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NEWSLETTER

WINTER 2025

A TEEN'S VIEW OF TS

by Derick Valencik

I was first introduced to PATSA a long time ago, in 1990 to be exact, not long after I was diagnosed with this wonderfully infuriating condition. My mother tried in vain to get me to attend various events over those early years.My wildly (un)intelligent thinking was that Tourette's would be more real if I spent time with a bunch of kids that shared the condition with me. I so desperately wanted to be "normal" that I had concocted a myth that I could hide my Tourette's if I stayed away from others who had it.

Authors note: As someone who lives with TS and a parent of a 9 year old with a mild case herself I have a perspective here that hopefully can be helpful. I understand as a child with TS that the battle to manage the condition is all consuming, there is fear and anger and more associated with the idea of getting to know others who live with it. And as a parent, seeing your child inhibited by TS is painful at times. Maybe you question if giving them the choice to be involved is better than taking away yet another area of their life form their control.To that I'd say trust your gut first and foremost, but also, as you'll read a little later I think connection with those that understand is one of the best gifts you can give your child. It's a better medicine in many ways than the best pill regimen out there right now. (cont. on page 3)

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PROVIDING ADVOCACY, TRAINING, SUPPORT & AWARENESS
PATSA
PA TOURETTE SYNDROME ALLIANCE

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MISSION:
To promote awareness and acceptance, provide education, and assist families, schools and communities while advocating for individuals with TS.

Disclaimer:
This newsletter is published two times per 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 (PATSA).

Volunteer Opportunities:

Volunteers are needed in a variety of positions! To start the process, complete a volunteer application online or request it by contacting derick@patsainc.org.

Committee Member — Join one of our active committees. Committees meet by zoom and have agendas and minutes to help you keep up with the activities. Our Public Relations, Fundraising, Legislative and Camp/ Retreat committees are all recruiting.

TS Family Camp and Retreat — A variety of volunteer positions are needed at Camp and Retreat, some of which receive free camp or retreat registration and a stipend.

Tic Connection Leaders - spearhead local meet up groups in your area. There is a need in our community to meet other families affected by TS in a relaxed setting. To get these started we need volunteers willing to step up and, along with help from PATSA, take the lead on organizing and scheduling a group in their area.

Community Speakers Program - This amazing new program will be announced soon! We plan to recruit volunteers and provide them with a video and talking points to share info on TS and our services to your local community organizations!

Why Invest in PATSA's SERVICES!

The amount of services we provide can only happen because of our donors, grant funders and corporate sponsors! During 2024 a total of $109,409 was provided to ensure we could continue **all of our services and events.** This included a total of 25 Educator Trainings, 7 Peer Trainings, 3 Nurse Trainings, 36 School meetings, TS Awareness Day at the Capital, TS Family Camp weekend, numerous info booths/outreach and ability to respond to over 600 emails/phone calls for support.

The State Budget year starts in July, but funding for grant agreements is often delayed for MONTHS! As this is written, **we still do not have a signed grant agreement with the PA Department of Health** to obtain the $159,000 assigned to Tourette Syndrome in the state budget for the current 2024-25 fiscal year.

This makes grants and donations even more important in providing services. We will be able to recoup the funds when we are able to bill the state, but that does not help us provide the much needed services to families and schools while we wait.

YOUR DONATIONS HELP US CONTINUE OUR VITAL TOURETTE SERVICES. MAKE YOUR DONATION AT WWW.PATSAINC.ORG TODAY!

(Article continued from page 1)

So, back to the story, Jim Eisenreich was in what would become his final year with the Philadelphia Phillies. He did this thing where he covered the tickets for kids with Tourette's for home games. My parents lived by the motto that "if it's free it's for the Valencik's" so I went, kicking and screaming and only partly because of my tics.

Eventually we arrived and were ushered by security into the belly of the belly of Veterans stadium. For a moment I thought we were all going to sit in jail for some crime I didn't know I had committed, (Anxiety and a strong imagination are a great combo aren't they!). Soon though I heard the unmistakable chorus of shared vocal tics. I was more than just a little angry, to say the least.

There were about 50 kids in the center of the room, their parents surrounding and sitting on the sides in folding chairs. Part of my wanted to run away but I noticed something. As the group all looked at the late arrival and saw my tics blossoming, I noticed a relief grow in many of their eyes. A relief that I was also feeling for the very first time that I could remember. My tics told them they were still safe and theirs said the same to me. This was new and it felt very good.

The moment was interrupted by an attendant trying to usher me quickly to an empty spot on the floor as he said something about starting soon. "Start what?" I mumbled with as much of a scowl as I could form in a desperate bid to regain my "this is stupid!" mentality. My dad said "Derick, look around! Look where you are." ADD overwhelm had prevented me from taking in more than what was right in front of me. Now I was struck by the sudden realization that I was in the Phillies locker room! My preteen moodiness vanished, and I allowed myself to feel eagerness for what came next.

Jim came out to speak to us briefly before he ran to the field for final warmups. I don't remember anything that he said to be honest, but he had tics, some that looked very similar to mine. And the spirit in the room was something so important. Up until this moment I didn't believe that anyone with Tourette's could live any semblance of a normal life, even though it was all that I desperately wanted. But here, in this room we saw someone who had "made it". It was possible to make this thing work for you, to make a live the life you wanted to live. I was inspired and my doubts loosened their indominable grip on me that day.

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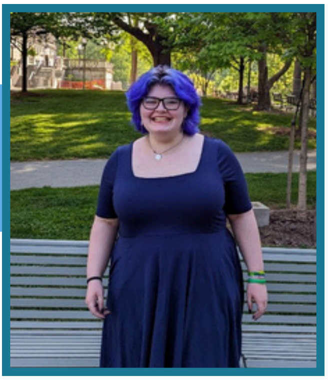
I was 12 then, I just turned 40 this past June. The memory is fresh, and the emotional impact is still paying dividends. That afternoon changed my life. As much as my preteen self would hate me for saying this, I know that it was as much from what I gained from the other kids as it was from Jim. I felt understood and could see that I was not the only one harboring these fears and frustrations that are so common with TS. I was not alone and that meant everything.

As I have gotten older, I have wondered how different my journey may have been if I had allowed others who understood into my life more regularly. Had I chosen not to place myself in a self-imposed isolation, and had I not rejected the support of the TS community how much more could I have learned. Not doing so is without a doubt my biggest regret. There is so much beauty in sharing a journey, and that is only made truer when the journey involves something as unique as Tourette's Syndrome.

It's why I am going to end this with a shameless plug for TS Family Camp this summer. So, if you have that first weekend in June open, (the 6th through the 8th) I want to do everything in my power to convince you to join us. Cost isn't an issue; we have installment plans and scholarships available. So, it really all boils down to you trusting your gut here. Look into camp more here if you are interested (TS Family Camp - PATSA), and if your instinct says to come, even if it's going to be a fight, I'd say go ahead and do it! I'll see you in June!

INTERVIEW WITH VOLUNTEER: HOPE NUNEMAKER

Hope is 19 years old and has been volunteering since 2022. She lives near Harrisburg and volunteers with PATSA's Camp Planning Committee, Fundraising for Silent Auction, Day at the Capital, and has been a Junior Youth Mentor at camp.



Hope Nunemaker

1. What inspired you to volunteer for PATSA?

The first year I went to camp I realized how much PATSA does. This place changed my life and I wanted to give other people the chance to have these kinds of programs to change their lives as well. I feel like I have another "family" in PATSA and I wanted to give back to my new family.

2. What is your favorite PATSA activity or event?

My favorite PATSA event is probably camp because people from all over can come together. You can meet people in person and have insightful speakers. Hearing the stories from the speakers is very cool. And I have volunteered with the children at camp. Seeing them come out of their shells and gain confidence despite their diagnosis is awesome.

3. What do you find rewarding about volunteering for PATSA?

Being at camp or the capital you get to see the friends you made, the changes you are helping to make and most importantly, spreading the word about Tourette. I am so thankful to be able to let people know about Tourette because it is not well known. Volunteering with PATSA just gives me great experience in general.

4. What else would you like to add?

After camp, I was inspired to give a speech to my grange organization and ask them to donate to PATSA's camp because of the impact it had on me. They have now made a large donation to help with scholarships for the past 2 years and I am proud to have been involved in making that connection.

IN THE TRENCHES WITH PATSA CONSULTANTS

Recently, a young boy, "Dustin", and his family, were facing significant hurdles with his transition to middle school. Dustin has been diagnosed with severe anxiety and Tourette Syndrome, and while he had made tremendous progress last year in an accommodating and supportive school environment, the leap to a new school setting this year brought new struggles.

Dustin's anxiety spiked, his tics worsened, and after weeks of mounting challenges, he began refusing to attend school altogether. His mom reached out to PATSA, unsure of what to do but desperate to help her son. Together, we built a plan to address his immediate needs and set him on a path toward success.

One of the key steps was advocating for Dustin during a 504 meeting at his school. We explained how his symptoms were affecting his mental health and ability to thrive academically. We proposed several changes, including switching him to a new team of teachers that his friend was already part of—giving Dustin a fresh start and a sense of comfort with a trusted ally by his side. We requested accommodations tailored to his needs and training for educators to better understand his diagnosis.

At first, Dustin's mom was hesitant, unsure if the school would be willing to implement these changes. But during the meeting, the school staff listened and agreed to everything we recommended. Dustin was granted the fresh start he desperately needed: his missing assignments were wiped clean, and he transitioned to a new team with teachers who better understood his needs.

The results were immediate and heartwarming. On his first day back, his mom emailed us to share how he came home happy, excited about school again, and looking forward to the next day—a feeling he hadn't had in months. She expressed her gratitude, saying this was exactly the right decision for Dustin and their family.

****Stories like Dustin's remind us why we do this work. With the right support, understanding, and advocacy, children like Dustin can overcome the barriers holding them back and rediscover their joy and potential. It's a privilege to be part of that journey.**

SPRING EVENTS!

See our webpage for info

Run, Sponsors, or create a Fundraising Team!

Use QR code
or link:
https://patsainc.org/events/cant-sit-still-run/

TS Awareness at the Capital

Tell Your Story on Monday, May 5th!

This incredible opportunity allows you to meet directly with the Legislators in Harrisburg that provide funding for Tourette syndrome. Hearing personal stories of TS, how PATSA has helped and how you support continuation of this funding is critical! Sign up NOW to join us!

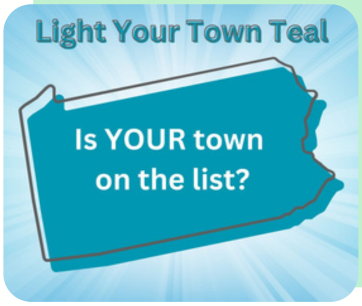
Link: https://givebutter.com/2025DAC

Info for All Events here: https://patsainc.org/events/

Light Your Town Teal

Our 3rd year for this Awareness Event!
Keep up with the buildings all over PA that will be lighting up during TS Awareness Month!

Most will be lighting on Tuesday, May 20th, but some will be lit all month long!



Follow the exciting event on Facebook at: https://www.facebook.com/patsalliance

TS Family Camp

Friday June 6-Sunday June 8, 2025 at
Black Rock Retreat in Quarryville, PA

Join us for this weekend of learning and fun!
Our Keynote Speaker is Craig Elgin, aka "Tourettes Cop"!
Registration fee includes lodging for 2 nights, 5 meals, snacks and all activities!

Read more and register here:
https://givebutter.com/Registerforcamp2025

OUR GENEROUS DONORS

From Jan 1, 2024 -Jan 31, 2025

Teal Visionary $15,000-$30,000
Anonymous donor family

Teal Advocate $5,000-10,000
Robert & Joan Dircks Foundation
Valley Grange #1360
The Huston Foundation

Leader $2,500-$4,999
FedEx Ground
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Andrea Worman's Birthday Fundraiser by Tricia Sassaman, Lisa Worman, Shannon Gaw, Diane Gaw, Karl Hagman, Krissy Iaci, Andrea Worman and Jackie Pingitore Forlino

Ashleigh Gilbert Gehret's Birthday Fundraiser by Barbara Eby, Jackie Vetovich, Gail Eberly Dengler, Lauren Erdman, Ben Robitzer and Yvonne Osiris

Brian Crawford's Birthday Fundraiser by Tim Claycomb, Nathan Jay, Terry Crawford, Ryan Bibbs, Tim Crawford, Joan Crawford, Jesse Buday, Michael Phillips and Brian Crawford

Diana Duarte's Birthday Fundraiser by Connie Kurtiz and Marie Dorothy

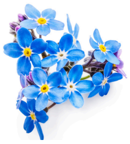
Eoin Connor's Birthday Fundraiser by Janet Klinger and Michelle Connor

Harrison Smith by Mandy Heron

Kimberly Craig Babik's Birthday Fundraiser by Kimberly Babik, Bonnie Bailey, John Chamberlin, Bonnie Bailey and Carol Hesz

Pam Bernet's Birthday Fundraiser by Randal Thompson, Ines Penn, Valerie Felicetti, Amber Montgomery and Mary Hill

Stephanie Dissen by Ken Cummings



DONATIONS IN MEMORY

Aaron "Twitch" Acri by Kathryn Bartizek, Sandra Bush, Lynn Carson Ann Marie Cavrich, Fidelity Charitable, Deborah & Joseph Cooney, Betty Fenicle, Virginia Ivanoff, Mary Karoly, Diane Matrese, ,Denise McGarvey, Darlene & Patrick McHugh, Linda Snow, & Madeline Taroli-Tarutis

Carmen Di Battista by Peggy Ann Cox

Mary Lou Reaver by Kevin Reaver

Ryan Nocero by Michael Serratore & Raymond & Josephine Roach

Susan Newman by Janis Lichtenstein and Arlene Weissman

PATSA thanks all of our donors!
We can only serve people, because of YOU!

If we have missed your donation or sponsorship in this newsletter from Jan 1, 2024 - Jan 31, 2025 please let us know. We want to acknowledge ALL donors.

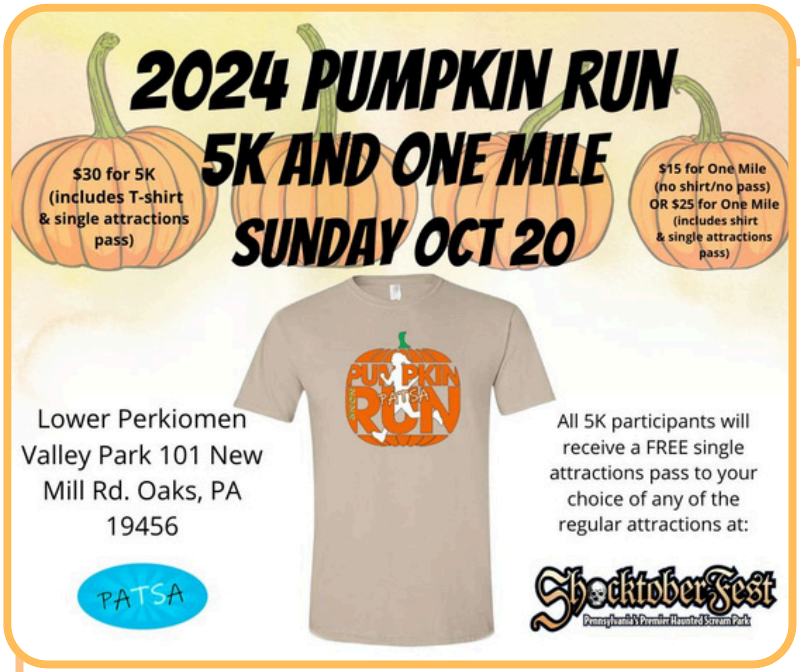
CAN YOU HELP?

The PA Tourette Syndrome Alliance seeks new ways to support families, schools and communities. This mission requires funding and new connections with businesses and organizations. Here are some ways other people have helped. Let us know if you can help connect us to a business or organization within your social network! Send your leads to info@patsainc.org.

Nathalie Anolik and her son Adam own Wireless Zone franchises and have helped PATSA receive a grant for $3,600 to scholarship 15 children with TS to camp in 2025!

Community Involvement:
PATSA staff and others volunteered at the Farm Show Milkshake stand to support Valley Grange in their efforts! They have donated several years to support camp and this was fantastic outreach!

Tidal Wave Auto Spa selected PATSA for their charity day in Hanover PA in Sept 2024. This allowed us to raise over $1200 in one day!



2024 PUMPKIN RUN
5K AND ONE MILE
SUNDAY OCT 20

$30 for 5K (includes T-shirt & single attractions pass)

$15 for One Mile (no shirt/no pass) OR $25 for One Mile (includes shirt & single attractions pass)

Lower Perkiomen Valley Park 101 New Mill Rd. Oaks, PA 19456

All 5K participants will receive a FREE single attractions pass to your choice of any of the regular attractions at:

ShocktoberFest
Pennsylvania's Premier Haunted Scream Park

SPONSORS:

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Wegmans

WaWa
Philadelphia Rock Gym
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Philadelphia Mission Experience

FUNDRAISERS:

Tara Lerman
The Lone Cheesehead
Pumpkin Smashers
JJ's Tic or Treat
Fantastic youtube site @jackdoeswhatever

Together $4,000 was raised!

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