



# First TS Family Retreat

*Thanks to our Sponsors:*



**Find us fast:**



### Mission Statement

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.

PA Tourette Syndrome Alliance, Inc.  
P.O. Box 148  
McSherrystown, PA 17344

Phone: 1-800-990-3300  
or 717-337-1134  
Fax: 717-698-1420

Web: www.patsainc.org

**STAFF**

Administrator/Consultant:  
Sherrie Sponseller

Assistant Administrator/Consultant:  
Sabrina Bosse

Outreach & Volunteer Coordinator  
Sara Woolf

**Volunteer Programs:**

We Need You! Anyone can join our volunteer programs at any time. Recorded trainings are available for most trainings and updates will be completed this summer. To start the process, just let us know what program you are interested in by emailing saraw@patsainc.org or by completing a Volunteer Application online.

- **Volunteer Consultant**—trained volunteers who can assist with IEP and other 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.
- **Outreach/Information Program**—knowledgeable volunteers who “staff” an information booth at local events.

**Speakers Bureau**



**Ilene Applebaum**  
Educator/business owner  
Philadelphia & Montgomery

**Jack Chambers**  
Retired Banker  
Adams & York

**Jay Geyer**  
Dept. of Navy  
Southern PA

**Lesley Geyer**  
Occupational Therapist  
Berks, Chester, Delaware & Montgomery

**Rachel Lewis**  
Customer Service  
Allegheny, Fayette, Washington, & Westmoreland

**Susan Lutz**  
Dental Hygienist  
Berks & Schuylkill

**Cheryl Malloy**  
Therapeutic Support Staff  
Cambria & surrounding counties

**Barbara Rushak**  
Retired Educator  
Allegheny, Washington, & western pa

**Karen Wilder**  
Counseling/Human Relations  
Chester, Delaware & Montgomery

**Volunteer Consultant**



**Aimee Denton**  
Demea Bakery Owner & Operator  
Bucks & Montgomery

**Lesley Geyer**  
Occupational Therapist  
Berks, Chester, Delaware & Montgomery

**Rachel Lewis**  
Customer Service  
Allegheny, Fayette, Washington, & Westmoreland

**Cheryl Malloy**  
Therapeutic Support Staff  
Cambria & surrounding counties

**Karen Wilder**  
Counseling/Human Relations  
Chester, Delaware & Montgomery

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**YAP**



**Youth Advocate Program**

- YAP Director**  
Jay Geyer
- YAP Committee**  
Lindsay Glass  
**Izaiah Bosse**  
York & Adams  
**Xandra Corso**  
Warren, McKean & Elk  
**Sydney Esquivel**  
Adams & York  
**Kylie Horton**  
Blair  
**Martin Hurston**  
Lancaster  
**Rebecca Kramer**  
Centre/ Central PA  
**TJ LePera**  
Montgomery  
**Magnus Lewis**  
Westmoreland/Western PA  
**Susanna Roode**  
Montgomery & Bucks

And other members not 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 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 PA Tourette Syndrome Alliance.



The following school districts and communities have received Trainings on Tourette Syndrome from PA-TSA over the past few months!

***Educators In-Service Trainings:***

*Garnet Valley SD, Delaware County  
Pocono Mountain SD, Monroe County  
Annunciation BVM, Adams County*

*Dallastown SD, York County  
Carlisle Area SD, Cumberland County  
North Schuylkill SD, Schuylkill County*

***Peer In-Service Trainings:***

*Lower Moreland SD, Montgomery County  
Dallastown SD, York County*

***Medical Related Training:***

*York College Nurses, York County  
Central York SD, York County  
Greater Altoona Career & Technical Center, Blair County*

***Community Training:***

*York County Optimist Club, York County  
Mon Valley Hospital, Westmoreland County*

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

# 2014 TS Family Camp Sponsors

**Held the weekend of June 6-8, 2014!**

**Thanks to the following sponsors:**



Highmark Walk teams & walkers  
West Manheim Twp Lions Club  
Fraternal Order of Eagles  
\*Littlestown Aerie 2226  
\*Hanover Aerie 1406  
\*Carlisle Aerie 1299  
Lowther Manor Lodge No. 781  
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Phyllis Sisco  
John Denora  
Scott Himmelberger  
Ilene Applebaum  
Clara Zalakar  
Allen E & Carol A Eustace  
Alan & Rebecca Fralin

**Thank You!**

***To support the 2015 Camp,  
contact [sabrina@patsainc.org](mailto:sabrina@patsainc.org)***

## **WARNING: FOR MATURE AUDIENCE ONLY!**

### **Growing up with Tourette's** By Stephanie Weaver

Growing up with Tourette's was like growing up with a scarlet letter stapled to my chest. It was a stigma I wore like a badge that everyone saw but didn't understand, including my own mother. Back in the early 90's, Tourette's was still a mystery to health professionals; a complex neurological enigma that even I couldn't unravel.

I started getting tics when I was about eight years old. They started subtly, with just the occasional nose twitch or gulp. By the time I was 11, my symptoms had blossomed into a full-fledged monster that I couldn't tame, no matter how many attempts I made to control it.

I always saw my Tourette's as a physical thing. It was something that had taken up residency in my body, even though it was unwelcomed. To me, the syndrome was a puppeteer, contorting my face into gruesome poses and making animalistic sounds come from my mouth that were completely foreign to other little girls.

I was finally diagnosed when I was 11. I remember the trips to the doctor's office well and the many attempts they made to medicate the monster out of me. Back then, professionals were still trying to figure out the best remedies for controlling tics and I viewed myself as a guinea pig for their experiments. Many times, the medicine would help, but the side effects were overwhelm-

ing. For a child going through puberty, the extreme physical and mental toll the different medications took on me, in addition to my own maturing body, made my adolescence an extremely difficult time in my life.

One type of prescription made me gain over 100 pounds in under a year. Another kind made me always want to sleep. I was so sick from all of the meds that my parents had to pull me out of school. I underwent extensive testing to see if the medication had negatively impacted my brain and heart. In one test, the doctors put electrodes around my head to monitor brain activity. EKGs and blood work were a routine for me. The abnormal side effects of the medication became my norm.

I blame Tourette's for destroying my childhood the way abused kids blame their parents. It robbed me of innocence and happiness at an early age and taught me that people can be cruel to those they view as different. My peers avoided me, saw my scarlet letter embroidered on my chest and treated me like a pariah. They would mimic my tics in class, giggle at me in the hallways and move away from me if I sat next to them at lunch. I was an untouchable. I would sit with my Tourette's in my room late at night, asking it why it had chosen to occupy *my* body; why it had chosen to destroy *my* life.

The Tourette's instilled a fear of abandonment in me early on that I'm still dealing with today. As a teenager, I clung to people the way barnacles cling to rocks. I never wanted my friends to leave me. I could not face rejection. The fear turned into hatred that I took out on my body. My body was the enemy that had caused me so much pain. When I was a junior and senior in high school, I was hospitalized many times for suicide attempts and cutting. Nobody under-

stood why I hurt myself. They didn't get that I was trying to cut myself out of myself, to remove myself from the skin and the flesh that I had come to loathe.

When I was 16, my English teacher gave us an assignment to write our own autobiographies. The last chapter was where we hoped to see ourselves in 15 years. The only words I wrote in that chapter were, "I wish I will be happy."

I am 30 years old now. I do what I love for a living. I have an amazing apartment in the city, loving and supportive friends, an adorable dog and a doting boyfriend. I have made peace with my body. My ties are few and far between now and I haven't been on medication for my Tourette's for more than 10 years. It's still there, however. It will raise its ugly head when I'm nervous, or when I am alone and let my guard down. It will come back late in the night and remind me that who I was and who I am now is the same person.

My Tourette's was both a blessing and a curse. It was my lighthouse and my albatross. It caused me so much pain, but it also taught me empathy and kindness. I am a better woman for what I have been through. I am stronger. It taught me that if I could conquer it, I could overcome anything.

It took me more than half of my life to figure out that my Tourette's wasn't me. Yes, it was a part of me, but it did not *define* me. I hope a teenager with Tourette's reads this someday, when she is sitting alone at night with her disease. And I hope she realizes that her body is not an enemy, that this syndrome is not a monster. It is a component of her, but not the whole her. She, like I, is a girl with Tourette's. Tourette's isn't the girl.

## **Understanding cutting and self-harm**

Self-harm is a way of expressing and dealing with deep distress and emotional pain. As counterintuitive as it may sound to those on the outside, hurting yourself makes you feel better. In fact, you may feel like you have no choice. Injuring yourself is the only way you know how to cope with feelings like sadness, self-loathing, emptiness, guilt, and rage.

The problem is that the relief that comes from self-harming doesn't last very long. It's like slapping on a Band-Aid when what you really need are stitches. It may temporarily stop the bleeding, but it doesn't fix the underlying injury. And it also creates its own problems.

If you're like most people who self-injure, you try to keep what you're doing secret. Maybe you feel ashamed or maybe you just think that no one would understand. But hiding who you are and what you feel is a heavy burden. Ultimately, the secrecy and

guilt affects your relationships with your friends and family members and the way you feel about yourself. It can make you feel even more lonely, worthless, and trapped.

**©Helpguide.org. All rights reserved.  
Helpguide.org is an ad-free non-profit  
resource for supporting better mental  
health and lifestyle choices for adults and  
children.**

\*\*Go to Helpguide.org for full article

# Pennsylvania's Yellow Dot Program



Pennsylvania's Yellow Dot Program was created to assist citizens in the "golden hour" of emergency care following a traffic accident when they may not be able to communicate their needs themselves. Placing a yellow dot in your vehicle's rear window alerts first responders to check your glove compartment for vital information to ensure you receive the medical attention you need.

The program is a cooperative effort among the Pennsylvania Departments of Transportation, Health and Aging; the Pennsylvania State Police, the Pennsylvania Turnpike Commission and First Responders and local law enforcement.

### How does it work?

Participants complete a personal information form, which includes the participant's name, contact information, emergency contact information, medical history and medications, allergies and the participant's doctors' names. A photo – showing only the participant's head and shoulders – is then taped to the front of the completed information sheet.

The yellow dot decal provided in the program kit is placed in the lower left corner of the participant's vehicle's rear windshield. The decal should be no higher than 3 inches from the bottom of the windshield. This decal alerts first responders that vital information can be found in the vehicle.

Place the completed information sheet, with the attached picture, into the Yellow Dot folder, and then place the folder into the vehicle's glove box.

Get your packet at <http://www.yellowdot.pa.gov/> or by calling 717-787-6746.

## Do you want to have an impact on the future of PA-TSA?

Are you feeling called to Board Service? Or do you know someone who would be perfect for the PA-TSA Board of Directors? If so, we are currently seeking new Board members and have the opportunity to DOUBLE our current Board.

As an elected Board Member some of responsibilities include a three year term of office, attendance at 3 yearly phone/online board meetings, and serving on one or more of our committees (possibly chairing a committee if needed).

We would love to have your nominations for these positions! Please carefully consider this opportunity to directly effect our organization. Please take some time to consider who you know that would be an asset to our Board--consider yourself too! Our Board Members are instrumental in helping us grow and promoting acceptance of TS!

To Nominate yourself or someone else, fill out the nomination form below and mail it to PA-TSA, P.O. Box 148, McSherrystown, PA 17344, Attn: Sherrie Sponseller. Nominations for 2014 candidates will be accepted until July 7, 2014.

Each nomination will remain anonymous. After the close of nominations, our nominating committee will contact each nominee, to further discuss board service. At that time the election slate will be finalized and we will vote on our new members. It will be so exciting to have more faces and fresh ideas added to our team! We cannot wait to hear your suggestions!

-----  
I nominate \_\_\_\_\_  
to the PA-TSA Board of Directors. Their contact  
information is: Phone: \_\_\_\_\_  
Email: \_\_\_\_\_  
Address: \_\_\_\_\_

*Donations In Memory:*

**Ryan Nocero**

Sharon Urban  
Linda Troiani  
Stacy Linneman  
Ajit Samsi  
Francis Serratore  
Hal Morris  
Frank Nocero Sr.  
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**Norman Grossman**

Arlene & Barry Weissman

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**Wilder Family**

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Stephen Blumenthal  
Kevin Auerbach  
Przemyslaw Grzywacz  
Jason Wilder

**Dakota MacLean**

Lowther Manor Lodge #781

**Kevin Reaver**

James & Mary Lou Reaver  
in honor of his promotion at  
Ohio State University

**Ernst & Maria Schirmer**

Minuteman Press of  
Hanover

**William Turk**

Clair Zalacar

**Mary Lou Reaver &  
Susan Lutz**

Linda Anderson



**A Special Thanks to our Highmark Walk Teams who raised \$8205 this year!!**

<b>Cooky's Kids</b>	<b>Look Who's Walking</b>	Michael Coppolecchia	Izaiah Bosse	Christina MacLean	Juda Kmiecik
Avery Sponseller	Carter Headley	<b>Team Blayden</b>	Len Bosse	Dakota MacLean	Malique Lee
Jamie Sponseller	<b>Nick's Crew</b>	Ashli Prosper	Brooke Bosse	Darren MacLean	Windell Lee
Joseph Sponseller	Bob King	Brenda barnhart	Kiersten Bosse	Katyana MacLean	Vicki Howard
Sherrie Sponseller	Nick King	Blayden Rosario	Sabrina Bosse	<b>The MustacheTeam</b>	<b>Individual Walkers</b>
<b>Geyer Team</b>	Parker King	James Kellert	<b>Team Magnus</b>	Ian Esquivel	Niles Malone
Lesley Geyer	Hanna Woolf	Becky Rosario	Magnus Lewis	Isa Esquivel	Maria Noel
Jay Geyer	Madelyn Woolf	<b>Team Bobo</b>	<b>Team Nathan</b>	Johnny Esquivel	Riley Malone
<b>Kellison</b>	Nadia Woolf	Charlie Tocci	Ty Stanton	Sydney Esquivel	Stephanie Malone
Tammy Kellison	Olivia Woolf	Chas Tocci	Nathan Maze	Faye Esquivel	Tyler Malone
Dylan Kellison	Sara Woolf	Marilyn Tocci	Robert Maze	<b>Windell's Walkers</b>	Melinda Platt
Trish Kellison	Bobbi King	<b>Team Bosse</b>	Susan Maze	Abreia Kmiecik	
Joe Kellison	<b>Sir Tics-a-Lot</b>	Tucker Marchio	<b>The MacLean Clan</b>	Ashley Lee	
	Melissa Binder	Ezra Bosse	Xander MacLean	Christina Kmiecik	

# Lifetime Memberships Now Available!

PA-TSA is replacing Yearly Membership with a Lifetime Membership option!! Join for the low price of \$100 and one family member (over the age of 18) will enjoy membership for their lifetime!! This includes: newsletters, consultation, information & referral, 10% discount on TS Family Camp & Retreat, privilege of voting for Board Members and a plastic Membership Card!! Parents, get your name on the Membership Card so your family can access all of our supports while your child is young and then give them the gift of Lifetime Membership when they turn 18!!

If you have joined in the past year, check your emails for a code so you can upgrade your membership to Lifetime for just \$65!! If you are a current member but we do not have your current email address, call for the code!! (Scholarships also available!)  
**Purchase now using the enclosed envelope or go to our website to review our FAQ's & purchase online!!**

## EVENTS:

### April 24, 2014

Dan Farron held a  
**Tourette Syndrome Awareness Fundraiser**  
At Texas Roadhouse, Stroudsburg PA!

## Tourette Syndrome Information Expo

Hosted By PA State Representatives

Ted Harhai, Deberah Kula and

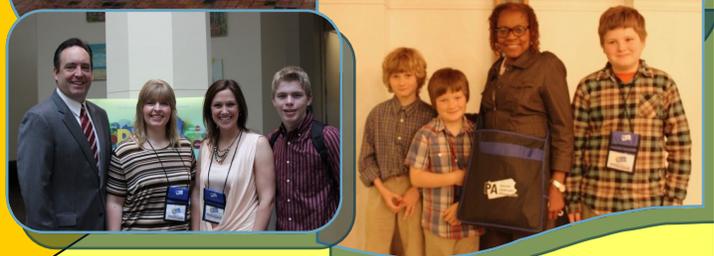
The PA Tourette Syndrome Alliance, Inc. (PA-TSA)

Thursday, May 15, 2014  
6pm-8pm



Monongahela Valley Hospital  
1163 Country Club Rd., Monongahela PA 15063  
Anthony M. Lombardi Education Conference Center

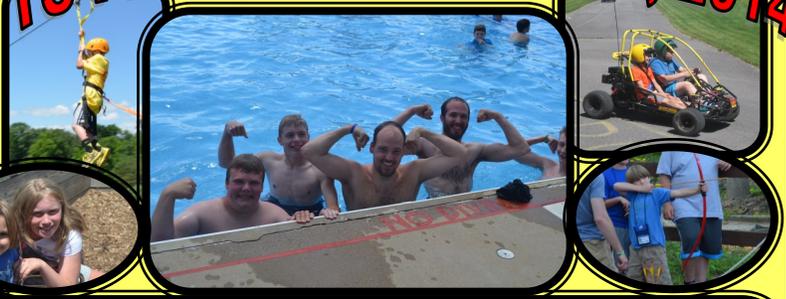
TS Awareness Day at the Capital - May 7, 2014  
Thank you to all the Families and Legislators  
that came out to support PA-TSA!



May 17, 2014  
**Highmark Walk for a Healthy Community**



## TS Family Camp June 6-8, 2014





## Board of Directors

### President

**Melinda Platt**

Inventory Specialist &  
Support Group Leader  
Adams County

### Vice-President

**Lesley Geyer**

OT & Support Group Leader  
Montgomery County

### Secretary

**Open**

### Treasurer

**Susan Lutz R.D.H.**

Dental Hygienist  
Berks County

### Members

**Leo Burke, Psy.D.**

Psychologist  
Philadelphia

**Jay Geyer**

Department of the Navy  
Virginia

**Rachel Lewis**

Customer Service  
Westmoreland County

### Open Positions

Email saraw@patsainc.org if you are interested in applying for a Board position

## Medical Advisory Board

**Lawrence W. Brown, M.D.**

Associate Professor of Neurology  
Philadelphia

**Peter Meyer, M.D.**

Pediatric Neuro Psychiatrist  
Montgomery County

This Newsletter was made possible through a grant provided by:



## *Acknowledgement of Thanks*

PERSONAL AND CORPORATE BENEFACTORS over \$200

**Thomas Walter**

**Margaret Lawson**

**Faternal Order of Eagles Carlisle Aerie No. 1299**

**West Manheim Township Lions Club**

**Friedens Church**

GRANTS

**Community Aid, Inc**

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**West Manheim Township Lions Club**

MONTHLY DONORS

**Jack & Lesley Geyer**

**Jay Geyer**

**John MacDonald**

**Penny Nicholson**

*Your kindness and generosity is greatly appreciated!*

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