



# tourette syndrome association of new jersey, inc.

---

Spring/Summer 2000

Vol. 2, No. 3

## Board of Directors

**Dennis Deutsch, Esq.**

**Allan Gorman**

**Vince Joseph**

**Tim Omaggio**

**Bonnie Price**

**Faith Warner Rice**

**Rebecca Spar, Esq.**

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.

## 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 1994 to better meet these objectives.

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

HELPLINE  
732-972-4459

## TSANJ PARTNERS WITH RUTGERS ON TOURETTE SYNDROME CLINIC

The Tourette Syndrome Association of New Jersey has partnered with the Psychological Clinic at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University in New Brunswick to initiate an effort that will result in the establishment of a student-clinician center for the treatment of Tourette Syndrome. Upon completion of the initial effort of educating faculty and students on Tourette Syndrome and developing treatment programs, doctoral students in psychology will begin working with TS patients under the supervision of licensed practicing psychologists.

The Psychological Clinic has developed a number of specialty sub-clinics that focus on a particular treatment approach or patient population. In partnership with TSANJ, this new sub-clinic for the treatment of Tourette Syndrome is being established to serve the needs of TS families in New Jersey and to educate professionals on the disorder.

Services that will eventually be provided include individual, group, and family therapy, psychological testing and assessment, and educational planning. Doctoral students providing these services will be taught by professionals with expertise in TS and its associated disorders. The program will provide a practicum year for Psy.D candidates with a particular interest in developing expertise in the treatment of TS.

In addition to establishing the TS Center, Rutgers GSAPP and TSANJ will develop a series of accredited workshops on TS and related disorders for doctors, psychologists, teachers, and other professionals. It is projected that the professional workshops will begin in September of this year and that the TS Clinic will begin seeing families in late fall.

Serving on the Advisory Board for these projects are: Dr. Adam Bloom of White Plains, NY; Dr. Cathy Budman of North Shore University Hospital, Long Island; Susan Connors, Chairman TSA National Education Committee; Dr. Larry Skahill of Yale Child Study Center; and Rebecca Spar, Esq., Educational Rights Attorney.

TSANJ will fund the Rutgers project. The total first-year budget for the TS Center is \$50,000. No final budget for the workshops has been determined. TSANJ is seeking major funding for these projects from the corporate and research and development communities.

As additional information becomes available, it will be posted on the website at [www.tsanj.org](http://www.tsanj.org).

# RESEARCH IN THE NEWS

Reuters Health, March 10, 2000. "**NEWER ANTIDEPRESSANTS OFFER MORE OPTIONS.**" A new wave of antidepressant medications offers more choices to keep depression -- and drug side effects -- under control, according to a report.

Reuters Health, March 10, 2000. "**THERAPY BEATS DRUG FOR HAIR-PULLING DISORDER.**" Trichotillomania -- compulsively pulling out one's own hair -- is a difficult disorder to treat. A recent study comparing the only two effective treatments -- a drug, and behavioral therapy -- found that behavioral therapy gets the best results.

Reuters, March 10, 2000. "**U.S. EXPERTS REJECT HALT TO GENE THERAPY.**" Scientists and other experts who advise the federal government on gene therapy issues rejected calls for a moratorium on experiments, but also warned researchers and patients against placing undue faith in the field.

New York Times, March 6, 2000. "**WEB RESEARCH TRANSFORMS VISIT TO THE DOCTOR.**" In interviews, doctors and patients say the Internet has profoundly changed their relationships. With an estimated 100,000 medical Web sites, patients can look up any disease, drug or medical condition in seconds.

AP, March 1, 2000. "**BRITAIN WARNS ABOUT ST JOHN'S WORT.**" Britain's Health Department issued a warning over the risks of taking St. John's wort after studies showed the popular herbal remedy may interfere with certain prescription drugs.

CNN, March 3, 2000. "**ICELAND SELLS ITS MEDICAL RECORDS, PITTING PRIVACY AGAINST GREATER GOOD.**" Iceland has sold the medical and genealogy records of its 275,000 citizens to a private medical research company, turning the entire nation into a virtual petri dish in hopes of finding cures to diseases that have afflicted humans for ages. But the promise of curing disease hasn't stopped critics from worrying about privacy issues created by the sale and storage of personal medical and genetic records.

Reuters Health, February 28, 2000. "**INTERNET FUELS GROWTH IN SUPPORT GROUP PARTICIPATION.**" More Americans are participating in health-related support groups, according to a report. One of the reasons for the boom in self-help groups: the growth of the Internet, where online chat rooms offer some degree of anonymity. "The self-help movement, both in face-to-face and virtual arenas, has tremendous therapeutic potential," according to a team of researchers from the University of Texas at Austin.

Reuters Health, February 28, 2000. "**TEACHERS HELP IDENTIFY KIDS WITH ATTENTION PROBLEMS.**" When it comes to diagnosing attention-deficit/hyperactivity disorder (ADHD), a parent's idea of "disruptive behavior" in a child may be different from a teacher's, study findings suggest. Therefore, doctors should try to talk to a youngster's teacher before they diagnose ADHD, according to a report in the March issue of the Journal of the American Academy of Child and Adolescent Psychiatry.

Reuters Health, February 24, 2000. "**DRUG IS SAFE FOR KIDS WITH TOURETTE'S SYNDROME.**" A drug known as ziprasidone can safely reduce symptoms in children with Tourette's syndrome. Although the drug is "somewhat less" effective than traditional drugs used to treat children, it may be more tolerable than other medications, according to Dr. Phillip B. Chappell, from Pfizer Central Research

Reuters Health, February 22, 2000. "**NIH STEM CELL GRANTS MAY START IN EARLY SUMMER.**" The National Institutes of Health (NIH) may start dispensing funds for research on human stem cells as early as this summer, an agency official said.

AP, February 21, 2000. "**NICOTINE MAY HELP BRAIN DISEASE.**" Despite its evil image, new research suggests that nicotine is a surprisingly potent drug for a variety of diseases that afflict the brain, including Alzheimer's, Parkinson's and Tourette's syndrome.

Reuters, February 18, 2000. "**FTC PROBES HEALTH WEB SITES ON PRIVACY.**" The U.S. Federal Trade Commission is investigating some health care Web sites over allegations they shared personal information collected from consumers with other companies without proper warnings, industry officials said. The probe follows a report by the California HealthCare Foundation blasting online health care sites for sharing personal information given by consumers with third parties despite promises that no data would be shared.

Reuters Health, February 3, 2000. "**ADHD TREATMENT NEEDS IMPROVEMENT.**" Despite the development of guidelines for the treatment of attention-deficit hyperactivity disorder (ADHD) in children, there are large gaps between the recommendations and the care many children receive, researchers report.

AP, January 12, 2000. "**ALTERNATIVE TREATMENTS LAW UPHELD.**" The Washington Supreme Court upheld a state law requiring health insurance companies to cover such alternative medical services as chiropractic care, naturopathy and massage therapy.

*Cont. pg.6*

**NOTE:** Many corporations offer matching funds, allowing you to double your contributions to TSANJ. Contact your employer's Human Resources or Personnel Department to find out if your company offers this benefit.



## MEET THE TSANJ BOARD

# VINCE JOSEPH



*Ed. note: In each issue of our newsletter, we will be introducing you to a member of the TSANJ Board of Directors. It is important to us that you understand the motivation for volunteering of time to our organization. Without the active participation of our Board of Directors and other volunteers, TSANJ would not be able to enjoy the success that it does today.*

I have been a member of the Board of Tourette Syndrome of New Jersey for over two years. It has been my privilege to work with this group of fiercely dedicated individuals who give of themselves for the advancement of the cause of Tourette Syndrome.

Through my involvement I have seen the efforts of many individuals across the state that all have one goal: to be advocates for individuals with Tourette Syndrome. We often discuss legislation that effects individuals with Tourette Syndrome and we review ways to deal with issues that these individuals are confronted with either at school or at work. We have all seen an increase in the news and entertainment shows that feature people with Tourette Syndrome. This does not happen by accident, it is only through the effort of chapters like TSANJ that present Tourette Syndrome through many public forums such as school presentations, support groups, medical forums, public service announcements, golf outings, help-lines and many other activities.

The members of TSANJ are from all walks of life. As the Administrator of Saint Barnabas Medical Center I was recently able to join TSANJ in sponsoring a very successful conference at Saint Barnabas Medical Center on such topics as medical therapies and various issues that are related to Tourette Syndrome and ADD. Our faculty was comprised of key leaders in the field. The conference evaluations revealed that the physicians in attendance, as well as members of TSANJ, found the conference to be outstanding.

Personally, Tourette Syndrome has had a major impact on my life. I am blessed to have a wonderful 17-year-old son who unfortunately has had to cope with severe Tourette Syndrome. Our first exposure to this organization was attending support meetings so that as parents we could learn from others. We have come full circle. When our son is home he attends support group and talks with worried parents of children who have recently been diagnosed with Tourette Syndrome. The commitment that my

*Cont. pg.8*

## LENDING LIBRARY NOW AVAILABLE

As a service to TSANJ members, we have established a lending library, available through local support groups. Current titles include:

RYAN

*Hi, I'm Adam*

*Adam and the Magic Marble*

*Echloalia - An Adult's Story of TS*

*Don't Think About Monkeys*

*Negotiating the Special Education Maze*

*Children With Tourette Syndrome - A Parent's Guide Book*

*Shelley, the Hyperactive Turtle*

*Teaching the Tiger*

*Search for the Tourette Syndrome and Human Behavior*

*The Gene Bomb*

*What Makes Ryan Tick?*

*ADD Kaleidoscope*

We hope that TSANJ members will take advantage of this opportunity to learn and share information with others.

## SURVEY TO ADDRESS NEEDS OF TS COMMUNITY

The survey that you will find enclosed in this newsletter is designed to gather information about the use of TS medications, nutritional supplements, and other non-drug approaches to control tics. The purpose is to determine if TS researchers should conduct scientific studies of supplements and other non-drug approaches.

All those with TS are encouraged to fill out the survey whether or not they have tried alternative approaches.

A group of parents, with the help of an epidemiologist at Columbia University, designed the survey. National TSA has distributed it to all chapter presidents in the United States - without endorsing alternative approaches - and we are passing it along to you.

The larger the response, the more valid will be the results. So please consider participating. Instructions for returning the completed form are located on the last page of the survey.

All responses will remain confidential with all identifying information removed prior to distribution of data to the research community.

## TEEN SUPPORT GROUP

TSANJ is considering the establishment of a Teen Support Group. If you are interested, please call the HelpLine at 732-972-4459.

*TSANJ, Inc. gratefully acknowledges the contribution of Data Mail of Newington, Connecticut for the production of this newsletter.*

## PHIL CORBO: KEEPS TSANJ COMPUTER RUNNING

Our society has reached a level of technological advance where no business, and in reality, no family, is able to function efficiently without a computer. Just looking through this newsletter you will find dozens of important references to information that is readily available on line, and very difficult to find without the use of a personal computer.



The ability for TSANJ to function in this technologically advanced society is attributable to one of our most cherished volunteers, Phil Corbo of Bridgewater. A retired building contractor, Phil has spent the last ten years, since divesting himself of his business, gathering used computers, rehabilitating them, and donating them to churches and non-profits. Despite no direct connection to TSANJ, Phil has become one of our most important assets.

Phil's volunteer computer operation began in 1995 when he went into his bank and saw a pile of computers sitting in a corner as a result of bank-wide computer upgrade. Taking the nearly four vans filled with computers back to his home, the self taught computer technician began rebuilding the units with new and used parts, donating his first 15 working computers to the local council of the Boy Scouts of America. He followed this contribution with one to the Somerville office of the American Red Cross, providing them with their first real computer network.

In addition to providing TSANJ with the entire office network, Phil has recently contributed nearly 50 machines to a Franklin Township Church and 100 to a parochial school in Jersey City.

Phil's next big project will be to take the computers donated to TSANJ by the law firm of Board Member Rebecca Spar, and upgrade them for distribution to families in need within the TS community in New Jersey.

Despite major contributions from companies like MetLife, British Oxygen, and law firms, banks, and doctors. Phil is still seeking used equipment for upgrade. In addition to TSANJ, Boy Scouts, and Red Cross, Phil is working with the Brain Injury Association of New Jersey, Habitat for Humanity, United Cerebral Palsy, Midland School, The Arc of Somerset County, and many more agencies in need of computers and technology.

To donate used computer equipment, call Phil Corbo at 908-725-1280.

## MAY 15 TO JUNE 15 DESIGNATED TOURETTE SYNDROME AWARENESS MONTH

New Jersey Governor Christine Todd Whitman has proclaimed May 15, 2000 through June 15, 2000 as Tourette Syndrome Awareness Month.

Through the cooperation of 16th District Assemblyman Kip Bateman, the proclamation was received earlier this month by Faith Rice, President of the Tourette Syndrome Association of New Jersey (TSANJ).

The proclamation states that "there is a need to broaden public knowledge of this much misunderstood condition, known as 'the world's most common unknown disorder.'" It further describes the mission of TSANJ "to support the needs of families dealing with TS, to advocate for individuals with TS, and to educate the public, the medical professionals and the educational communities."

### FORE!

It's time once again for the TSANJ Golf Classic. The 6th Annual event will take place this year at the beautiful Forsgate Country Club in Monroe Township, New Jersey on Monday, August 7, 2000. Forsgate is located just off exit 7A on the New Jersey Turnpike.



The Golf Classic is our one major fundraising event of the year and helps TSANJ raise the funds required to educate, inform, and advocate on behalf of individuals with TS and their families. The Golf Classic provides funds necessary to operate the 24 hour HelpLine, run the organization, and contribute to TS research.

## SUPPORT GROUP INFORMATION

**BERGEN/PASSAIC COUNTY FAMILY SUPPORT GROUP**  
Location: Valley Hospital, Terrace Room, North Van  
Dien Avenue, Ridgewood  
Time: 7:00 p.m. to 9:00 p.m. - Wednesday  
Coordinators: *New Coordinator Needed*

**BURLINGTON/CAMDEN COUNTY FAMILY SUPPORT GROUP**  
Location: West Jersey Hospital, Barry D. Brown  
Building (next to hospital), Voorhees  
Time: 7:30 p.m. to 9:00 p.m. - Monday  
Group Leader: Dr. Judy Newman  
Facilitator: David Osterhout, LCSW

**MIDDLESEX/UNION COUNTY FAMILY SUPPORT GROUP**  
Location: JFK Medical Center, Edison, NJ  
Time: 7:30 p.m. to 9:30 p.m. - Tuesday  
Coordinator: Debbie Kaserki

**MORRIS/SUSSEX FAMILY SUPPORT GROUP**  
Location: Morristown Memorial Hospital Office  
Building Cafeteria, 3rd Floor, Morristown  
Time: 7:00 p.m. to 9:00 P.M. - Thursday  
Coordinators: Dolores Colalillo & Rose Ann Zaloshinsky  
Facilitator: Dr. Jeff Lichtman

**OCEAN/ATLANTIC COUNTY FAMILY SUPPORT GROUP**  
Location: Southern Ocean County Hospital,  
Manahawkin  
Time: 7:00 p.m. to 9:00 p.m. - Wednesday  
Coordinator: Gail Smithson

**SOMERSET/HUNTERDON COUNTY FAMILY SUPPORT GROUP**  
Location: Somerset Medical Center, Somerville  
Time: 2:00 p.m. to 4:00 p.m. - Sunday  
Coordinator: *New Coordinator Needed*

**STATEWIDE ADULT SUPPORT GROUP**  
Location: Robert Wood Johnson Medical School,  
Room 108, Robert Wood  
Johnson Hospital, New Brunswick  
Time: 1:00 p.m. to 4:00 p.m. - Sunday  
Coordinator: Jerrilyn Forti  
Facilitator: Gayle Forman, LCSW

## RESEARCH IN THE NEWS (Cont.)

AP, January 13, 2000. "**ANTISOCIAL BEHAVIOR IN BOYS STUDIED.**" Very aggressive boys have been found to have lower-than-expected levels of a stress hormone in their saliva, suggesting that their behavior might be biologically based and hard to treat with counseling, researchers reported.

Reuters Health, January 7, 2000. "**DRUGS PRESCRIBED FOR CHILDREN NEED BETTER TESTING.**" The widespread practice of prescribing drugs for children that have not been specifically approved for pediatric use calls for better drug testing to ensure their safety, European researchers report.

AP, December 16, 1999. "**NEW BRAIN SCAN MAY DIAGNOSE ADHD.**" For the first time, brain scans have revealed measurable biochemical differences in people with attention deficit hyperactivity disorder, a discovery that could reduce the number of children mistakenly diagnosed and put on drug treatment, researchers say.

Science News Online, December 4, 1999. "**GENE MAY ALTER RITALIN'S EFFECTS IN ADHD.**" Many children diagnosed with attention-deficit hyperactivity disorder (ADHD) calm down and otherwise improve when given the stimulant methylphenidate, or Ritalin. Others derive no benefit from the same medication. Reasons for this variation in methylphenidate's impact on ADHD remain unclear. A new study, however, suggests that the drug fails to help youngsters who have inherited a specific form of a gene involved in dopamine transmission in the brain.

AP, December 13, 1999. "**REPORT: MANY IGNORE MENTAL HEALTH.**" In an exhaustive review of research on mental disorders, Surgeon General David Satcher concludes negative stigmas and difficulty paying for care are keeping millions of Americans from treatments that have been proven effective.

Reuters Health, December 6, 1999. "**ADVOCACY GROUP CRITICIZES NIMH RESEARCH PRIORITIES.**" The National Alliance for the Mentally Ill released a report that criticizes how the National Institute of Mental Health (NIMH) allocates research money, charging that the federal agency spends less on serious mental diseases than it should, but finds resources to conduct research on a variety of behavioral problems, including the parentage of eastern bluebirds.

*Cont. pg.7*

**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).

## CALENDAR OF EVENTS

### September

- 6 Ocean/ Atlantic Group
- 10 Somerset/Hunterdon Group
- 12 Middlesex/Union Group  
Adam Perlman, M.D., M.P.H., will present an overview of integrative medicine and its application for patients with Tourette Syndrome. Dr. Perlman is a Board Certified physician with extensive expertise in both conventional as well as complementary (integrative) medicine. He is director of Integrative Medicine for the Saint Barnabas Health Care System and Medical Director of the Carol and Morton Siegler Center for Integrative Medicine at the Saint Barnabas Ambulatory Care Center
- 14 TSANJ Board Meeting

### October

- 2 Burlington/Camden Group
- 5 Middlesex/Union Group  
Dr. Perlman will be doing the second half of his presentation. See September 12 meeting date.
- 5 Morris/Sussex Group  
Dr. Perlman will be speaking. See September 12 meeting date.
- 11 Bergen/Passaic Group  
Adam Bloom, Psy.D., will be the speaker. Dr. Bloom is the Associate Clinic Director, Bronx Family Court, Forensic Clinic. Dr. Bloom maintains a private practice in Westchester County, specializing in the diagnosis and treatment of TS and related disorders. Dr. Bloom has appeared on the Maury Povich Show and has presented at the TSA National and Statewide conferences.
- 12 TSANJ Board Meeting
- 22 Statewide Adult Group  
Rick Considine, Director of Communication and Outreach, New Jersey Protection and Advocacy, Inc., will be the speaker.

### November

- 1 Ocean Atlantic Group
- 2-5 TSA National Conference - Alexandria, Virginia
- 9 TSANJ Board Meeting
- 12 Somerset/Hunterdon Group
- 14 Middlesex/Union Group  
Adam Bloom, Psy.D., will be the speaker.

### December

- 4 Burlington/Camden Group
- 7 Morris/Sussex Group  
Suzanne Mouldovan from SPAN will present a workshop, "Basic Rights in Special Education"
- 14 Bergen/Passaic Group  
Dr. Adam Perlman will Be the Speaker. See September 12 for description.

For future dates & further information, please visit our web page at <http://www.tsanj.org>

## RESEARCH IN THE NEWS (Cont.)

AP, December 1, 1999. "**SCIENTISTS MAP HUMAN CHROMOSOME.**" For the first time, scientists have mapped virtually an entire human chromosome, one of the chains of molecules that bear the genetic recipe for human life. The achievement is an important step for the \$3 billion Human Genome Project, which is attempting to detail the tens of thousands of genes that carry instructions for everything in a human - from brain function to hair color to foot size.

New York Times, November 25, 1999. "**BEHAVIORAL DRUGS FOCUS OF DEBATE IN COLORADO SCHOOLS.**" A resolution recently passed by the Colorado Board of Education to discourage teachers from recommending behavioral drugs like Ritalin and Luvox has intensified a national debate over the growing use of prescription drugs for children.

Reuters Health, October 1, 1999. "**NEW THERAPIES HELP OBSESSIVE-COMPULSIVE, TIC DISORDERS.**" New therapies-namely plasma exchange and intravenous immunoglobulin- can help treat obsessive-compulsive disorder and tic disorders in children where these disorders are triggered by streptococcal infections, according to results of a study published in the October 2nd issue of the Lancet.

Reuters, June 11, 1999. "**HUMAN GENOME SEQUENCE NEARING COMPLETION.**" The catalog of the human genome, the genetic blueprint for all of humankind, will be 90 percent complete in less than a year, a major step toward understanding and potentially treating hereditary disease, the project's chief scientist said.

Reuters, April 13, 1999. "**HERBAL REMEDIES INFUSE MAINSTREAM MEDICINE.**" Herbs, once relegated to the ranks of snake oil or voodoo in the eyes of the medical establishment, are joining the mainstream as people look for fast, cheap ways to cure ailments such as depression, anxiety and memory loss.

## NATIONAL CONFERENCE: 2000

Reserve Thursday, November 2 to Sunday, November 5 for the TSA National Conference at the Hilton Alexandria Mark Center in Alexandria, Virginia.

On Thursday, the conference will feature leadership training, a trip to Capitol Hill, and a seminar addressing the needs of the newly diagnosed. On Friday and Saturday there will be six symposia focusing on Adult Issues, Advocacy, Education, Family Issues, Medicine, and Parenting. Sunday morning will feature group discussions and Q&A panels.

For further information, call TSA at 718-224-2999.

## MEET VINCE JOSEPH (Cont.)

fellow Board members and I have to the research, advocacy, public awareness and support for those with Tourette Syndrome has never wavered.

The next time you're asked to support a golf outing, volunteer your time or help in some other way-don't take the easy way out. Give of yourself to help others. We can't do it alone; we need your help. I assure you that it will be a rewarding experience.

## THANKS TO RETIRING BOARD MEMBERS

The entire TSANJ community would like to express our gratitude to retiring Board members, Arleen Segall, Larry Segall, and Neil Mulcahy.

Their contributions over the years are far too many to be enumerated. Their time and expertise has allowed TSANJ to grow, helping individuals and families across the state.

THANK YOU!



**tourette syndrome association of new jersey, inc.**

P.O. Box 1251  
Marlton, NJ 08053

## TSANJ - IMPORTANT INFORMATION

HELPLINE 732-972-4459

TSANJ - Incorporated in 1988 - Reorganized in 1994

WEBPAGE ADDRESS <http://www.tsanj.org>

EMAIL ADDRESS [NJTSA@aol.com](mailto:NJTSA@aol.com)

MAILING ADDRESS  
P.O. Box 1251  
Marlton, NJ 08053

ADMINISTRATIVE OFFICE  
26 West High Street  
Somerville, NJ 08876

MEMBERSHIP  
Approximately 2,500  
families and  
professionals

UNITED WAY - Please write in  
TSANJ  
P.O. Box 1251  
Marlton, NJ 08053

Bulk Rate  
Non-Profit  
U.S. Postage  
PAID  
Flemington, NJ