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TSANJ's Efforts Pay Off

In early November 1997, Education Commissioner Leo Klagholz unveiled proposed changes to New Jersey's special education code. This code regulates the way in which school districts provide special education services to children with disabilities. As proposed, these changes would have a significant impact on the education of children with disabilities, including children with Tourette Syndrome. A change which would have had a particular impact on children with Tourette Syndrome was the proposal to redefine the classification of "neurologically impaired" to apply only to those children who had suffered a traumatic brain injury.

In the weeks following the introduction of the proposed code changes, the TSANJ aggressively opposed redefining "neurologically impaired" to include only traumatic brain injured children. Letters were sent to all 1500 Association members urging them to write each State Board of Education representative and explain that the proposed change could leave children with Tourette Syndrome and other neurological impairments without the special education and related services that are now available. TSANJ also sent letters to each member of the State Legislature opposing the change. Press Releases were distributed, along with letters to the editor and after dozens of calls to the media, we appeared on Channel 7 Eyewitness News. In addition, TSANJ testified at a public hearing held by the State Board of Education.

Due to the persistence and efforts of many members of our organization, changes were made to the proposed code so that Tourette Syndrome is now expressly listed as one of the disabling conditions which may qualify a child for special education and related services under the classification of

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Tourette Syndrome Association of New Jersey, Inc.

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. Our Association was reorganized in August of 1994 to better meet those objectives.

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 and all of our workers are volunteers.

Chapter-Wide Picnic in July

Come one, come all (children, adults and all those in between) to our first annual chapter-wide picnic. Greet old friends, meet new friends and mingle with some of the most special people you'll ever meet. Volleyball, softball, races, a cookout and lots of fun.

Sunday, July 19

Duke Island Park

Bridgewater, New Jersey

1:00 p.m. - 5:00 p.m.

We'll supply the hot dogs and lemonade - you bring a side dish or dessert! Call the HelpLine (732) 972-4459 ASAP to let us know that you'll be part of the fun and we'll send you directions. For planning purposes we need to hear from you by July 12 at the latest.

We Need Some Help to Run Games, Cook and Clean Up that Day!

Ongoing Programs...

HelpLine

To date over 3000 calls have been handled by our HelpLine volunteers and several thousand packets of information have been distributed to newly diagnosed families, doctors, school professionals and others. Our HelpLine is the first point of contact with TSANJ and source for:

- literature and books on TS (both free and fee)
- video lending library (over 20 tapes on TS)
- referrals: medical, social services, and legal
- school in-service and educational materials
- other chapter related business

Family Support/Adult Support Groups

- 6 groups across New Jersey (soon to be 7)
- All groups are hospital affiliated; 4 of the 6 have professionals as facilitators (psychologists and social workers)

Overheard at a recent Adult Support Group meeting: "You're right - having TS is hard, but for every one person who walks away from you there are ten people waiting in line to be your friend." Words of encouragement from the heart! This is what support groups are all about.

In-service and Advocacy

Approximately 100 in-services have been conducted in New Jersey from Mahwah to Cape May - in the past three and a half years. We estimate we have reached over 5000 teachers, administrators, school nurses and business leaders on behalf of kids and adults with Tourette Syndrome.

For more information visit us on the Web or call the HelpLine.

Website
<http://www.tsanj.org>

HelpLine Telephone
(732) 972-4459

"...for every one person who walks away from you there are ten people waiting in line to be your friend."

United Way Helping Us To Help You

The United Way provides a vehicle for contributors to route donations to the charity of one's choice. All you have to do is designate that some portion of the donation you give be directed to TSANJ. Here's how:

If your company provides an option to designate a charity and their donation form contains the fields to direct funds to a specific charitable organization, simply enter our name and address as listed below.

Or, if your company's form does not contain the specific field, ask your United Way representative for the special form. It is a common request, so the representative will know which form you need. Then enter: Tourette Syndrome Association of NJ, Inc., P.O. Box 1251, Marlton, New Jersey 08053 (732) 972-4459

It's really that simple! We will acknowledge all donations as they are received. Your family, friends, and co-workers may also want to help by directing their United Way contribution to TSANJ. Let them know how!

TSANJ's Efforts Pay Off

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"Other Health Impaired". It is hoped that with the change, children with Tourette Syndrome who were previously classified as "neurologically impaired" will continue to be eligible for special education and related services, just under a different classification. The State Board of Education voted on the proposed changes at its June meeting and it is expected the new code will go into effect this summer.

Disclaimer

All information contained in TSANJ's Newsletter is for informational and educational purposes only. TSANJ makes no express or implied warranties or representations of any kind regarding any information contained in this newsletter, disclaims all liability of any kind for the content of any information contained herein, and does not endorse or recommend in any way any such information. With respect to treatment you should contact your own medical provider(s). With respect to legal issues, you should contact your own legal advisor(s).

Support Group Info

TSANJ has 6 support groups – 5 for families of individuals with TS and 1 for adults with TS. If you currently attend one of the support groups or are planning to attend, please note that **we will not be mailing support group announcements anymore**. Instead, see *"At a Glance"* below for scheduled dates or visit the Web.

South Plainfield Family Support Group

This will become the Middlesex/Union County Support Group when it moves to JFK Hospital in Edison.

Hunterdon/Somerset County Family Support Group

Location: Hunterdon Medical Center, Flemington

Time: 2:00 – 4:00 p.m. Sunday

Support Group Coordinator: Bonnie Price

Burlington/Camden County Family Support Group

Location: West Jersey Hospital, Barry D. Brown Bldg. (next to hospital), Voorhees

Time: 7:30 – 9:00 p.m. Monday

Support Group Leader: Dr. Judy Newman

Facilitator: David Osterhout LCSW

Ocean/Atlantic County Family Support Group

Now Forming

Morris/Sussex County Family Support Group

Location: Morristown Mem. Hospital Office Building Cafeteria, 3rd floor, Morristown

Time: 7:00 – 9:00 p.m. Thursday

Support Group Coordinators: Dolores Colalillo and Rose Ann Zaloshinski

Facilitator: Dr. Jeff Lichtman

Bergen/Passaic County Family Support Group

Location: Valley Hospital, Terrace Room, North Van Dien Avenue, Ridgewood

Time: 7:00 – 9:00 p.m. Wednesday

Support Group Coordinator: Eloise Ware

Facilitators: Kathleen Crowley LCSW and Monique Mollet LCSW, MSW

Statewide Adult Support Group

Location: Robert Wood Johnson Med. School - Rm. 108 Robert Wood Johnson Hospital, New Brunswick.

Time: 1:00 – 4:00 p.m. Sunday

Support Group Coordinators: Peter Garfield and Rosemarie Rogers

Facilitator: Gayle Forman LCSW

Most groups do not meet during summer months.

At A Glance - 1998

July

16 Board of Directors Meeting

19 Chapter Wide Picnic

August

3 Burlington/Camden Family Support

10 Tee Off for TSA Golf Outing

September

9 Bergen/Passaic Family Support

10 Board of Directors Meeting

14 Hunterdon/Somerset Family Support

20 Adult Support

October

1 Morris/Sussex Family Support

5 Burlington/Camden Family Support

14 Bergen/Passaic Family Support

15-18 TSA National Conference

November

8 Hunterdon/Somerset Family Support

11 Bergen/Passaic Family Support

12 Board of Directors Meeting

15 Adult Support

December

3 Morris/Sussex Family Support

7 Burlington/Camden Family Support

9 Bergen/Passaic Family Support

National Conference - Washington, D.C.

The Tourette Syndrome Association's 1998 national conference will take place in Alexandria, Virginia, October 15 - October 18.

This year's conference, "The Road to Understanding", will feature an educator forum, a medical symposium, a leadership session, and a general session with programs spotlighting adult issues, advocacy, education, family issues, and medical information.

Don't miss this opportunity to meet with people from all over the world who deal with TS every day! Parents, adults, doctors, researchers, educators - all together for 3 days to discuss Tourette Syndrome.

In 1994 the conference was held in Houston, in 96 Los Angeles and now convenient to New Jersey in Alexandria, VA! For details contact:

The road to understanding is coming to a state near you!

Don't delay, register now!

**Tourette Syndrome Association
National
(718) 224-2999**

Movie Reviews



Niagara, Niagara

The Friday, March 20, 1998, New York Times Film Review section by Stephen Holden gave a rather unfavorable review of the recently released movie "Niagara, Niagara". Although the film's main character, Robin Tunney won a best-actress award at the Venice Film Festival for her performance, Mr. Holden commented that "her brutally repellent performance is a tour de force so uncompromising that your sympathy for the character periodically gives way to a sickening sense of disgust." In the movie, Robin Tunney portrays Marcy, a teenager with Tourette Syndrome and also, apparently, an addiction to alcohol and miscellaneous legal and illegal drugs. Unfortunately, the film gives a very negative depiction of Tourette Syndrome, and even the movie's newspaper ad describes TS inaccurately. Regrettably, these are the kinds of incidents that foster misunderstanding of Tourette Syndrome and underscore the importance of educating the public with accurate information about TS and its symptoms.

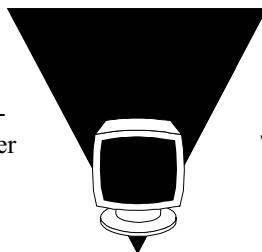
The Tic Code



"The Tic Code", starring Gregory Hines and Polly Draper - is being released shortly. Filmed in New York last summer, this film tells the story of a young man with TS and a jazz musician who befriends him. That's all we know. Let's hope it is a "thumb's up". Submit your comments for the next issue.

We're On The Web

Information on the Tourette Syndrome Association of New Jersey may also be accessed via the Internet. The website has information about information about Tourette Syndrome events. The site also has links to other



drome Association of New Jersey may Our address is <http://www.tsanj.org>. TSANJ in general, recent TSANJ news, drome, support groups and upcoming Tourette Syndrome related sites on the Web.

Contact WebMaster - Wain Schroeder with your ideas and comments.

Message From The President

Dear Members:

When the NJ State Board of Education wrote Tourette Syndrome into the Special Education Code, I realized that we were well on our way to achieving a goal set a little over three years ago - a goal of building an organization that would make a difference in the lives of people dealing with Tourette Syndrome here in New Jersey. As a result of our efforts, the State Board of Education received hundreds - if not thousands - of letters from our Association members, doctors and other interested people asking that the rights of our children be protected. They heard us and specifically included TS in the category of "Other Health Impaired". Could any one of us have accomplished this alone? No, only a team focused on a common goal could have made this happen.

In 1994, four people came together to rebuild TSA of NJ. We established a mission for our organization, developed short and long term goals and agreed that in all our dealings "respect for the individual" would be critical to our success.

Short term goals have included establishing ongoing programs for family support, education and advocacy and beginning an awareness campaign within the state to ensure greater understanding and acceptance of people with Tourette Syndrome. With the help of many, we have done all this and more.

Long term, we need to have a more proactive membership to help make a NJ medical conference, educators conference and state funding for our organization a reality -- while ensuring that family support and public awareness programs continue. We need many more people who are willing to put forth the effort and take responsibility for moving TSA of NJ forward. We need you to volunteer your time and your talents. And we need you now!

I look forward to working with you to ensure that our victory in the area of special education is just one in a series of accomplishments. Only as a team, will we continue to make a difference here in New Jersey.

Faith W. Rice
President - TSANJ

Advocates for Children with Special Needs

TSANJ has joined forces with eleven other New Jersey associations to form a coalition known as Advocates for Children with Special Needs. The coalition was organized primarily in response to proposed revisions to the state special education code by the NJ State Board of Education.

"it is important to work together toward greater collaboration..."

The Coalition believes that "it is important to work together toward greater collaboration among all stakeholders in special education – students, parents, school employees, health care providers, and legal advocates." In addition to TSANJ, members of the Coalition include:

- Association for Children of NJ
- NJ Association of School Social Workers
- Brain Injury Association of NJ
- Learning Disabilities Association of NJ
- NJ State School Nurses Association
- Statewide Parents Advocacy Network
- New Jersey Education Association
- Association of Learning Consultants
- NJ Parent Teacher Association
- NJ Association of School Psychologists
- Education Law Center



If You Don't, Who Will?

- Raise awareness about TS?
- Educate your school about TS?
- Advocate for your child or yourself?
- Help raise money for research and a cure?

The Tourette Syndrome Association operates on 100% volunteer power. Every service that TSANJ provides is made possible by people who volunteer their time and talents to make it happen. There are plenty of opportunities to help, and volunteer opportunities are as varied as TSANJ's membership.

Help Wanted!

Volunteers for Education/Advocacy Team

No better time to join than now! TS has been written in to the Special Education code; senators, assemblymen and the State Board of Education know about TS and TSANJ. We've come a long way; but there's still much more to be done and we need to take advantage of the momentum we've achieved with our Special Education lobby.

Newsletter Editor/Staff

We need writers, editors, researchers and creative folks. Our hope is to bring you "TSANJ News" three times (at least) a year. Give us a call. Not a big time commitment, but big results!

Envelope Stuffers

This highly paid position (just kidding) is for folks who want to jump in (sometimes on short notice) a few times a year and do mailings for our various projects.

Volunteers to Man our Somerville Office

We have the space, we're well equipped and there's enough work to keep you busy one day a week or once every two weeks. The office is convenient to Routes 78, 287, and 22. Help us to help you!

Information Coordinator

Gather and distribute information for our Website, HelpLine, etc. Give us a call and we'll explain this to you.

Statewide Support Group Coordinator

We need someone to help with information flow and uniformity across our growing number of support groups.

Spotlight On Adult Support

TSANJ sponsors several support groups throughout the state. While most of these groups focus on the needs of parents and families with children that have TS, one is for adults only and centers on the needs and interests of adults with Tourette Syndrome.

The adult group meets the second Sunday of every other month from 1-4 p.m. at Robert Wood Johnson Medical School. Each meeting includes a discussion period where members can share experiences and provide support for each other. Discussion topics include the emotions and feelings associated with TS, medications, dating, self-image, finding and holding a job, learning about and explaining TS symptoms, and living with others who may or may not have Tourette Syndrome. Attendees generally find a sense of kinship as they find that they share the same problems and feelings as others in the group.

A recent guest speaker at the adult support group was Donna Chavez, a Genetic Counselor Supervisor from the Institute for Reproductive and Perinatal Genetics at St. Peter's Medical Center. The topic was "Genetics and Tourette Syndrome". Future speakers will include a nutritionist, psychologist and neurologist.

Did You Know?

Our administrative office in Somerville is donated by the Generative Leadership Group and in particular by Marty Butterfield.

Our computer setup - new keyboard, new modem, memory upgrade, new software and trouble shooting are through the generosity of Phil Corbo.

Our membership listing/database was created by John Papa. Santana Reichenbach is responsible for maintaining this resource and was also responsible for moving our chapter financials to Quicken!

Danny Plenzo donated an HP 590 OfficeJet. We can now fax, scan, print and copy!

We are grateful for their kindness and generosity. They join our list of "truly special people" who have no connection to TS - just a desire to help us make a difference. Thank You

One of our biggest challenges is to provide our membership with the names of MD's and other professionals who are knowledgeable and competent in treating families with Tourette Syndrome.

You can help by completing this form. Please fold, staple, stamp

TSA of New Jersey

Physician's Information Questionnaire

All information will be kept confidential. The information provided by you will be considered along with other factors when the Physician's Referral List for New Jersey is updated by the National Medical Board.

NAME: _____

ADDRESS: _____

STREET

CITY

STATE

ZIP CODE

COUNTY

Individual with Tourette Syndrome: Male _____ Female _____ Date of Birth _____

Name of Physician treating TS: _____ Specialty: _____

Physician's Address: _____

Physician's Telephone #: _____

Are you satisfied with the care you are receiving from this physician? _____

Would you recommend this physician be added to TSA's Physician Referral List? _____

Why or Why Not? _____

What other professional's are you using to manage TS? (Name and Address)
(e.g. social worker, psychologist, other)

Would you recommend these professionals be added to TSA's Information and Referral Database? _____

Why or Why Not? _____

Comments: _____

TSA of New Jersey Family Support Program

I, _____ GIVE PERMISSION TO TSA OF NEW JERSEY TO ADD MY NAME, ADDRESS AND PHONE NUMBER TO THE LIST OF INDIVIDUALS WILLING TO BE CONTACTED BY OTHER FAMILIES IN NEW JERSEY WHO ARE DEALING WITH TOURETTE SYNDROME.

Signature

Fold at the Dotted Line



Tourette Syndrome Association of New Jersey, Inc.
P.O. Box 1251
Marlton, New Jersey 08053

A Special Gift

Dear TSA,

I would like to make a donation of \$180 to the Tourette Syndrome Association of NJ. The reason is I know many people with this disease. The money will help people get educated about Tourette. It could be hurtful if people just don't know. It is a great idea to keep everyone informed. That is why I am donating to this cause. This money is from my Bar Mitzvah. It should be dedicated to the Community/School In-service program.

Danny Arnold

Thank you, Danny, for your very special gift. Your donation will be used to help pay for the literature which is distributed to teachers and school nurses when we teach them about Tourette Syndrome. Congratulations on your Bar Mitzvah!

"It could be hurtful if people just don't know."

Calling All Doctors!

New Jersey Medicine, the magazine of the Medical Society of New Jersey, will feature an article on Tourette Syndrome and TSANJ in its July 1998 issue. We contacted them in January and were delighted when they agreed to do our story. New Jersey Medicine has a circulation of 16,000 doctors, hospitals and universities in NJ. Our mission, as you know, is to "educate the public and professionals on TS" and this is our first big opportunity to do just that!

Pen Pals

Does your child wonder if there are any other children with Tourette Syndrome? Perhaps a pen pal is the answer. All we need is your child's name, birthday, grade in September and interests. We will then try to match your child to another from our chapter. Give the HelpLine a call to let us know you're interested.

Dear Friends,

1997 was my first year chairing the SuperBowl Raffle. I've agreed to run it again for 1998 and with your support make it an even bigger success.

We will be kicking off the SuperBowl Raffle Fundraiser with a mailing of tickets soon. Last year we all know who the big SuperBowl winner was. It was TSA of NJ and its member families. Let's win by an even bigger margin this year!



Cordially,
Dennis Boyle



There is no separate membership or dues for TSANJ. Your status as a paid-up member with National TSA automatically enrolls you as a TSANJ member if you live in New Jersey. If you haven't paid your dues or want to join, call National TSA.

TSANJ's Useful Information

HelpLine (732) 972-4459

Incorporated in 1988.
Reorganized in 1994.

WebPage Address <http://www.tsanj.org>
Email Address: NJTSA@aol.com

Mailing Address: P.O. Box 1251
Marlton, NJ 08053

Administrative Office: 26 West High Street
Somerville, NJ 08876

Membership:
Approximately 1500 families and professionals.

National TSA: (718) 224-2999

Tourette Syndrome Association of NJ, Inc.
P.O. Box 1251
Marlton, New Jersey 08053
