

TSANJ Today

NEWS AND EVENTS OF NEW JERSEY'S
TOURETTE SYNDROME COMMUNITY

Breaking the Code—The Search for the Tourette Syndrome Gene

It's long been the quest of researchers to trace Tourette Syndrome to its ultimate genetic source. Now the trail of that quest is passing through New Jersey with what may be the first TS genetic research conducted on Garden State soil.

Fueled by grants from the National Institutes of Health, this research effort will be conducted by an experienced team of professors, physicians and researchers. They have performed similar studies that have led to the discovery of genes responsible for a kidney stone disease, for susceptibility to alcoholism, for a form of muscular dystrophy and for other diseases.

HOW THE STUDY WILL WORK

"Right now, we're looking to see if there are enough people to conduct the genetics study," a project researcher

explains. "We'll send the data to our statisticians, and see if there are enough subjects to make the research viable. We'll also be looking to see how the responses fit into various research models—sibling or extended family, for example."

If we get enough of a response and sufficient funding for the project, researchers will recontact those who sent in questionnaires. All those who may be involved in the study will need to review and sign a consent form. This form will address any risks and tell you how the interview data and blood samples may be used scientifically. All subjects may withdraw from the study at any time.

DNA will be extracted from the sample and a regional genome scan will be performed. Eventually, researchers

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“ Understanding the genetics of TS genes will strengthen clinical diagnosis, improve genetic counseling, lead to the clarification of pathophysiology, and provide clues for more effective therapies. ”

—National Institute of Neurological Diseases and Stroke Web site

2004 IDEA Reauthorization— What You Need to Know



The educational community has come a long way in recognizing Tourette Syndrome as a genetic disorder that's biochemically driven. Important steps have been taken to foster a better learning environment. Still, overcoming old, harmful assumptions about children with TS as emotionally or behaviorally disturbed (or even blaming parenting) is a continuing battle. It's a battle fought on the fields of categorization, eligibility, discipline and training in the 2004 Individuals with Disabilities Education Improvement Act (IDEA) Reauthorization, where we'll find building blocks for continued improvement.

After a few years of examination and dialogue, on December 3rd, the 2004 IDEA Reauthorization was signed into law. A bird's eye view reveals that the latest version of the education legislation makes some progress, gives

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Member Spotlight

From Tennis Court to Congress, Evan Israelsky Scores Well



When Roberta and Brad Israelsky moved their son Evan to a private school in his junior year, they knew he'd gain a lot from an environment better suited to his academic and social needs. But they didn't know Evan would lose something very important to him—tennis.

Evan has Tourette Syndrome and a great serve. So it was quite a blow when he discovered that, even though his new

school had no tennis team, he couldn't continue to play on his public school's team. The New Jersey Interscholastic Athletic Association rules only allow enrolled members of a school to play on its teams.

But that might change now that the Israelsky's and New Jersey Assemblyman Louis Greenwald are on the case. By a unanimous vote, Assembly Bill No. 2391 was successfully moved out of committee. If a disabled student is placed into a private school to treat a disability, this bill

would allow the student to participate in the public school district's athletics programs. The student will merely need to meet eligibility requirements and have the written approval of the principal at the school he or she is attending.

Stay tuned. Evan Israelsky may have just helped to serve up an important change for disabled students across our state.

Breaking the Code

Continued from cover

hope to narrow the field to a small number of candidate genes, each of which will be evaluated for a possible role in TS. Some of the information used in this evaluation will come from the Human Genome Project.

HELP CHART THE COURSE TO THE TS GENE

The research has come closer to us than New Jersey; it has come to our doorsteps. You're encouraged to participate in this very important research project that will make a difference in the lives of people with TS. Call our office at 908 575 7350 and ask how to participate.

TSANJ Today

NEWS AND EVENTS OF NEW JERSEY'S
TOURETTE SYNDROME COMMUNITY

TSANJ TODAY IS A PUBLICATION OF:

THE TOURETTE SYNDROME ASSOCIATION OF NJ, INC.

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IDEA Reauthorization

Continued from cover

us some reasons to be cautious, and presents us with some setbacks. The important thing about IDEA Reauthorization, which goes into effect July 1, is to be aware of some key points that have changed.

DISCIPLINE PROTECTION IN SOME TROUBLE

One of the most significant changes to IDEA is the relaxation of discipline protection. In fact, it was this issue that divided the House and Senate most sharply. Now, if a child's IEP team decides that a child's behavior was not a direct result of TS or other disability, the district can immediately place the child in an interim alternative placement. They can now do this immediately regardless of whether a parent believes their child's action was, in fact, a result of TS and calls for a hearing. In the previous version of IDEA, a child had the right to "stay put" during the parent's appeal.

The question of who's responsibility it is to prove whether a child's behavior was the direct result of their disability is the source of a lot of debate. The question is, does the school have to prove that the

child's action was not directly related to his disability, or does the parent have to prove that it was? Courts across the country have come to different conclusions about this, so the question is before the Supreme Court now, and a decision should be reached in a few months.

EARLY INTERVENTION

Early intervention can be very important in the success of a child with TS. The 2004 IDEA now allows funding to go to students who have not yet been categorized under a disability, so they can receive additional academic and behavioral support before they begin to fail. This effort will be focused on kindergarten through the third grade.

A QUESTION OF ELIGIBILITY

Under 2004 IDEA, schools are no longer required to define a learning disability as a severe discrepancy between a child's achievement and his IQ score. This is a small step, but a positive one for TS families. The law, however, doesn't prohibit the use of such a "discrepancy." Instead it leaves it up to the schools.

A CHANGE OF PLANS FOR IEPs

There are a few changes in the 2004 IDEA that affect how IEPs work. Short-term objectives are no longer required. This can be problematic for TS families who benefit from short-term benchmarks to assess their child's performance. Despite the law, parents should still encourage their IEP team to make short-term goals. As a part of this same trend toward taking the long view, 3-year IEPs will now be available. 3-year plans may not be appropriate for children with TS, and it's yet to be determined whether New Jersey will be one of the 15 states to adopt this. And in a coup for convenience and accessibility, parents and guardians can now engage in IEP meetings by telephone or video conference.

There's a lot to the new IDEA, and these are just some key points to consider. For a more complete discussion of changes, see Rebecca Spar's Special Education Alert posted on TSANJ's Web site (www.tsanj.org).

If you're pleased or frustrated with elements of the IDEA Reauthorization, make your opinions known to the New Jersey Department of Education, which is due to create new state regulations.

Announcing the

NEW JERSEY

Center of Excellence

for the Treatment of Tourette Syndrome and Associated Disorders

It took almost seven years from the time her son first exhibited symptoms until the time he finally began to receive treatment for his Tourette Syndrome. They were bounced from family doctor... to pediatrician... to specialist... even to family counseling before being properly diagnosed. It was a trying and frustrating time for the entire family. For the most part, they were on their own because nobody knew exactly what TS was, what to do, how to treat it, or where to send her struggling child for help.

"I've heard hundreds of similar heartbreaking stories from those who seek support from our helpline," explains TSANJ President Faith Rice, whose story is described above. "I know first-hand what a frustration finding proper care can be, and I'm delighted that we are finally able to do something so that other families in New Jersey won't have to go through the same kind of frustrations."

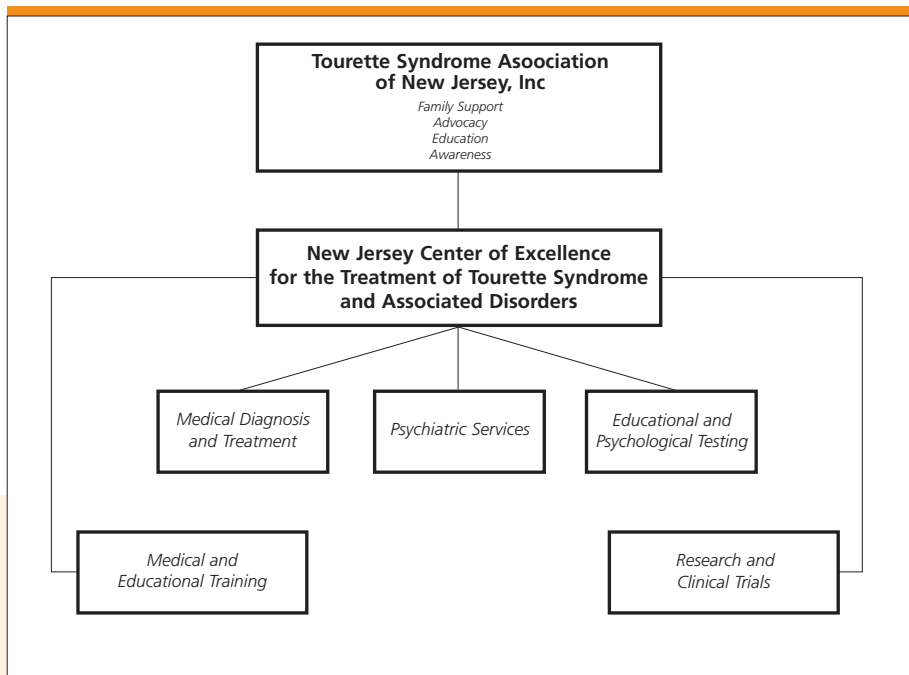
With funding from Special Child Health and Early Intervention Services, New Jersey Department of Health and Senior Services, TSANJ is collaborating with UMDNJ Medical Schools and Rutgers University to create a **New Jersey Center of Excellence for the Treatment of Tourette Syndrome and Associated Disorders**.

The New Jersey Center of Excellence will be patterned, in part, after programs in other states such as the TS/OCD Clinic at the Yale University Child Study Center in Connecticut, and the TS Program at Children's Hospital in Philadelphia. The NJ Center will offer a much-needed diagnosis and treatment resource for the thousands of New Jersey families with TS.

"The demand here is great, and specialists are at a shortage. Just getting an appointment for diagnosis at one of the out-of-state centers can take up to a year, and neither specifically serves the needs of adults with TS," Rice adds. "Kids and adults who need help shouldn't have to wait a year. Even a month is way too long."

Tourette Syndrome affects as many as 7000 New Jersey residents, with thousands more experiencing at least mild TS symptoms. Many people with TS also exhibit symptoms of related neurological disorders, such as OCD (Obsessive Compulsive Disorder), Rage Syndrome and ADHD (Attention Deficit Hyperactivity Disorder), Depression and Learning Disabilities.

"Kids and adults who need help shouldn't have to



This multi-disciplinary center will serve the needs of thousands of families with TS

According to Rice, the New Jersey Center of Excellence will offer an innovative and comprehensive approach for families with TS:

- Medical diagnosis and treatment
- Psychiatric and psychological services
- Educational testing services
- Coordinated patient care among partner and community organizations throughout the state
- Educational training in UMDNJ medical schools and the Rutgers University Graduate School of Applied and Professional Psychology to develop a new generation of professionals knowledgeable about TS and associated disorders
- Professional and educational training for practicing physicians and educators and allied professionals

In addition to serving the medical and psychological needs of TS families, the Center will become a recruitment resource for TS patients and families willing to participate in controlled research studies into the causes and effective treatments of TS and associated disorders. *(See the organizational chart above.)*

“The goal is to create a Center here in New Jersey that can serve as a model for the country, and help more people with TS more efficiently and more successfully,” claims Rice. “It’s going to mean a lot for the thousands of New Jersey families dealing with Tourette Syndrome.”

If you are a family living with TS, this new Center is for you. Call the TSANJ Office at 877 NJTS INFO for details.

wait a year. Even a month is way too long.”

—Faith Rice, President, TSANJ

The Neighborhood

A place for your stories, insights, letters
and personal expressions to come
together and be heard.

Andrew Jemas comments at his Bar Mitzvah

(edited for length)

We study Torah to see the problems that people faced thousands of years ago and understand how they worked through them. The challenge for my BAGEL Group of Bar and Bat Mitzvah friends is to search for the answers to the question of what it means to be an adult.

Now, as all of my family and friends know, I have Tourette's Syndrome, a neurological disorder. My body moves involuntarily: I stutter, I blink my eyes, clear my throat, or sniff—the tics are always changing, and I cannot stop them. This makes it hard for me to fit in the same way that other people do. Many people who first meet me just see a twitchy kid and don't ever see beyond that.

In a way, Tourette's has actually helped me with my outlook on life. I don't have to worry about fitting in because I know that I will never be like everyone else. If people make fun of me, it does not bother me as much as it might someone else, because I am so used to it.

I think I am lucky to be different. It is as if I have a built-in meter that tells me if the person is a surface character who only cares about what is on the outside, or someone who seeks to dig below the surface.

When I think about fitting in, I think about finding a meaningful responsibility, not about trying to be like everybody else. I can, with Tourette's, make a useful contribution to society, and this is something I feel blessed to be able to do. If I was given the choice to completely take away my disorder, I would refuse, because my tics make up who I am. I choose to work with Nature, rather than to fight it.

The Cold Loneliness of the Tourette

—Daniel North

They think that I won't notice
When they try to avoid me in the street
Or how it feels to want to break out
From under an intangible sheet.
The mocking still haunts me behind the glass
As my eye tics and my face erratically creases
Besieged with a mouth that has no control
Of the words it untimely releases.
I see a group of teenagers laugh at me
As I yelp, bark, swear and shout
Taking turns to point at me
And saying "O no! The madman is about".
But I just wish they would look a little deeper
Into the cold loneliness of the Tourette.

Send us your stories of struggle, strength and success to NJTSA@aol.com or mail them to TSANJ Newsletter, 50 Division Street, Suite 205, Somerville, NJ 08876 for our next newsletter.

Support your favorite game and your favorite organization at the same time.

Buy tickets to the LPGA tour at the Hamilton Farm Golf Club through the TSANJ office 908 575 7350.



The LPGA and the Hamilton Farm Golf Club have agreed to support TSANJ by donating back 20% of our ticket sales to support the efforts of TSANJ. This is a great opportunity to see 54 of the greatest women golfers on earth compete for the biggest prize in LPGA history at one of the most beautiful golf courses on earth.

The HSBC Women's World Match Play Championship runs June 30–July 3, 2005.

Call TSANJ for tickets: 908 575 7350.



Training the Brain Rutgers Researches Two New TS Treatments

The TS Program at the Rutgers Graduate School of Applied and Professional Psychology (GSAPP) in Piscataway is researching two treatments that may be helpful for people with Tourette Syndrome.

NEUROFEEDBACK

Neurofeedback is a method of training the brain using an instrument that registers the electrical signal from the brain and provides feedback on a computer screen. Some preliminary studies of neurofeedback therapy have reported the method to be helpful to TS patients as well as others with movement disorders, OCD, ADHD and sleep disorders.

BIOFEEDBACK

The other treatment being researched uses biofeedback from muscle tension, providing computer screen feedback to help train the muscles to relax. The experience of biofeedback is almost always pleasant and relaxing.

HOW YOU CAN PARTICIPATE

The Rutgers TS program is in the process of selecting interested TS patients for a randomized study of these treatments. Patients will be assigned to one or the other treatment group and will have two training sessions per week for 20 weeks. If one treatment proves to be more helpful, participants in the other group will then be offered the more successful treatment.

This therapy will be provided free of charge. Participants will be asked to fill out rating forms before and after their treatment. For more information please call the Rutgers GSAPP Psychological Clinic at 732 445 6111 and press option 4 to speak to a coordinator.

TSANJ + Rx4NJ A formula for greater healthcare access

Rx4NJ is a free service connecting people with free or lower-cost access to their prescription medications. There are hundreds of drug company and government programs to help people afford their prescriptions, but they're no good to anyone unless we know they're out there. That's where Rx4NJ comes in. By visiting www.rx4nj.org or calling 1 888 RX FOR NJ (1 888 793 6765), you can find out if you're eligible for one of these programs.

TSANJ IS PROUD TO BE A SUPPORTER OF SUCH AN IMPORTANT MISSION.

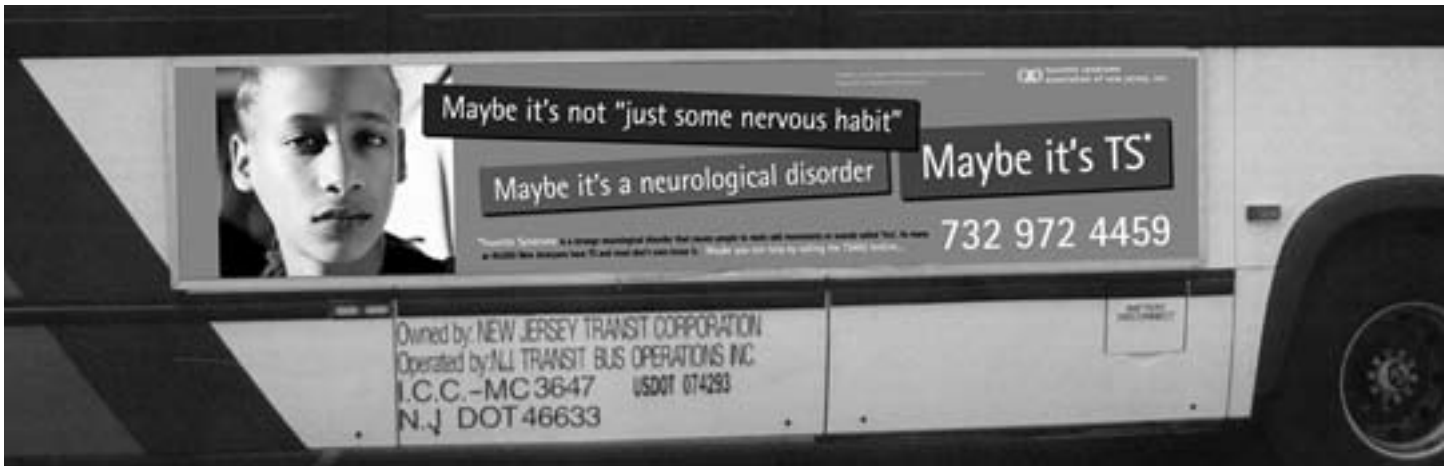
Rx4NJ

TSANJ Public Awareness Campaign Launches in New Jersey

Imagine if the strangers your family bumps into every day had a better understanding of TS. Imagine what that could mean. Even more, what if children could get to a TS diagnosis earlier. The Tourette Syndrome Association of New Jersey, Inc. is helping to make that happen. A new advertising campaign created by Brandspa, LLC, of Montclair, is reaching out to New Jersey through radio, bus cards and billboards, letting them know that, when people exhibit unusual behaviors, it might be TS, and that there's help available.

This statewide mission to raise awareness begins its focus in the inner cities and will radiate out from there.

Buses, trains, billboards and radio stations will be broadcasting TSANJ's message all over the state. In all, it is estimated that over 60% of New Jerseyans will see the advertising, which is funded by Special Child Health and Early Intervention Services, New Jersey Department of Health and Senior Services.



Ads are raising TS awareness by raising an important question.

TSANJ Needs Volunteers

TSANJ provides services that range from help in locating a physician to courses in educating the educators. Whether you've sought help from the services or just quietly thought about it, you know TSANJ revolves

around the dedication of these volunteers.

Many of the people who work the Helpline, run the Support Groups and bring In-services to our schools have

been doing so for many years. Now, they're looking for fresh faces to join the ranks so they can continue the programs that make TSANJ the successful support network that it is.

Think about it; there's nothing more rewarding than knowing that you've helped someone through a difficult time, or made a child's life better by educating his teacher and peers about his disorder.

Everyone is welcome. We need help in all areas, and you'll be trained in whatever position you choose. Reap the rewards of volunteering. Be a role model for your child. Call TSANJ at 732 575 7350 today and ask what you can do to help.

"Do you remember the first time you called the helpline? I do. It was a dark moment when I just needed someone to listen. I can still remember the volunteer's voice as she calmed me down and assured me she would send out some material that would help me to understand more about Tourette Syndrome. She was just a voice at the other end of the phone, but to me she was a lifeline."

—Eileen D'Andrea

Is There a New Support Group Near You?

ATLANTIC-OCEAN COUNTY

Atlantic City Medical Center
Pomona, NJ

MERCER COUNTY

**RWJ Hamilton – Center for Health
& Wellness**
Mercerville, NJ

MONMOUTH-OCEAN COUNTY

**Wellness Center at Jersey Shore
University Hospital**
Neptune, NJ

MORRIS-WARREN-SUSSEX COUNTY

Morristown Memorial Hospital
Morristown, NJ

BERGEN-PASSAIC COUNTY

Valley Hospital
Ridgewood, NJ

BURLINGTON-CAMDEN COUNTY

West Jersey Hospital
Berlin, NJ

MIDDLESEX-UNION COUNTY

JFK Hospital Neuroscience Institute
Edison, NJ

SOMERSET-HUNTERDON COUNTY

Somerset Medical Center
Somerville, NJ

See our Web site for meeting dates and directions: www.tsanj.org



Our TSANJ Support Group Coordinators

LEFT TO RIGHT: Tom Blundetto, Wendy Zwoboda, Deb Kaserkie, Irma Chazotte, Lori Foster, Brad Israelsky, Esther Howard. Seated: Roberta Israelsky

United for TSANJ through the United Way

One of the easiest ways to support TSANJ is by designating it as your charity of choice for the United Way, or Employees Charitable Campaign (ECC), at your workplace. United Way is about supporting the community, and few community needs are closer to us all than the mission of improving the lives of families with TS, advocating for positive change, and supporting TS educational and research goals. So when you're filling out your pledge card, remember that you can direct your contribution to:

TOURETTE SYNDROME ASSOCIATION
OF NEW JERSEY, INC.

50 Division Street
Suite 205
Somerville, NJ 08876

Give us a call at 908 575 7350
if you have any questions.

Upcoming Events



COMING IN OCTOBER!!!
4th Annual TSANJ Gala
to be held at the **NEW LIFE SCIENCES**
ATRIUM at **RUTGERS UNIVERSITY**
*(We'll be sending out details soon —
watch your mail)*

JUNE 2005

- June 6 Burlington-Camden Support Group, Peg Kinsell, SPAN: *Basic Rights in Special Education*, 7:30 pm
- June 8 Bergen-Passaic Parent Support Group – Attorney Lori Wolf: *Estate Planning for Special Needs Families*, 7:00 pm
- June 8 Mercer Parent Support Group—Attorney Herb Hinkle: *Educational Rights for the Special Needs Child*, 7:00 pm
- June 9 Morris-Warren-Sussex Parent Support Group, 7:00 pm
- June 11–12 TSANJ Statewide Meeting, YMCA Camp Bernie
- June 25 *NJ Chapter of American Academy of Pediatrics Convention, New Brunswick, NJ
- June 28 Monmouth-Ocean Parent Support Group, 7:00 pm

SEPTEMBER 2005

- September 5 Burlington-Camden Parent Support Group, 7:30 pm
- September 8 TSANJ Board of Directors Meeting, 6:30 pm
- September 8 Morris-Warren-Sussex Parent Support Group, 7:00 pm
- September 8 Mercer Parent Support Group, 7:00 pm
- September 8 Middlesex-Union Parent Support Group, 6:30 pm
- September 26 Somerset-Hunterdon Parent Support Group, 7:00 pm
- September 27 Monmouth-Ocean Parent Support Group, 7:00 pm

OCTOBER 2005

- October 6 *NJ Chapter of American Academy of Pediatrics & School Nurses Convention, New Brunswick, NJ
- October 12 Bergen-Passaic Parent Support Group, 7:00 pm
- October 25 Monmouth-Ocean Parent Support Group, 7:00 pm
- October 28-29 *NJ Psychological Association Fall Conference
- Also in October 4th Annual TSANJ Gala Dinner*

NOVEMBER 2005

- November 7 Burlington-Camden Parent Support Group, 7:30 pm
- November 10 Middlesex-Union Parent Support Group, 6:30 pm
- November 10 Morris-Warren-Sussex Parent Support Group – Attorney Rebecca Spa: *Special Education Law*, 7:00 pm
- November 10 Mercer Parent Support Group, 7:00 pm
- November 10-11 *NJ Education Association Convention, Atlantic City, NJ
- November 22 Monmouth-Ocean Parent Support Group, 7:00 pm
- November 28 Somerset-Hunterdon Parent Support Group, 7:00 pm

DECEMBER 2005

- December 14 Bergen-Passaic Parent Support Group, 7:00 pm
- December 15 TSANJ Board of Directors Meeting, 6:30 pm
- December 27 Monmouth-Ocean Parent Support Group, 7:00 pm

Atlantic-Ocean Parent Support Group Stay tuned for announcement of dates and times

* Convention attended by TSANJ

Past Events

JANUARY 2005

- January 12 Board of Directors Meeting
January 13 Middlesex-Union-Monmouth Support Group Meeting
January 24 Somerset-Hunterdon-Warren/Mercer Support Group Meeting

FEBRUARY 2005

- February 2 Inservice, Spotswood School District, 9:10 am
February 2 ASPEN Middlesex-Union County Chapter meeting, JCC, 1775 Oak Tree Rd., North Edison, 7:30 p.m.
February 7 Burlington-Camden Support Group Meeting
February 9 Bergen-Passaic Support Group Meeting
February 14 Inservices, Marlboro School District, Mountainside Schools District
February 16 Inservice, Titusville Academy
February 16 Inservice, Lawrenceville

MARCH 2005

- March 1 Bipolar support group: Piscataway Meeting (Details at www.POKIBID.org)
March 2 Bipolar support group: Livingston Meeting
March 8 Bipolar support group: Madison Meeting
March 10 Bipolar support group: Paramus Meeting
March 10 Middlesex-Union/Monmouth Support Group Meeting
March 12 *"Update on Tourette's and Psychiatric Comorbid Disorders: Diagnosis and Treatment"* at NYU in Manhattan.
March 12 School Nurse Conference, 7:00 am–3:15 pm
March 15 *"Organizing the Disorganized Student"*, Myrna G. Wasserman, M.A., Certified Learning Consultant, Educational Therapist. Bleiwise Conference Center, Alex Aidekman Jewish Community Campus, 901 Rt 10, Whippany, NJ
March 16 Association of Learning Consultants
March 24 Regional Family Support Planning Council, Neptune, Presentation, 7–10 pm
March 28 Somerset-Hunterdon Support Group, Speaker: Linda Robinson, Esq. Topic: *Estate Planning for families with children with disabilities*
March 31 East Brunswick School District, Inservice, 1:30–3:30 pm

APRIL 2005

- April 1 Educator's Workshop
Richard Stockton State College
April 2 Educator's Workshop, Kean University
April 4 *"The Impact of Special Needs Children on the Family"*, Debra Smith, MSW, LCSW, Bleiwise Conference Center, Alex Aidekman Jewish Community Campus, 901 Rt 10, Whippany, NJ
April 4 Middlesex County Family Support Group
April 4 Inservice, North Brunswick, 6:30–8:30 pm
April 4 Burlington-Camden Support Group Meeting
April 8 School Counselors Presentation, North Brunswick
April 8 NJ Psychological Association Conference
Woodbridge, Evening
April 9 NJ Psychological Association Conference
Woodbridge, All day
April 13 Bergen-Passaic Support Group Meeting
Speaker Penny Dragonetti: *"Positive Behavior Support Workshop"*.
April 13 Union County School Nurses, Inservice Presentation
April 13 Linden Board of Education, The Parent 2 Parent Meeting, Office of Special Services 6:30–8:30 pm
April 22 Health Fair, Manchester High School, Haledon, 8:30 am–2 pm
April 30
 - Scholarship Applications Due
 - Educator of the Year Nominations Due
 - Health Care Professional Nominations Due

MAY 2005

- May 2 Annual Meeting, TSANJ Board of Directors, 6:30 pm
May 2 Inservice, Harrison School District
May 2 School Social Workers Conference, Princeton
May 12 Middlesex-Union Parent Support Group, 6:30 pm
May 12 Morris-Warren-Sussex Parent Support Group, 7:00 pm
May 23 Somerset-Hunterdon Parent Support Group, 7:00 pm
May 24 Monmouth-Ocean Parent Support Group, 7:00 pm

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