



# PA-TSA Newsletter

VOLUME 37, ISSUE 1

The PA Tourette Syndrome Alliance is a non-profit organization that promotes awareness and acceptance, provides education, and assists families, schools and communities while advocating for individuals with TS.

## Great Things are Happening!

**12th Annual TS Family Camp**  
(Black Rock Retreat, Quarryville)  
**June 8-10, 2018**  
featuring our Keynote Speaker:  
**Twitchy!**  
(aka Stuart Ellis-Myers)

Private rooms for each family!



**TS Awareness at the Capital**  
(Harrisburg)  
**Wed. May 2**

**Highmark Walk for a Healthy Community**  
(Pittsburgh) **May 12**  
(Harrisburg) **May 19**  
(Lehigh Valley) **June 2**

**Registration starts Feb 1**



To find out more about upcoming events  
make sure you are on our email list by registering for free!



PA Tourette Syndrome Alliance, Inc.  
 P.O. Box 148  
 McSherrystown, PA 17344  
 Phone: 1-800-990-3300  
 or 717-337-1134  
 www.patsainc.org

**STAFF**

Administrator/Consultant:  
 Sherrie Sponseller

Outreach & Volunteer Administrator:  
 Sara Woolf

Western PA Consultant  
 Rachel Lewis

Eastern PA Consultant  
 Nicole Wesner

**Volunteer Programs:**

**We need you!** Anyone can join our volunteer programs at any time. Recorded trainings are available for most positions. To start the process, just let us know what program you might be interested in by emailing saraw@patsainc.org or by completing a volunteer application online.

- **Committee Member** — Volunteer your time to help a committee provide guidance and work to assist PA-TSA. Public Relations, Fundraising, Legislative and Strategic Planning are all looking for more members.
- **Volunteer consultant** — trained volunteers who can assist with disability advocacy at school meetings.
- **Speaker's Bureau** — trained volunteers who can provide trainings for educators, peers and other community members.
- **Youth Advocate Program** — youth ages 12-25 who have trained and have materials to do an information board, bulletin board and give a basic training on TS.
- **Support Group Leader** — start a local support group in your area.

**Speakers Bureau**



**Ilene Applebaum**  
 Philadelphia & Montgomery

**Madelyn Bender**  
 Bucks

**Janet Curren**  
 Chester & Delaware

**Jay Geyer**  
 Southern PA

**Lesley Geyer**  
 Berks, Chester, Montgomery & Pocono Region

**Patty John**  
 Washington, Butler & Beaver

**Susan Lutz**  
 Berks & Schuylkill

**Christina MacLean**  
 Dauphin & York

**Cheryl Malloy**  
 Cambria & surrounding counties

**Barbara Rushak**  
 Allegheny, Washington, & Western PA

**Azlen Theobald**  
 Bucks, Delaware, Montgomery & Philadelphia

**Michelle Ulishnev**  
 Cumberland, Dauphin, Lancaster & York

**Karen Wilder**  
 Chester, Delaware & Montgomery

**Elena Wiseley**  
 Delaware County

**Volunteer Consultants**



**Aimee Denton**  
 Bucks & Montgomery

**Kelly DiGiacomo**  
 Pittsburgh

**Lesley Geyer**  
 Pocono Region

**Lori Harvey**  
 Allegheny, Armstrong, Fayette Greene, Indiana, Washington, & Westmoreland

**Christina MacLean**  
 Dauphin & York

**Cheryl Malloy**  
 Cambria & surrounding counties

**Jana Schoch**  
 York

**Karen Wilder**  
 Chester, Delaware & Montgomery

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**YAP**



**Youth Advocate Program**

**YAP Director**  
 Jay Geyer

**YAP Committee**  
 Adam Fishbein  
 Lindsay Glass  
 Magnus Lewis

**YAP Members**

Xandra Corso  
 Sydney Esquivel  
 Kristen Harvey  
 Kylie Horton  
 Martin Hurston  
 Rebecca Kramer  
 TJ LePera  
 Magnus Lewis  
 Aries Noel  
 Susanna Roode

And other members who did not choose to be publicly listed.

**Disclaimer**

This newsletter is published two times a year. Opinions expressed in this publication reflect the views of its editor and contributors. They are not necessarily the views of the PA Tourette Syndrome Alliance (PA-TSA).

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

The PA-TSA, Inc. does not endorse products, services, or manufacturers. Such names appear only as information for our members. PA-TSA assumes no liability whatsoever for information about 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 PA Tourette Syndrome Alliance.

# Elevated Rate of Autism Symptoms Found in Children with Tourette Syndrome

Restrictive Interests, Repetitive Behaviors Common in Both Disorders, UCSF-Led Study Shows



By Suzanne Leigh on June 22, 2017

Around one in five children with Tourette syndrome, a neurological disorder characterized by

involuntary movements and vocalizations, met criteria for autism in a study headed by UC San Francisco. But this prevalence may be more a reflection of similarity in symptoms than actual autism, according to the study's researchers.

Researchers tested 535 children and adults with Tourette's for autism, using a self-reporting test called the Social Responsiveness Scale. Among the 294 children tested, 22.8 percent reached the cutoff for autism, versus 8.7 percent of the 241 adults. In contrast, autism is estimated to affect between 0.3 and 2.9 percent of the general population, according to studies cited in the paper. The Social Responsiveness Scale Second Edition is a 65-item quantitative measure of autism symptoms that assesses the ability to engage in "emotionally appropriate reciprocal social interactions." It evaluates levels of social awareness, social cognition, social communication, social motivation, and restrictive interests and repetitive behavior. Its threshold for autism compares favorably with the diagnostic gold standard, the Autism Diagnostic Interview, the researchers noted.

The study published on June 22, 2017, in the *Journal of the American Academy of Child and Adolescent Psychiatry*.

## OCD, ADHD Frequent Co-Occurrences

The researchers wanted to examine autism symptoms in patients with Tourette's, including those whose diagnosis was coupled with obsessive-compulsive disorder (OCD) or attention deficit hyperactivity disorder (ADHD), conditions that frequently co-occur. Tourette's, OCD and ADHD have been shown to share common symptoms and genetic relationships in a recent study by the same researchers.

"Assessing autism symptom patterns in a large Tourette's sample may be helpful in determining whether some of this overlap is due to symptoms found in both disorders, rather than an overlapping etiology," said first author Sabrina Darrow, PhD, assistant professor in the department of psychiatry at UCSF.

"Our results suggest that although autism diagnoses were higher in individuals with Tourette's, some of the increase may be due to autism-like symptoms, especially repetitive behaviors that are more strongly related to obsessive-compulsive disorder."

The researchers found that the highest scores on the Social Responsiveness Scale, which met autism criteria, were found in participants with Tourette's and either OCD or ADHD. Among those with Tourette's who met the cutoff for autism, 83 percent also met criteria for OCD, the researchers found, noting that high scores were especially evident in the part of the autism test that measures

restrictive interests and repetitive behavior.

## Wide Gulf Between Adults, Kids with Autism Diagnosis

A potentially compelling argument against the surprisingly high rates of autism found in this sample was the wide discrepancy between children and adults who met the diagnostic criteria. Tourette's is usually diagnosed between the ages of 3 and 9; symptoms most often peak in the early teens and start to abate in the early 20s, with continued improvement in early adulthood.

"Children were more than twice as likely to meet the cutoff than adults, indicating that as tics recede, so do symptoms of autism. In contrast, autism is usually lifelong," said Darrow.

"Previous studies have shown that children with mood and anxiety disorders also have higher rates of autism symptoms, based on the Social Responsiveness Scale," said senior author Carol Mathews, MD, who did the research while professor of psychiatry at UCSF. She currently is adjunct professor of psychiatry at UCSF and professor of psychiatry at the University of Florida in Gainesville.

## Psychiatric Impairment Possible Factor in Diagnosis

"This suggests that some of the increase may reflect underlying psychiatric impairment rather than being specific for autism. Some of the children in the study probably have autism, others have symptoms that mimic autism, but are not really due to autism. These symptoms are called phenocopies."

Tourette's affects between one and 10 in 1,000 children according to the National Institutes of Health. Like autism, it is significantly more prevalent in males. Common tics include repetitive throat clearing, blinking or grimacing. Most people do not require medication to suppress their symptoms, but treatment may be recommended for co-occurring ADHD and OCD.

The study was supported by funding from the National Institutes of Health and the Tourette Syndrome Association.

Co-authors are Matthew Hirschtritt, MD, MPH, and Kevin Delucchi, PhD, from UCSF; Marco Grados, MD, from Johns Hopkins University School of Medicine, Baltimore; Cornelia Illmann, PhD, David Pauls, PhD, Erica Greenberg, MD, and Lisa Osiecki from Massachusetts General Hospital, Boston; Jeremiah Scharf, MD, PhD, from Massachusetts General Hospital and Brigham and Women's Hospital, Boston; Paul Sandor, MD, from the University of Toronto; Yves Dion, MD, from the University of Montreal; Robert King, MD, from Yale University School of Medicine, New Haven, Conn.; Cathy Budman, MD, from the North Shore Long Island Jewish Health System, N.Y.; Danielle Cath, MD, PhD, from Utrecht University, Netherlands; Gholson Lyon, MD, PhD, from the Stanley Institute for Cognitive Genomics, Cold Spring Harbor, N.Y.; William McMahon, MD, from the University of Utah, Salt Lake City, and Paul C. Lee, MD, MPH, from the Tripler Army Medical Center, Honolulu.

## Q & A with Volunteer:

### Heather DiGiacomo



Wife and mom of five

**1. How long have you been volunteering for PA-TSA?** I have been volunteering for a little over a year now. Once I found the group and the wonderful support it has given our family, I wanted to help in any way that I could.

**2. In what capacity do you volunteer & how did you get started?** So far I have reached out to friends and family and on social media to bring about awareness. When there was a Pirates baseball game & High Mark walk fundraiser in Pittsburgh, I reached out to Family to attend and contribute. In a larger capacity I reached out to our school district Superintendent, Pupil Services Director, building principals, and Best Friends Clubs to get on board with our awareness and acceptance fundraising campaign. We got to have a consultant come in and speak to the public, and one to come in and present to the entire Middle School of more than 300 in attendance. Also in

doing so I organized a district-wide day during the wear blue/teal campaign in which students and staff were asked to bring in any donations to add to a large blue water jug for each district building, 5 in total- to raise funds to continue PA-TSA's mission of support, education and the annual summer camp for families. We also sold TOMUS t-shirts and stickers. Students and staff represented their awareness and acceptance of TS by wearing a blue or teal shirt at the end of the week.

**3. What inspired you to volunteer for PA-TSA?** As TS has impacted our family in several ways, I have become painfully aware of the lack of awareness and true understanding of the disorder. I'm very passionate about trying to educate others and raise money for the cause. Fortunately I have had a lot of support within our community and school district and the event that I have organized has grown since last year! We have raised more money and expanded district-wide.

**4. What is your favorite PA-TSA activity or event?** When I first became aware of the family camp I knew it was something we needed to attend but frankly it was very costly coming from western Pennsylvania and for a family of seven. I also knew I would meet a lot of resistance from some members of our family so the first year we attended only half of us went. Truly gave me all of the feels. There were times we shared in sadness, frustration, joy and hope. The feeling of being able to relate and understand with other families is such an incredibly valuable experience! The following year after fundraising, all seven of us attended. it was truly a wonderful experience. I hope to continue each summer.

**5. Do you encourage others to volunteer, if so, why?** I have always found it very important to volunteer and pay it forward

whenever possible. When there is a cause that personally impacts your family, I believe the passion becomes amplified. I encourage everyone to volunteer in some way. Not only is it a rewarding experience, when you are able to help others that you can identify with, it is even more so. Whether you choose to do something behind the scenes or front and center every little bit makes a difference!

**6. What successes have you seen with PA-TSA since you started volunteering?**

Since I became a member of the organization and began volunteering, the growth and changes I have seen have been so encouraging and inspiring. I love to see that the organization is open to member feedback and truly listens and tries to accommodate and help as many families as they can. I would love to see that continue to expand and the numbers of families that we reach and are able to help, to increase.

**7. What are your aspirations for PA-TSA moving forward?**

I personally have learned by starting small and trying to help at least one family as a goal, there has been a compounding effect. By being a voice with in our school district I was able to help others find their own. One moment that will always stick out to me was when I realized this through putting out education and offering a meeting to the community. I had no idea if we would be the only ones in attendance or how many to expect. When I walked into the room there were some familiar faces and attendance was low. But as the educator began presenting, a couple came in. We learned that they were not a family in our school district however because of the continuous posts and word-of-mouth, they learned of the meeting and traveled more than 30 minutes to attend. In that moment I was overwhelmed with emotions and knew right there all of the work I had put in was worth it.

# Give Support...Get Support

We have local support groups in several areas of the Commonwealth, along with an online support group on Facebook that is available 24/7! If you are interested in starting a support group or helping with an existing support group please contact our Outreach & Volunteer Administrator

Sara Woolf at [saraw@patsainc.org](mailto:saraw@patsainc.org).

# PA-TSA Trainings

The following school districts and communities have received FREE trainings on Tourette Syndrome from PA-TSA July 1 – December 31, 2017!

### **Educator Trainings:**

Owen J. Roberts SD (2), Chester County  
Marple Newtown SD, Delaware County  
East Stroudsburg Area SD, Pike County  
Swiftwater SD, Monroe County  
Pleasant Valley SD, Monroe County  
Garnet Valley SD, Delaware County  
Wissahickon SD, Montgomery County  
West Chester SD, Chester County  
Stroudsburg Area SD, Monroe County  
Grey Nun Academy, Bucks County

### **Medical Related Trainings:**

Lehigh Nurses, Lehigh County  
Schukill IU Nurses, Schukill County  
Butler County Nurses, Butler County

### **Peer Trainings:**

Chambersburg SD, Franklin County  
Carlisle Area SD, Cumberland County  
St. Teresa of Calcutta, Montgomery County  
Tuscarora SD, Franklin County  
Grey Nun Academy, Bucks County  
Pleasant Valley SD, Monroe County  
Owen J. Roberts SD, Chester County  
Swiftwater SD (4), Monroe County  
Stroudsburg Area SD, Monroe County  
Garnet Valley SD, Delaware County  
Spring-Ford Area SD, Montgomery County  
Keystone Oaks SD, Allegheny County  
Holy Cross Academy, Allegheny County  
North Penn SD, Montgomery County  
Immaculate Conception, Northampton County

For more information on available trainings refer to [www.patsainc.org](http://www.patsainc.org)  
or contact us at 1-800-990-3300 for help in scheduling your training!

## *Donations In Loving Memory:*

### **Mary Lou Reaver**

By Michael & Maureen Wilkin

## *Donations In Honor:*

### **Natalie Sevcik**

By Stephanie & Derek Sevcik

### **Lydia Savage**

By Dolores & Lydia Savage

### **Steven Hill**

By Thomas Walter

### **John McLaughlin's 40th**

By Robert Eisenberg  
Robert Reeves  
Christopher & Sara Dryka  
Michael & Ru Min Tarn  
Ryan & Karla McCleary  
Marissa Mayo  
Paul Wilson  
Amanda McLoughlin  
Susan Zingone & others

### **Chris & Vanessa Tomlinson**

By Elizabeth Tomlinson

### **Jay Geyer**

By Jack & Lesley Geyer



# TS Family Retreat 2017

With old friends and new, we enjoyed two relaxing days crafting, meeting animals, having fun and connecting! From ducky dash to campfires, we did it all with a true sense of community! Thank you to Camp Eder for hosting!



## Pumpkin Run 2017

5K and 1 Mile Fun Run  
Saturday October 28th

Run for  
Tourette Syndrome  
Awareness

Shirt  
Sponsors:



Christina Jeremicz - Realtor  
Scott, Nancy, Gavin and Trevor Doyle  
Our Fundraising Teams

- \* Game Changers \* Team McLaughlin \* Team Van Ruler \* Luke Davis
- \* Team Ujobai \* Team Jeremicz \* Defying the Ticing Odds
- \* The Salio's \* Monica \* Alex's Avengers



## RECENT MEDIA



In case you missed it, ABC did a segment this year on their show “What Would You Do?” about Tourette Syndrome. It was fantastic, filmed in New Jersey. Catch just the clip of TS here: <http://abcnews.go.com/WhatWouldYouDo/video/child-tourettes-syndrome-bullied-49885650>

***Hichki*** (English: *Hiccup*) is an upcoming Indian [Bollywood](#) drama film, directed by Sidharth P Malhotra and produced by [Maneesh Sharma](#) under the banner of [Yash Raj Films](#).<sup>[1][2]</sup> The film is an adaptation of Hollywood film [Front of the Class](#) (2008), which itself was based on the book, *Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had* by [Brad Cohen](#), of which Yash Raj Films acquired the rights.<sup>[3]</sup> The film stars [Rani Mukerji](#) in the lead role of a teacher having [Tourette syndrome](#). The film's trailer was launched on December 19, 2017 and was attached to the movie [Tiger Zinda Hai](#)<sup>[4]</sup>. The film will be released on February 23, 2018.



## Sponsor PA-TSA TS Family Camp!

**Include your name on the back of an event t-shirt for \$100,  
your logo on the back for \$250 or choose higher levels for more rewards!  
Send your sponsorship form to  
PA-TSA at P.O. Box 148, McSherrystown, PA 17344**

All Sponsors also receive recognition on website and in upcoming newsletter that reaches 6000+ addresses.

**Yes, I would like to sponsor TS Family Camp at the following level:**

**Platinum Keynote Sponsor \$1000**   
  **Gold Sponsor \$500**   
  **Silver Sponsor \$250**  
 **Bronze Sponsor \$100**   
  **In-kind Sponsor for Silent Auction/Snacks/Beverages**

My donation is enclosed                      **OR**                       Bill my credit card  
 Visa                       Master Card                       Discover                       American Express

Credit card # \_\_\_\_\_ Exp. Date: \_\_\_\_\_ CVV#: \_\_\_\_\_

Cardholder signature: \_\_\_\_\_

Your Name \_\_\_\_\_ Best Phone # \_\_\_\_\_ Email Address: \_\_\_\_\_

Business Name/Recognition Name: \_\_\_\_\_

Address: \_\_\_\_\_

All contributions are tax deductible in accordance with I.R.S Section 501 (c) (3). The official registration and financial information for PA-TSA, Inc. may be obtained from the PA Department of State by calling toll-free within PA 1-800-732-0999. Registration does not imply endorsement.

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**New Directors will be  
elected soon!**

**Acknowledgement of Thanks**

Monthly Donors

**Dorothy Bollinger Peggy Ann Cox  
Jay Geyer Lesley Geyer**

BENEFACTORS & FUNDRAISERS over \$250

**John & Linda Bergen  
New Oxford Social & Athletic Club  
Fraternal Order of Eagles Carlisle Aerie No. 1299  
Bedford Moose Lodge No 480  
Susan Millheim  
Debra Hunt  
Fraternal Order of Eagles 2226  
Patty John**

**Your generosity is greatly appreciated!**

(If we have missed anyone, please contact PA-TSA and your name will be mentioned in our next newsletter.)

**Medical Advisors:**

**Lawrence W. Brown, M.D.**  
Associate Professor of Neurology  
Philadelphia  
**Peter Meyer, M.D.**  
Pediatric Neuro Psychiatrist  
Montgomery County