

# support services

TSA National, 42-40 Bell Blvd. Bayside, Queens, NY -718.224.2999-

## Groups for Parents

Twice per month,  
Monday at 6:00 pm.\*

Our Manhattan support group meets periodically through the year; please check our website, [www.tsa-usa.org](http://www.tsa-usa.org), for dates.

## Group for Adults

Twice per month,  
Tuesday at 7:00 pm.\*

## Group for Children

Twice per month,  
Monday at 6:00 pm.\*

\*Please call 718.224.2999

## Information Line

If you have questions about Tourette Syndrome or any of our services in the NYC chapter, call 646-395-0162.

## Referrals

TSA maintains a list of medical, mental health and legal professionals who are able to diagnose, treat and aid individuals with TS. To obtain a copy of our referral list, call 646-395-0162 or visit [www.tsa-nyc.org](http://www.tsa-nyc.org).

## Counseling

The New York City Counseling Program offers individual, family and couple counseling and case management for people with Tourette Syndrome and their families who live in New York City. Services are provided by Certified Social Workers, professionally trained and experienced in issues related to TS.

## Education Advocate

The Chapter has an educational advocate who can speak with teachers to explain TS. Call 646-395-0162 for more information.

Additionally, upon request, educational presentations are offered to schools, hospitals and other settings. Fees are based on a sliding scale. However, no one will be denied service if they cannot pay the fee. Services are offered at two locations:

26 Court Street (@ Renssen Street)  
Suite 504  
Brooklyn

42-40 Bell Blvd.  
Bayside, Queens

For an appointment, call Emily Kelman-Bravo or Evan Michaels at 718-224-2999

## wanna be in touch?

please send your e-mail address and you will receive all the latest news in the tourette community as it happens via e-mail!

 tourette syndrome  
association, inc.

new york city chapter

# newsletter

winter 2010

Keep your calendars open for the upcoming

## Tourette Talk and Annual Board Meeting

The NYC Chapter will soon be hosting the Annual Board Meeting where new and returning board members will be elected for the year 2010. If you are interested in becoming a board member, please email us your name and let us know that you would like to be nominated. Members will be elected on February 21st at Volunteers of America, 340 West 85th Street (between West End Avenue and Riverside). The Tourette Talk and Board Meeting will run from 1pm to 3pm.

## Our Tourette Talk will feature the following speakers:



**Dr. Moira Rynn** is Deputy Director of Research in the Division of Child and Adolescent Psychiatry, Department of Psychiatry at Columbia University (CU)/ New York State Psychiatric Institute (NYSPI). She is the Medical Director of the Columbia University Clinic for Anxiety and Related Disorders (CUCARD) and Director of the Children's Day Unit and the Child and Adolescent Psychiatric Evaluation Service at NYSPI and CU. Dr. Rynn's area of research has been focused on pediatric psychopharmacology with an emphasis on anxiety disorders, specifically general anxiety disorder and obsessive compulsive disorder. Dr. Rynn completed several studies in the area of pediatric anxiety studies showing the ef-

ficacy of sertraline and venlafaxine ER. Dr. Rynn participated as an investigator in the Pediatric OCD Treatment Study (POTS) Team. As co-Principal Investigator, Dr. Rynn worked on the largest published study in pediatric anxiety disorders, the Child/Adolescent Anxiety Multimodal Treatment Study (CAMS) which showed the treatment efficacy of the combination of cognitive behavioral therapy and medication. In addition she is currently examining the efficacy of novel compounds for the treatment of pediatric obsessive compulsive disorder. Dr. Rynn has been providing pharmacologic treatment for adults and children diagnosed with mood and anxiety disorders since 1991.

**Anthony Puliafico, PhD** is an instructor in the Division of Child and Adolescent Psychiatry at Columbia University and co-director of psychology at the New York State Psychiatric Institute Children's Day Unit. He is also a clinician at the Columbia University Clinic for Anxiety and Related Disorders, where he provides individual and group treatment for chil-

dren, adolescents, and adults with anxiety and mood disorders. Dr. Puliafico specializes in the cognitive-behavioral treatment of anxiety disorders, including obsessive-compulsive disorder, social phobia, and generalized anxiety disorder. He is also actively involved in research examining the treatment of anxiety disorders in children and adolescents.



 tourette syndrome  
association, inc.

New York City Chapter TSA

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New York, NY 10024

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This newsletter is published by



**Tourette Syndrome Association**  
**New York City Chapter**  
PO Box 273,  
New York, NY 10024

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## What The Chapter Does

- **TouretteTalks** - periodic presentations by experts on various aspects of TS
- **Annual Mentoring Brunch** - successful adults with TS talk about their lives
- **Social Get-Togethers** for families and friends
- **Information Phone Line** - staffed by volunteers
- **Educational Advocacy** - trained educators who raise awareness about TS in schools
- **Annual Gala** - fundraising and networking event
- **Medical and Mental Health Referrals** - provided by mail or via our website on request
- **Newsletters** - in depth publication, twice a year
- **Public Relations** - ongoing effort to educate the public about TS
- **Comprehensive website** - www.tsa-nyc.org
- **Literature** - brochures, bookmarks, public service announcements explaining TS

## Support NYC TSA Today

The New York City Chapter of the Tourette Syndrome Association provides assistance and information to newly diagnosed individuals and their families.

The membership dues paid to TSA National only cover a fraction of the costs needed to support our families. Please help us by making a financial contribution to support our efforts to advocate and raise awareness, provide training, and day-to-day support to those who need us most. Donations are vital to the organization's ability to provide the community with both services and events. **Your donation is 100% tax deductible.**

You can make a donation by going to our website at [www.tsa-nyc.org](http://www.tsa-nyc.org) and clicking on the "Donate" link. You will receive an autogenerated email confirming your donation for tax purposes. You can also send a check in the name of the New York City Chapter of the Tourette Syndrome Association to: **PO Box 273, New York, NY 10024**

## THANK YOU FOR YOUR SUPPORT.

## The Fastest Way to Hear of Upcoming Events and the Latest News!

Do we have your most recent email address and mailing address? Call us at (646) 395-0162 and tell us your email address, or email us at [chapter@tsa-nyc.org](mailto:chapter@tsa-nyc.org) and let us know you would like to be added to the mailing list. You will receive all of the latest Chapter news as it happens.

This newsletter is published twice annually. Opinions expressed in this publication reflect the views of its editor and contributors. They are not necessarily the views of the Tourette Syndrome Association.

While we will attempt to respond to all mail, we are not able to answer medical questions.

The TSA, Inc. and the New York City Chapter do not endorse products, services or manufacturers. Such names appear only as information for our members. TSA assumes no liability whatsoever for information about or the use of any product or service mentioned.

Support group leaders and individual volunteers who have agreed to accept telephone calls concerning Tourette Syndrome are knowledgeable about TS; however, their comments reflect their personal background with TS and do not necessarily reflect the views of the chapter.

## Taking the Marathon in Stride

Jonathan Marks



My brother Brian, who has Tourette Syndrome, inspired me to run the 2009 NYC Marathon and raise money for the TSA. Watching Brian triumph over TS and meeting people at the TSA National and NYC Chapters inspired me to not only fundraise, but to help the TSA in any way that I can. Being involved with the TSA enables me to educate others about the "real" effects of Tourette Syndrome. Fundraising and training for the NYC Marathon was an emotional experience. I take pride in the money I raised, and I look forward to seeing it put to good use. I hope to continue to work with, and raise money for the TSA for years to come.

## REGISTRATION NOW OPEN!

**Tourette Syndrome Association, Inc.**  
**2010 National Conference**  
**April 15 - 18, 2010**  
**Hilton Alexandria Mark Center**  
**Alexandria, VA**

We're delighted to announce that registration for TSA's 2010 National Conference is now available on the TSA Website [www.tsa-usa.org](http://www.tsa-usa.org)!

### Who Should Attend?

*Families and individuals with a new TS diagnosis – for the Newly Diagnosed Seminar and other informative sessions!*

*People of all ages with TS and their families – for the latest information, updates, and networking*

*Chapter/Support Group leaders and volunteers who serve people with TS – for the Leadership Conference April 14-15 and informative sessions throughout the weekend*

From the TSA home page, click on the Conference Information link to learn more about what will be offered throughout the conference weekend. From there you can click to register online or download a registration form to mail in with your payment.

We look forward to seeing you in April!

## TEEN TIME LAUNCHED

Teen Time is a new initiative of the NYC Chapter. The focus of the initiative is on getting teens with TS together from NYC, Hudson Valley, Long Island and New Jersey to share their experiences and have fun!

January 16th was the kick-off of Teen Time for TSA NYC at Dave & Buster's in Manhattan.

The group met first for lunch at the venue, the kids talked to each other over chicken fingers, sliders, French fries, mini-pizzas, chips & salsa, and sodas. When they had their fill, everyone headed to the game room. The teens

were issued pre-paid game cards and were off to play the large array of games! They all racked up hundreds of tickets and redeemed them for stuff they wanted in the Dave & Buster's Shop.

Three parent volunteers were on hand to chaperone. The Dave & Buster's staff was outgoing and welcoming—everyone had a blast. The age range for the group spanned 12-18.

One parent commented "Just wanted to thank you again. Everyone had a great time."

The Teen Time group is very grateful for the TSA-NYC Chapter's ongoing sponsorship of this program to get kids with TS together for casual interaction in fun settings around NYC.

Stay tuned for news on our next event in 2010..... in the planning stages now.



# Katie Robinson

## Interview with the NYC Chapter Administrative Assistant



**Q:** How did you become involved with the New York City Chapter?

**A:** Shortly after becoming a member of TSA, I moved back to New York City to attend graduate school at Columbia University Teachers College. When I emailed TSA to find out how I could become involved with the chapter they notified me that there was an open part-time position for an administrative assistant. It was perfect timing!

**Q:** What do you do when you are not doing chapter-related activities?

**A:** I'm getting certification in Teaching English to Speakers of Other Languages. I am a licensed school counselor and have previous school counseling and teaching experience, but with the job market the way it is, I was having trouble finding a school counseling position in New York City. I decided to pursue the additional certification to increase my odds of getting hired. I previously taught English in Japan for two years through the Japan Exchange and Teaching Program, so I knew it would be an interesting subject to study. I also am a licensed real estate agent and do real estate on the side to help pay for school!

**Q:** With all of the different activities that you do, how do you maintain balance?

**A:** I find that jogging is a real stress reliever for me. I also enjoy walking my dog through the neighborhood park every day. Having a creative outlet is helpful too- lately I've been working on creating my own jewelry.

**Q:** How are you connected to TS?

**A:** I developed tics at the age of 8, and was diagnosed with TS at age 9. I was and still am the only member of my family to have TS, so it came as a bit of a shock to them. I actually felt relieved with the diagnosis. Finally I understood what I was struggling with and could see that I didn't need to feel bad for not being able to control it. With diagnosis, I could create a plan of action to manage my tics. My vocal tic eventually went away as did many of my outward tics, but I still struggle with less visible tics on a regular basis. Being involved with the NYC Chapter has been a meaningful experience for me because I understand the struggles of TS on a personal level.

**Q:** Did you at one point or do you currently take medication for your tics?

**A:** As a child, I was given a small dose of Haloperidol on a daily basis which is no longer a common mode of treatment for TS. I decided to stop taking it at about the age of 13 and haven't taken medication for TS since that time. I didn't feel that the medication was helping anymore so instead I focused on managing my TS through natural means.

**Q:** How did you and your parents deal with your TS in your school setting?

**A:** My parents and I struggled at first about what to do. I fought against being put in the special education program as it would have isolated me from my peers in that particular school, and my parents agreed. The one accommodation I found really helpful was the special permission I had to step out of the classroom and get a drink of water when I needed it. It gave me an opportunity to release tics and therefore reduce my stress level about being in the classroom and being able to manage my tics.

### Do you know a child who is frequently misunderstood at school because of his or her Tourette Syndrome?

We are here to raise awareness amongst educators and school communities about Tourette Syndrome and how it might affect school life for a child, as a part of our campaign, One Tic at a Time. Diane Rabstenek and Katie Robinson, both experienced educators, are available to speak at schools upon request. Diane Rabstenek is a licensed Speech Pathologist and a trained Montessori teacher with extensive experience in schools. Katie Robinson is a certified school counselor who has worked as both a counselor and teacher in public schools and also has TS.

If you would like help explaining Tourette Syndrome to your child's educators and school professionals, please call the chapter at 646-395-0162 or email us at [chapter@tsa-nyc.org](mailto:chapter@tsa-nyc.org).

## Nominees for the Board

**Lil Arbogast**, *chair, (returning)* has a teenage daughter with Tourette Syndrome. Raising a child with TS has inspired her to take an active role in the TSA community. Lil works in the apparel industry and her husband, Jeff Feuer, works in the real estate industry. She and her family live in Manhattan.

**Frank Rango**, *treasurer, (returning)* a resident of Manhattan, has worked in the financial industry for more than twenty-five years. He has been a constant supporter of the Chapter and served as co-chair of one of the Chapter's most successful annual fundraisers. Frank and his wife have several relatives with Tourette Syndrome.

**Chelsea White**, *secretary, (returning)* moved to Astoria, Queens in September of 2005 and soon attended her first TSA-NYC event: the bowling social in January 2006. From there she did some volunteer work for the TSA NYC website and has become a co-chair of the Young Adult Committee with Jimonn Cole.

**Hilary Bowers**, *(returning)* After many years in marketing and PR in the film and fashion industry, Hilary started banzai! to service a highly selective group of clients in the luxury category. Clients include: Marithe + Francois Girbaud, HOUSE of WARIS, YOOX.COM, The Apartment, Travel Alberta Tourism, Karen Karch and more.

**Linda McAndrew**, *(returning)* is a family therapist, licensed in Creative Arts Therapy, working for the Children's Aid Society in a program for at-risk teens and their families. She is the mother of an adult son who has Tourette Syndrome and OCD. She has been active in the Family TSA Support Group for many years and attended most of the Chapter events. She has also been actively involved with the OCFoundation.

**Dan Kamanga**, *(new)* is a former senior vice president of investment banking who has worked on Wall Street for over twelve years. He recently began his own investment firm. He has an MBA in finance and strategy and has been

awarded the CFA designation. Dan first became involved with TSA last year and has looked for ways to volunteer his time and expertise.

**Jonathan Marks**, *(new)* a resident of Manhattan, has worked in the financial industry for the past 2 years. His brother has Tourette Syndrome, and has inspired him to raise money for the TSA. His first experience was raising over \$6,500 from sponsors before he ran the 2009 NYC Marathon. He looks forward to continuing to raise money and to working on innovative ways to educate the community about Tourette Syndrome, with the TSA-NYC chapter, for many years to come.

**Diane Rabstenek**, *(new)* has an MA in Speech and Language Pathology and is Montessori trained. As a Speech Pathologist, she worked for 15 years with children and their families providing direct therapy as well as parent education for all age groups, including adult clients, mainstream programs, high-risk programs and infant/early childhood education programs. She took time to be a stay-at-home Mom and raise 2 children, now 29 and 26 years old. As a teacher, she worked in a Montessori school serving children from 3-12 years of age and their families for 15 years. While there, Diane helped begin the Learning Specialist Department in the school and worked directly with children with learning issues and provided guidance for their teachers and parents. Diane became involved with TSA while teaching through working with a student diagnosed with Tourette Syndrome. She is currently involved with TSA-NYC working to increase awareness, especially fostering early recognition and intervention, amongst educators and school professionals about Tourette Syndrome and discover the support they can provide to the student and parents. Diane has lived on the UWS of Manhattan, where she and her husband raised their children, for 37 years.

**Caroyl Renner** *(new)* A native New Yorker, Carolyn has a BBA from Baruch College, CUNY, with a major in Industrial Psychology. Prior to leaving the work-

force to care for her 3 children, Carolyn worked in Training and Development at Bloomberg, LP. She is a certified yoga instructor, teaching beginner/intermediate hatha yoga. She has served on the Executive Board of her children's elementary school for 2 years and is currently involved in numerous fundraising projects and event planning including an annual auction and spring fair. She is a volunteer ESL teacher for new moms at a parenting center run by the Dominican Sisters. Her 9 year old son was diagnosed with TS two years ago.

**Linda Baker** *(new)* is a resident of New Rochelle located in Westchester County. She is the mother of three sons, all three years apart in age. Her oldest son, who is now 18, was diagnosed with Tourette Syndrome at age 12 and went from a well rounded, popular kid to one with pronounced motor and vocal tics. With support and education, he learned to self-advocate during this challenging transition from middle school to high school. He went on to become the star pitcher of his H.S. Varsity Baseball team. He inspired the family to want to be involved in a greater good. They admire and respect him for all his accomplishments. For many years, Linda worked as a NYC special education teacher and made the move three years ago to the suburbs where she is employed as a special education teacher in the Mamaroneck School District. She looks forward to serving the many needs and interests of the diverse members of TSA and sharing her time and energy with a great community of people.



We welcome **Dr. Ruth Nass** to our Honorary Board. Ruth Nass, M.D., is a professor of Pediatric Neurology and Child and Adolescent Psychiatry at New York University. She is also a member of the NYU Child Study Center. Thank you Ruth, for your support.

# The Mentoring Brunch this fall was a hit!



Guest speakers Sue Conners, Gary Schneidkraut, Jen Zwilling and Kellie Haines.

Over 120 local TSA members came out to listen to this year's outstanding speakers at the annual Mentoring Brunch, where guest speakers who have achieved success in their respective fields share their experiences with fellow members of the TSA community.

The ever popular event provides an opportunity for young people to meet with role models, while giving parents and adults a chance to exchange information and ideas with one another.



Volunteer photographers from Kingsborough Community College's Learning Service Program captured the eventful day on camera as a community service

project to raise awareness and educate others about TS. A special thanks goes out to Professor Donald Donin, Professor Susan Spivack, Andy Ventura, and all the volunteers from Kingsborough.

#### The mentors at the brunch included:

**Jen Zwilling**, the co-founder of National TSA's Youth Ambassador Program, who has received several awards for her work including People Magazine's Heroes Among Us Award.

**Sue Conners**, a former middle school French teacher of 30 years who currently serves as an educational specialist for students with TS all over the country.

**Gary Schneidkraut**, also known as Gary Scott in the entertainment world, is a stand-up comedian who currently works for one of New York's most iconic hotels as a Catering Coordinator and Sales Manager.

Finally **Kellie Haines**, a talented entertainer who delights and amazes audiences of all ages with her lively and interactive performances. Kellie draws on her background in theater, puppetry, dance and clowning as she explores a wide variety of topics with humor, compassion and boundless energy.

**Dr. Gary Heiman** was the guest speaker of the afternoon who shared information about the data he is collecting that seeks to identify genetic factors that affect the liability toward developing Tourette Syndrome, chronic tics, obsessive compulsive disorder, and related clinical entities. Dr. Heiman is an Assistant Research Professor at Rutgers University and the Director of the New Jersey Center for Tourette Syndrome Sharing Repository.

If you are interested in participating in this study, email [familystudy@biology.rutgers.edu](mailto:familystudy@biology.rutgers.edu), or call 732-445-1145.

