanding ADHD". Children with Attention Deficit Hyperactivity Disorder (ADHD) represent 3 - 5 % of America's school age population. They can and do succeed when adults who work with them understand that their behaviors respond to instruction and intervene in positive ways. This workshop has been developed to help educate parents, teachers and others about ADHD. It consists of areas addressing diagnosis (what it is, who can diagnose it, services/interventions), disability categories under which a child may qualify for services, behavior management and instructional strategies.

September 22 - Somerset Medical Center - Somerville

"Basic Rights in Education Workshop". This workshop provides families with an introduction to their rights and responsibilities as parents of children with special needs under the Individuals with Disabilities Education Act (IDEA), the New Jersey Special Education Code and Section 504 of the Vocational Rehabilitation Act. Parents learn to identify their dreams and goals for their children and learn laws and advocacy strategies that will help them help their children reach those goals. Parents of classified children and children who are having difficulty in school but may not be classified will benefit from this training.
