



tourette syndrome association of new jersey, inc.

Spring, 2003

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The Tourette Syndrome Association of New Jersey is a nonprofit organization whose membership includes individuals with Tourette Syndrome, their families, friends, and interested professionals. All of our funding comes from contributions.

MISSION STATEMENT

The mission of our organization is to support the needs of families with TS, to advocate for individuals with TS, and to educate the public and professionals on TS.

Website
www.tsanj.org

24 Hour HelpLine
732-972-4459

RUTGERS UNIVERSITY/ TSANJ PARTNERSHIP

We are extremely proud to report that we are completing the third year of our Partnership with the Rutgers Graduate School of Applied Psychology. To date eight PsyD candidates have completed this one-year practicum studying TS, working with TS families, and developing and conducting social skills workshops specifically for TS children.

Five additional doctoral students joined the program in September 2002. They will be working with us through August 2003. Last February, TSANJ was invited to conduct a 3-hour lecture in Child Psychopathology at the University. This is a required course and we therefore reached every psychology student in the graduate school. On March 25, 2003, we will again lecture in the same course.

TSANJ funds the TS Partnership program. Objectives set when we entered the Partnership were: to generate expertise and interest in treating TS families, develop programs specifically for children with TS and create an awareness of TS in the University community. We are pleased to say that those objectives are being met. As you may know, this is the only program of its type in the nation. The success of this program is creating interest in TS among the faculty at other colleges and universities within our state.

VOLUNTEERS NEEDED!

Your talent will be put to good use in the following programs and initiatives:

School Inservice & College Workshops
HelpLine
Support Groups
Fund Raising
Newsletter Editor

Call 908-575-7350 and volunteer today!

TSANJ ANNUAL FUNDRAISING DINNER

The 2003 TSANJ Annual Fundraising Dinner is scheduled for 6:30 P.M. on May 8, 2003, at Johnson and Johnson World Headquarters in New Brunswick. Guest speaker will be Jean Driscoll. Tim Howard, goal keeper for the NY/NJ MetroStars and Team USA, will help emcee the event.

Ms. Driscoll is an Olympic wheelchair athlete, winning two Silver medals in the 1992 and 1996 Games. She is a world record holder in the 10,000 meter track event and the 10K and marathon road racing events. She is an eight-time winner of the Boston Marathon and has been recognized by *Sports Illustrated* as one of the top 25 female athletes of the twentieth century. Her message of inspiration is "Dream Big - Work Hard." Ms. Driscoll's autobiography, *Determined to Win*, is available in bookstores.

An important part of the evening's program will be the announcement of TSANJ's Teacher of the Year and the introduction of

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"DREAM BIG" RAFFLE

Through the generosity of some very special friends, TSANJ has received a donation of 2 week long stays at oceanfront villas on the beautiful Caribbean Island of St. Maarten

St. Maarten visitors enjoy the ultimate in adventure, excitement, and relaxation with its ideal mix of sporting activities, vibrant nightlife, natural beauty and secluded comfort. Opportunities abound to windsurf, snorkel, go hiking, horseback riding, enjoy great cuisine, shop to your heart's delight or test lady luck in the many world-class casinos. With its dual Dutch/French heritage, St. Maarten offers a unique experience for every visitor.

The trips are being made available to our members and friends as two grand prizes in our first annual "Dream Big" raffle. Tickets are enclosed with your invitation to the "Dream Big - Work Hard" annual fundraising dinner at \$25 each or 6 for \$100.

We ask that everyone please support this very important fund raising opportunity by buying and selling raffle tickets. Have fun in the sun!

FUNDRAISING DINNER (cont.)

the 2003 TSANJ Children's Scholarship winner. Big evening? Absolutely! Fun? Inspirational? Without a doubt!

We need your help to make this annual fundraiser a success. We need you to buy and sell seats and tables and to bring in corporate sponsors to underwrite the effort. So far, Janssen Pharmaceutica, AT&T, Dietz & Watson and Anheuser Busch have signed on as corporate sponsors. Seats are \$175 and sponsorships begin at \$1,000. All donations are welcome.

Your invitation will arrive in the mail by April 1. Please call the TSANJ office at 908 575 7350 with any questions you may have.

Please help us raise the funds necessary to continue TS family support, education and advocacy here in New Jersey by contributing to this annual event.

LINK OF THE MONTH -

Looking at the strep link to OCD and tics - PANDAS research at NIMH

<http://intramural.nimh.nih.gov/research/pdn/web.htm>
PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. This term is used to describe a subset of children who have Obsessive Compulsive Disorder (OCD) and/or tic disorders such as Tourette Syndrome, and in whom symptoms typically worsen following strep infections such as "strep throat" and Scarlet Fever. This NIMH website answers questions about PANDAS, provides links to recent publications, and details research.

CALENDAR OF EVENTS

- April 3 Educators Workshop
Middlesex County College
- April 3 Family Support Group -
Morristown Memorial Hospital, Morristown
Speaker: Ariel Penkow, doctoral student in the
Rutgers University/TSANJ Partnership
Program. Subject: *Social Skills for TS Children*
- April 4 Educators Workshop: TS & Associated Disorders
Raritan Valley Community College
- April 7 Family Support Group
West Jersey Hospital
- April 8 Educators Workshop: TS & Associated Disorders
Ocean County College
- April 9 TSANJ Board of Directors Meeting
- April 9 Family Support Group
Valley Hospital Doctor's Cafeteria
Speaker: Wendy Zwoboda - TSANJ Board
Member, special education teacher and mother
of twins with TS. Subject: *Home and School
issues and concerns with the TS child*
- April 24 Educators Workshop: TS & Associated Disorders
Richard Stockton College
- April 25 Inservice Volunteer & Parent Training
Richard Stockton College
- April 27 TS & Associated Disorders Presentation
NJ State Social Workers Conference
- April 30 Peer Inservice
Mercer County Community College
- April 30 Deadline-Children's Scholarship applications
- May 1 Family Support Group
JFK Neuroscience Center, Edison
Speaker: Penny Dragonetti, Statewide Parents
Advocacy Network. Subject: *Overview of
ADHD - a TS Associated Disorder*
- May 7 Family Support Group
Southern Ocean County Hospital
- May 8 TSANJ Fundraising Dinner - Johnson & Johnson
World Headquarters, New Brunswick
- May 9 Educators Workshop: TS & Associated Disorders
Mercer County College
- May 14 TSANJ Board of Directors Meeting
- May 26 Family Support Group
Somerset Medical Center

Visit www.tsanj.org for directions and registration information.

THE LEGISLATIVE EFFORT

We learned a lot about politics, funding and state legislators last year in our effort to educate the state's decision makers on the magnitude and impact of Tourette Syndrome in New Jersey. For much of the year, TSANJ was a weekly visitor at the NJ State House meeting with legislators, testifying before the Assembly Health Committee, and making ourselves known to the Dept of Health, Budget and Finance Committees.

In the 2002 tight budget year, we were one of just a handful of organizations to receive grant money, an occurrence that does not happen by chance. Between trips to Trenton, we also visited legislators on their home turf - from Camden and Cherry Hill, to Lafayette to Jersey City. The message was always the same: TS is an underserved, underdiagnosed population in NJ and across the country. Our kids and adults face problems and discrimination in the classroom, the workplace and in public places. Diagnosis is slow, treatment can be poor, and education and advocacy are the keys to making the difference in their lives. In addition to personal visits, four separate mailings went to each legislator documenting our needs and asking for their support.

TSANJ's grant was issued as part of the 2002 state budget through Department of Health for the period 7/2/02 through 6/30/03. Quarterly, we report our performance against objectives to the DOH. Accurate record keeping allows us to ensure that documentation on inservices, college workshops, support group meetings, helpline intake, Rutgers Partnership progress, fundraising, education, awareness, and advocacy is available. Our financial records and general program documentation are audited at the end of the grant period and our books are open to inspection by the DOH at all times.

We are grateful to Assembly Speaker Sires and many others for their support and hard work in obtaining this much needed grant. We have asked that the State fund TSANJ at the same level for year 2003 to allow us to continue our work within New Jersey.

TSANJ CONTINUING TO PROVIDE SUPPORT & EDUCATION

Professional Development Program for Educators NJ Department of Education Provider #976

The Tourette Syndrome Association of New Jersey conducts on-site district wide public and private school inservices, providing education on Tourette Syndrome and associated disorders. The workshops are also offered to colleges, universities, residential facilities, and police departments.

All New Jersey teachers are strongly encouraged to attend and parents are requested to encourage your child's teachers to participate in these important training sessions. See the listing of scheduled sessions in this newsletter's Calendar of Events Visit our website <www.tsanj.org> for registration information or call our office at 908 575 7350 with any questions you may have.

SPOTLIGHT ON SOUTH JERSEY

Workshops Planned for April.

On April 24, Sue Conners, nationally known educator and advocate for children with TS will present *Tourette Syndrome: A Seminar for Educational Professionals*. The session will be held at the Richard Stockton College of New Jersey with sign in beginning at 8:00 am. The program is hosted by the Atlantic/Cape May/Cumberland County Unit of NASW-NJ.

The program will offer 3.5 professional development hours for NJ teachers and 3.5 NJ Social Work non-clinical credits will be awarded to social workers. A fee of \$35 will be charged which includes materials and a continental breakfast. Although the session is geared to a professional audience, parents are welcome to attend. Registration must be made in advance. Call the Richard Stockton College of New Jersey directly at 609 626 3418.

On Friday, April 25 from 4:00 pm to 7:00 pm, TSANJ and Sue Conners will conduct a special session for people interested in volunteering as an education/school inservice volunteer for TSANJ. The session will also take place at the Richard Stockton College of New Jersey.

A sample school inservice will be presented along with information about the 504 and IEP. A Q&A session and group discussion will also be conducted. This is the only session of its type currently scheduled for the 2003 calendar year. Although the session is directed to volunteers interested in learning to present an inservice, others are welcome to attend. Registration is required and may be made by calling the TS office at 908 575 7350. Space is limited so call today to reserve your seat.

The programs on April 24 and April 25 will be held in the Townsend Center at the Richard Stockton College of New Jersey. Parking in lots 4 and 5 is recommended.

On Sunday, April 27th, volunteer professionals will present a 4-hour workshop at the Annual New Jersey Chapter's NASW (National Association of Social Worker's) conference to be held in the Bally's Casino in Atlantic City. This session, entitled *"Demystifying Tourette Syndrome,"* is being presented to social workers attending the annual NASW-NJ conference. We are grateful for this opportunity to educate social workers who work in a variety of settings. The workshop is not open to the public.

"I can't change the direction of the wind, but I can adjust my sails to always reach my destination."

Actor Jimmy Dean (Thanks, Alaska)

KIDS INVITED TO PARTICIPATE

Dear Parents,

This year's Tourette Syndrome Fundraising Dinner is in large part dedicated to the children who deal with TS daily. As one of those children, I felt that it would be only fitting that the children do something to show what we endure constantly and how well we are able to overcome.

I feel grateful that I have been put in charge of this project and I hope that every other child who participates will as well. The project involves anything made exclusively by the children or siblings of the children pertaining to Tourette Syndrome (poems, pictures, photographs, etc.....) and will be displayed either in the TSANJ Newsletter or at the May 8 Fundraiser at Johnson & Johnson World Headquarters. I ask that a brief explanation be included as to why the child chose to use that type of work to express how he or she feels about Tourette Syndrome to make others understand better the constant influence that TS has in our lives. Please encourage your children to participate because the more knowledgeable people are about TS the easier it is for people to accept those with it.

Please send your work to TSANJ, 1031 Route 22 West, Bridgewater, NJ 08807

Thank you so much.
Marisa

If you have questions, Marisa can be reached at 732 821 2666.



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1031 Route 22 West
Bridgewater, New Jersey 08807

NJ SCHOOL NURSES AND SCHOOL PSYCHOLOGISTS LEARN ABOUT TOURETTE SYNDROME

During March 2003, all school nurses across New Jersey received information on TS and TSANJ. The mailing to 3700 nurses included the following brochures: What Makes Them Tic (Questions and Answers about Tourette Syndrome TS); Professional Development Program for Educators; The TSANJ Rutgers University Partnership Program; and The Not So Secret Life of Hank (a comic book used for peer training to educate children on TS). The nurses have been asked to share the information with other school personnel and to contact us for additional support for families dealing with TS. Last November, a similar distribution was made to all New Jersey School Psychologists.

ATTENTION: GRADUATING HIGH SCHOOL SENIORS

Applications for the 2003 TSANJ Children's Scholarship Award must be received in the TSANJ office by Wednesday, April 30, 2003. Visit www.tsanj.org to download the application.

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