

TSANJ NEWS AND EVENTS FROM NEW JERSEY'S TOURETTE SYNDROME COMMUNITY

today

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Happy New Year from TSANJ!



tourette syndrome association of new jersey, inc.

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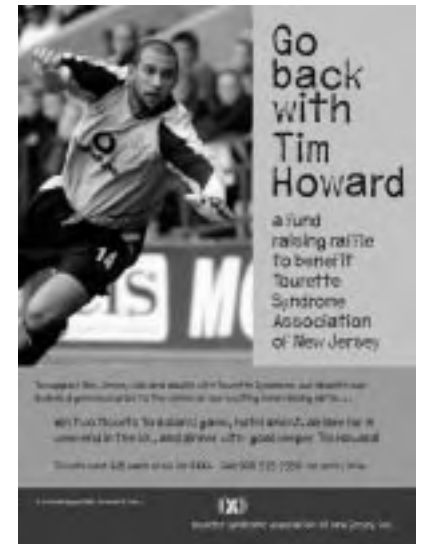
A Camper's Chronicle A Mom's Eye View of Camp Bernie 2005

—Eileen D'Andrea, TSANJ Volunteer and Mom

As I popped the top off the Advil bottle, I smiled at the muscle aches that reminded me of the fun activities that made them happen. TSANJ's First Annual Camp Bernie Weekend may have made me aware of muscles I haven't used in years; but it also made me think of the many NJ families sharing the larger trials and tribulations of TS—and how great it was to meet them.

June 11th and 12th, 2005 proved to be an exciting, fun and memorable weekend as 31 families (totaling 115 people) joined together to experience the kind of camaraderie that you only experience with people who have walked a mile in your shoes.

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Christopher Vitale Scores a Trip to England with Tim Howard

At the last fundraising dinner, Tim Howard was not only the guest speaker, he was also the grand prize. One lucky family was chosen to fly to Manchester, England, to cheer on Tim Howard at a Manchester United Game. As United's opponents know, Tim is the kind of goalkeeper who consistently keeps people from scoring, but in the case of Christopher Vitale, Tim was pleased to allow the win.

Christopher and his family had been looking forward to TSANJ's annual fundraising dinner at Robert Wood Johnson Hospital, and when they heard that Tim Howard was going to be the guest speaker, they could hardly wait.

Christopher knew about Tim's starring role as goalkeeper for one

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tourette syndrome association of new jersey, inc.

Camp Bernie 2005

Continued from cover



Clownin' around

We were greeted at TSANJ's First Annual Family Weekend with the official TSANJ shirts and hats. I had expected to "rough it" in a classic broken down wooden cabins, but had to admit to being pleasantly surprised by a newer building with a large porch. It entered into an inviting gathering spot complete with couches, game tables, and a fire-place. Off to one side we had bunk beds and a nice bathroom with showers for the girls to share, and on the other side of the living room the boys had the same.

BREAKING THE ICE

We quickly dropped off our bags and headed over to the recreation field for some social ice-breaking games, including archery. My 14-year-old boy and 11-year-old girl may not have landed any bull's-eyes, but you wouldn't have known it from the looks on their faces; they had a ball.

At the lunch tent, we got to mingle with other families and let the kids

strike up some friendships. At first you notice everyone checking out each other's tics. Heads shyly turned to see who was making a noise here and there. However, by the end of lunch, you heard things like, "Wow, I used to do that tic, too." It's amazing to see kids connect on that level. I am sure that people there may never have met anyone else with TS, let alone be surrounded by peers with similar symptoms. For me, personally, it was the first time in years that I wasn't worried if my son's tics

were bothering the other diners. Everyone was in the same boat, and it was comforting to see the kids accept one another and to see parents being able to relax and let their guard down.

SLIP-AND-SLIDE FUN

We didn't linger over lunch very long; there was too much to do! It was a very hot day and the staff quickly made up for the lack of an available pool by setting up a giant Slip-and-Slide. A crowd gathered, and it looked like so



115 people from 31 families took part in our family weekend

much fun that I'm sure some of the adults even contemplated taking a turn. I saw one of the dads looking around in a pile of discarded clothing for his son's new TSANJ shirt. He chuckled that it should be easy to find it because (due to his hyper-sensitivity) his son would have already ripped out the tag. "I smiled and said, "Look where you are...I bet more than half of those shirts also had the tags ripped out!"

After paddling around in a canoe with my daughter—the first time I'd ever canoed, and undoubtedly the main reason for my need of Advil—the clouds started rolling in and we headed out to meet with the Rutgers Graduate Psychology Students. It was a mini support group meeting where we were able to meet other parents and the children were introduced to others in their age group to share their experiences with TS.

HALLMARK MOMENTS

After dinner was free time, where we made good use of the game room upstairs playing ping-pong, air hockey, knock hockey and various board

games. We soon caught the whiff of a campfire and made our way to the dining tent to indulge in some S'mores. The children participated in some sing-alongs and some silly skits and then it was time to call it a night. Well, technically, at least.

The end of the organized activities was just the start of opportunities for basketball, volleyball and tetherball (if you had any energy left in you). For those who wanted to wind down, movies were being shown in the dining hall. The adults lounged out on the porch chairs comparing stories until almost midnight, while the kids played card and board games inside the cabins. It was one of those 'Hallmark' moments—kids and adults all sharing common ground.

The next day everyone was up by 7:30 a.m., dressed and headed to the dining hall for breakfast. We hungrily scarfed down our food, knowing we would need some extra energy to get us through the day—horseback riding, a low ropes course and rock tower

“Everyone was in the same boat, and it was comforting to see the kids accept one another and to see parents being able to relax and let their guard down.”

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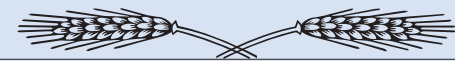
The climbing tower and trail rides were a big hit

climbing. Reluctantly, after lunch, my kids packed their bags and loaded up the car. They had exchanged email addresses with their new friends and were already planning what things they should bring for next year's gathering.

A DEFINING WEEKEND

We don't get many opportunities in life to totally relax and just enjoy our children without interruptions. The staff at Camp Bernie were very kind to the children and never seemed to get ruffled, no matter what tics appeared. Most of all, the children should be applauded

for their behavior, their participation and their compassion for their peers. It was a defining weekend. Here we were, in the middle of nowhere, surrounded by people facing the same problems as my family. I've always felt like the 'odd man out' when people discussed their children. Suddenly, I felt so much a part of things. And I know I'm not the only one who got goose bumps that weekend realizing that we are all part of a 'bigger family', the TSANJ family. [TSANJ](#)



2006 FAMILY CAMP WEEKEND SCHEDULED!

We have scheduled a Family Camp weekend at Camp Bernie again this coming year with an added bonus of an extra night. The weekend will begin with registration on Friday evening, June 9th, 2006 and end at lunch on Sunday June 11th, 2006. This will give us the extra time to do the things we really like, whether it's the climbing tower or archery or canoeing. We look forward to meeting new friends this year and renewing our friendships from last year. **Call the office at 908 575 7350 to join the Camp Bernie Planning Committee.** **TSANJ events are even more rewarding when you get involved.**



New TS Documentary Airs on HBO

HBO's face of TS is smiling on a community group near you. On Saturday, November 12, 2005, a compelling new film entitled *"I have Tourette's, but Tourette's Doesn't Have Me"* made its national debut on HBO. The half-hour documentary, which aired through mid-December, highlights the experiences of over a dozen American kids suffering with the neurological disorder which causes individuals to make uncontrollable vocal and/or motor tics that they "just can't help." Through interviews with kids... 6 and 13, the film explores what it is like to grow up with Tourette Syndrome, what measures kids are taking to control it, and the challenges they face in their efforts to be accepted into the social mainstream as a "normal" kid.

The film is being shown at TSANJ hospital-affiliated support group meetings during the first quarter of 2006.

Please plan to attend one of those meetings to view the film and participate in discussions with other families. Check our website www.tsanj.org for times and locations.

In addition, TSANJ's Community Education Committee will use the film in its presentations to Rotary Clubs, Kiwanis Clubs, and other service organizations throughout the state. Service organizations represent an audience of local business people, corporate employees and community leaders we might not otherwise reach. This film adds a face to a very misunderstood and underdiagnosed disorder and we are delighted to be able to use it to create awareness throughout New Jersey.

The TSANJ Community Education Committee is looking to add volunteers from across the state. If you are interested in participating in this community outreach program, please give us a call at 908 575 7350. [TSANJ](#)

Thanks!

TO OUR TSANJ VOLUNTEERS

TSANJ is your statewide Tourette Syndrome resource.

In New Jersey, we provide support groups throughout the state; a 24-hour help line; in-services for schools; programs and events like Camp Bernie and annual student scholarships, education, awareness and so much more.

And most of this is the direct result of the hard work and dedication of our wonderful volunteers! A big THANK YOU! to one and all who make TSANJ and all the things we do possible.

If you or someone you know wants to lend a hand, support and services are always welcome. Please call us at 908 575 7350 or drop an e-mail to njtsa10@aol.com.

New Jerseyans Participate in TS Genetics Research

In 2005, TSANJ sent letters to all member families asking them to participate in the "first-ever" genetics research study on Tourette Syndrome to be conducted in the state of New Jersey. Hundreds of families responded by completing a questionnaire and declaring their interest in participating. We are delighted to tell you that the genetics study will go forward and that all families who have indicated interest will be contacted starting in February 2006.

This important genetics research will be conducted by an experienced consortium of professors, physicians and researchers. The director of the study has collected patients from around the world for similar studies of other disorders, and his work has led to the discovery of genes responsible for a form of kidney stone disease, for susceptibility to alcoholism, for a form of muscular dystrophy and for other diseases. [TSANJ](#)

We urge you to participate. For more information, please call TSANJ at 908 575 7350.

Now's the time to support TSANJ the "United" way

THE UNITED WAY HAS KICKED OFF ITS CAMPAIGN AROUND THE COUNTRY, SO IT'S AN EASY WAY TO SUPPORT FAMILIES LIVING WITH TOURETTE SYNDROME RIGHT HERE IN NEW JERSEY. BY DIRECTING YOUR PLEDGE TO THE TOURETTE ASSOCIATION OF NEW JERSEY, YOU'LL BE CONTRIBUTING TO THE SUPPORT OF FAMILIES, EDUCATION, RESEARCH AND ADVOCACY FOR TS IN YOUR OWN BACKYARD.

Ask your employer for a pledge card and direct your contribution to:

Tourette Association of New Jersey
50 Division Street
Suite 205
Somerville, NJ 08876

And if you're a state employee, you can contribute to TSANJ through the Employee Charitable Campaign by using the code #6563.

GIVE US A CALL AT 908 575 7350 IF YOU HAVE ANY QUESTIONS.

Educating the Educators: TS IN THE CLASSROOM

Tourette Syndrome is a complex disorder that has the potential to disrupt learning for the student with TS or his classmates. The biggest problem is that TS is so often misunderstood. It can be disruptive or unnerving in a setting where people don't understand it, and therefore don't know how to manage it.

Children with the motor and vocal tics of TS are often disciplined as if their tics were bad behavior. This misunderstanding can impact a child's educational performance and emotional wellbeing. Teachers and administrators want to create the best learning environment they can, but if they don't have the latest information on TS, they are at a great disadvantage.

TS takes such unique forms in each child that it's not easy to apply universal methods for managing it. But when teachers, administrators, parents and students are working together, the foundation can be laid for success.

HOW THE WORKSHOPS WORK

TSANJ's inservice workshops bring key advice and insights about Tourette Syndrome and its associated disorders right to the educators. These are 1-2 hour programs for both public and private schools, as well as colleges, universities and community group settings.

Because TSANJ is registered with the New Jersey Department of Education, those who participate earn a professional development certificate. Inservice instructors have been trained to follow a curriculum designed by the National Tourette Syndrome Association, and are usually teachers, school nurses or have a medical background—and most have first-hand knowledge of TS.

INSERVICE INSTRUCTORS DEMYSTIFY TS

- Creative classroom coping
- Ideas about IEP and 504 plan goals
- Criteria for diagnosis or clinical assessment of TS
- Current medical interventions
- The challenges and strengths of those with TS
- Instruction and testing strategies
- Creating a learning environment that works for all students
- Partnering with parents and teachers

Beyond the tics, these are just kids like everyone else in the classroom. Teachers and administrators and other school staff can provide a more ideal learning environment for all students when they have current information on TS.

To learn about scheduling an inservice workshop for your school district, call TSANJ's HelpLine at 732 972 4459. [TSANJ](#)

David Brummer Raises Money for TSANJ With a Twist of the Wrist



David Brummer (right) and his friend Dean Roncati sell bracelets from the back of the Brummer family car

David Brummer is a 13-year-old boy who lives in Livingston, New Jersey. When he was approaching his Bar Mitzvah, he was fulfilling his commitment to community service and philanthropy as a pet therapist, much to the delight of the residents in the nursing homes he served. Suddenly, though, one day he was struck by something and he went to his mom and said "I have Tourette Syndrome. I think I should be doing something for that too."

He felt strongly about this. After all, he'd enjoyed participating in TSANJ events like the dinner with Tim Howard and the trip to the New Jersey State House. And connecting with other kids with TS was important to him. When asked about his decision to raise money for TSANJ, David explains, "I think it is important for everybody to at least try to pitch in for the cause."

THE BRACELETS BRAINSTORM—LENDING A HAND FOR TS

So he and his mother Suzanne called the Tourette Syndrome Association to see if they had any fundraising programs in place, if they had anything to sell. Although there was nothing in place then, David lead the charge. He searched out a silicone company that would produce the bracelets that had become popular in school. He chose the colors, teal blue and a tie dye of blue and green, and he chose the theme: "Free to be me" is what the bracelets would say.

Then it was time to get the word out. David created a poster to advertise his charitable work at his Temple. Because he was working with the therapy dog and raising money for TS, David called his project: "Dogs and Tics (but no fleas)."

A PHILANTHROPIC FRENZY

David sold them at school, with the help of his brother, Aaron. He sold them at fairs, and sells them tirelessly wherever he goes. The bracelet idea was also put to the test at Camp Bernie, where it was met with unbridled enthusiasm as David and his newly found friend, Dean Roncati, sold them out of the back of David's family car. They grew close during camp, and when they left, Dean brought bracelets back to his home in Bergen County. When he came down to David's Bar Mitzvah a few weeks later, Dean was carrying a bag of cash for the TS cause.

If you didn't meet this quick-thinking young man at Camp Bernie, they'll have a booth at the National Conference of TSA in April. Be sure to have \$3 in your pocket for one of these coveted wristbands.

For the record, so far David's bracelets have raised a whopping \$1,068 for TSANJ. **If you'd like to help, you can e-mail David at suzanneklar@aol.com. [TSANJ](#)**

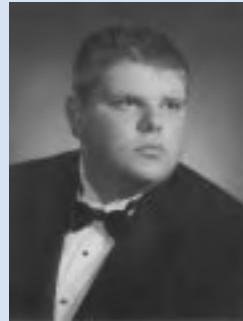


It's worthy to note that the Brummer family is no stranger to innovative charitable acts. David's dad Marc, the owner of Hobby's Delicatessen in Newark, was the mastermind of what's become known in the media as "Operation Salami Drop," supporting the troops with his deli delectables. \$10 will get salami to a service man or woman in Iraq. Donations can be made through the website operationsalamidrop.com.

TSANJ Scholarships go to Three New Jersey High School Seniors

In fall 2005, three young men with Tourette Syndrome got a healthy jump-start at their new colleges with a \$1,000 educational scholarship awarded by TSANJ. Now in its fifth year, TSANJ's scholarship program was created to help promote the success of students living with Tourette Syndrome, and to help advance them in the community. As evidenced in their essays and recommendations, having Tourette Syndrome has contributed to making these three young men determined and accomplished.

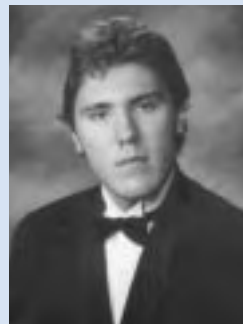
Congratulations!



MEET WESLEY LANZ

Fueling the fire of a diesel mechanic

Whether it's because of the inherent satisfaction in the power to fix things, of being in a position to help others by making their critical machines work, or even the practical understanding that this is an industry in demand, Wesley Lanz is headed to Universal Technical Institute to earn his chops as a diesel mechanic. Throughout his life, he has hit the walls TS put before him and worked hard to overcome them. Wesley explains, "I feel I have accomplished a lot, despite dealing with Tourette Syndrome; however, I have my adult life ahead of me with many more barriers to overcome." Wesley is a resolute young man who has chosen a profession that offers rewarding challenges and the pride of good workmanship.

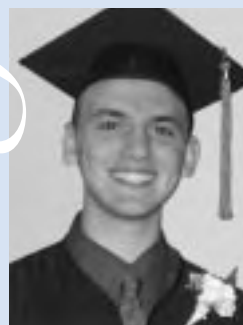


MEET PATRICK ANDRUSHIEWICZ

From martial arts to the fine arts

As a blue belt in tae kwon do, Patrick Andreushiewicz knows a thing or two about self-discipline and focus. These are skills complemented by what his school counselor refers to as charm, intelligence and creativity, all of which come together in a portfolio of personal advantages that will serve him well in pursuing art at Pratt Institute. He has overcome a lot in dealing with Tourette Syndrome, and has flourished despite and because of it. He has already been commissioned to create a book jacket and has been recognized in many art shows and competitions. His artistic interests look toward a

career in animation, a vocation that relies upon the optical phenomenon of "persistence of vision," a character trait Patrick has demonstrated throughout his life.



MEET JOSHUA JAY

Different by design

Joshua is many things—oboist, French-speaker, anime enthusiast—and unabashedly different. He has said "growing up with Tourette's, I had to get used to being different... Having to acclimate to feeling somewhat different eventually allowed me to unreservedly pursue certain uncommon interests." It is this renaissance man quality that makes him a good fit for Yeshiva University. His principal describes him as "a true scholar" with "real intellectual curiosity and openness to new ideas and experiences." Not unlike the Japanese anime he loves, he is a colorful and vibrant character. And it's not surprising

that for many years he has played the oboe, an instrument that is difficult to master, and the instrument that sets the pitch for the whole orchestra. Joshua explains, "overcoming Tourette's has been all about control and my level of resolve."

Christopher Vitale

Continued from cover

of the most prominent football clubs (soccer to us) in the world. He knew about Tim's battle with TS, and he was looking forward to hearing what Tim had to say. At the dinner, as he hung on Tim's every word, Christopher never imagined it would be his name that would be announced as the winner of the "Go Back with Tim" raffle. But before he knew it, he and his family were flying across the Atlantic to England. Christopher's parents and grandparents were with him as they counted down the time zones—Christopher's devoted support team who would soon be cheering on another kind of team entirely.

Christopher and his mom had dinner with Tim and his wife Laura, who was 4 months pregnant the time. Both families then all sat together as Tim regaled

them with stories, and spoke of his struggles of being a teen with Tourette Syndrome. Although, for Christopher, this seemed truly the height of the trip, the crowning moment was when his whole family was seated as Tim's guests at a game, cheering him on in a stadium electric with excitement. Looking back on the trip, Christopher's grandmother Kathy remarks that "watching Tim in action playing goalkeeper reinforced

Christopher's belief that anyone who suffers from Tourette Syndrome can overcome any obstacle." [TSANJ](#)



ABOVE: Christopher and his mother Dina enjoy dinner and conversation with Tim and Laura Howard at a Manchester restaurant. BELOW: Tim Howard and Christopher Vitale



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"Tim gives me hope just knowing all that he's accomplished. He made me feel normal."

—Christopher Vitale, Winner of "Go Back with Tim" Raffle

\$20,000 for TSANJ was a Slam Dunk, Thanks to Hoop-A-Paluzza



Emily Levitt with Bridget Taylor after winning the iPod Nano in the hoola hoop contest, Emily chose to give it to one of the children with autism.

Every year, Hoop-A-Paluzza chooses worthy children's charities for its successful fundraising events. This year TSANJ's Inservice Program for educators was

chosen to catch a much-needed \$20,000. The TSANJ In-Service Program provides training to educators to enable teachers to better recognize and work

with TS and its associated disorders in the classroom.

On November 6th, Millburn High School was transformed into an exciting carnival-like celebration as participants backed by sponsors took their chances with 20 free throws at the basket. It was a day filled with activities for children of all ages, like moon bounces, inflatable slides, music, crafts, face painting, tattoo art and more.

In previous years, tens and even hundreds of thousands of dollars have gone to charities like the Burn Center at Saint Barnabas, Pediatric Diabetes Support Program at Morristown Memorial Hospital and for The Valerie Fund, which assists children with cancer and blood disorders.

HOOP-A-PALUZA, INC., a New Jersey nonprofit corporation (HAPI), is a public charity that concentrates its efforts in improving the physical and mental well being of children in New Jersey. The Foundation focuses its grant making on organizations that serve children locally, including children's health services, outreach to affected families, and pediatric medical or scientific research.

Thank you HOOP-A-PALUZA! [TSANJ](#)



New Jersey Center for Tourette Syndrome.

A MUCH NEEDED RESOURCE FOR NEW JERSEY FAMILIES

Until now families affected by Tourette Syndrome in New Jersey were hard pressed to find a sufficient support network where they could access specialists for diagnosis and treatment and where they could

participate in influential research to help advance the understanding of TS. Educators and community organizations had few resources to turn to for training and coordination of care.

THERE'S NOW A PLACE FOR ANSWERS, UNDERSTANDING AND ACTION

Things are changing now with the opening of the New Jersey Center of Excellence. The Center is the result of a partnership between UMDNJ Medical Schools, Rutgers University, and TSANJ. It has been created to help people with TS more effectively and more efficiently by offering

innovative and comprehensive approaches to treatment and by training a new generation of professionals who will be knowledgeable about TS and its associated disorders.

CENTER SERVICES INCLUDE THE FOLLOWING IMPORTANT ACTIVITIES:

- Medical diagnosis and treatment
- Psychiatric and psychological services
- Educational advocacy and support
- Coordinated referrals to practitioners throughout the state
- Educational training in UMDNJ medical schools and the Rutgers University Graduate School of Applied and Professional Psychology

To find out how the Center of Excellence could help you, your family, or your community, call 1 877 NJTS INFO

TSANJ at the Annual Teachers' Convention

On November 10 and 11, 2005 TSANJ again had a booth full of helpful information and volunteers, and conducted a 3-hour workshop at the NJEA Convention in Atlantic City. Better known to New Jerseyans as "The Teachers Convention," this annual convention is the largest event of its kind in the world with more than 65,000 educators attending each year. This is the fifth year TSANJ has participated. There were 11 volunteers at the TSANJ



Volunteers at the TSANJ Booth in Atlantic City

booth answering questions about TS and distributing literature to the thousands of teachers, school nurses and administrators who stopped to inquire. A highlight of the convention is the large number of professional development workshops available

to attendees. Our workshop, "Understanding TS in the Classroom" conducted by volunteer Julie Swenson, M.Ed. was well received by the 450 educators who attended.

If you are interested in volunteering for this event in 2006, or for any of the other professional conferences in which TSANJ participates throughout the year, please call us.

Some of the other conferences include: American Academy

of Pediatrics (NJ), NJ Conference on School Health, NJ School Nurses Association, NJ School Counselor Association, NJ School Psychologists, NJ Psychological Association, Association of Learning Consultants, and more. [TSANJ](#)



Coming this May!

Watch your mailbox for an invitation

Featuring special guest JAY TISCHFIELD, world renowned geneticist, and director of the National Institutes for Mental Health DNA & Cell Repository at Rutgers University

We need your help with corporate supporters... have any corporate friends who might like to sponsor our dinner?; or perhaps you'd like to be on the Dinner Planning Committee. Call the office at 908 575 7350 to get involved.