

# NEWSLETTER

WINTER 2024



## 2023 DONOR IMPACT:

PATSA's vital services and supports could simply not happen without the donors, grants and sponsors that help to provide the funding we need to provide them.

In 2023 your support meant:

- A total of 51 trainings.
- A total of 54 families at TS Family Camp -- 48% received FULL scholarships!
- A total of 120 registrants for our free Tic Connection events (unfortunately, rain affected attendance.)
- A total of 40 disability advocacy meetings attended.
- Continuation of two full-time consultant positions which is an additional 1040 program service hours.
- New volunteer project to light it up teal for Tourette in May.

We continue to look for more ways to impact the TS Community through outreach, training and events that promote awareness and acceptance.

Helping YOU is our greatest mission!

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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 the application by contacting Sara Woolf.

**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!

**Donors and Corporate Sponsors Invest in PATSA's SERVICES!**

None of our services could happen without our donors, grant funders and corporate sponsors! During 2023 a total of \$112,635 was provided to ensure we could continue all of our services and the following events:

- Virtual Retreat \* TS Awareness at the Capital
- 17th Annual TS Family Camp \* Tic Connections at the Zoo

Did you know that the State Budget starts in July, but funding 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.

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 PATSA while we wait.

**YOUR DONATIONS HELP US CONTINUE OUR VITAL TOURETTE SERVICES. MAKE YOUR DONATION AT [WWW.PATSAINC.ORG](http://WWW.PATSAINC.ORG) TODAY!**

**WE ALSO TAKE VENMO!**



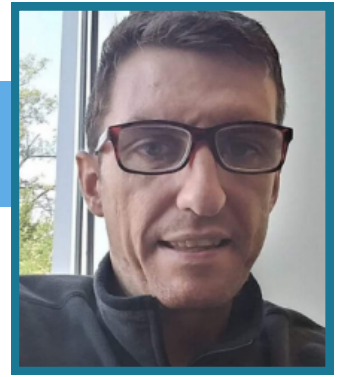
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venmo

# INTERVIEW WITH VOLUNTEER: JEFF MASON

Jeff is our Legislative Committee Chair and helps plan our Day at the Capital yearly. He lives in western PA.



**1) What inspired you to volunteer for PATSA?** I started with PATSA as an everyday family getting help after being diagnosed in the 90's by Dr. Lawrence Brown at CHOP in Philadelphia who referred my family and I to PATSA as he was heavily involved at the time so we could get the valuable resources and guidance to get through the school aged years like many of our families do now with PATSA. In 2016, I had cut back on my work hours while also serving with Lions Clubs International (which deals with the blind and visually impaired children and adults in our communities) and I found myself with some extra free time. I threw my name into the ring for the Board of Directors election and discovered PATSA needed a Legislative Committee Chair. This is what I studied in school and had previous work experience, so I stepped to the plate very quickly on that front as well. Now I can happily say I am just finishing up my 8th year of serving the individuals/families in every nook and cranny of the Commonwealth.

**2) What is your favorite PATSA activity or event?** My obvious answer is PATSA's "Day at the Capitol" not because I plan the day but because it's rewarding bringing new families to Harrisburg's Capitol Building (If you haven't gone inside it is a site to behold). I get to show them the advocacy side of fighting for their children while also seeing the very children share their experiences with a wide array of things that come with Tourette's. It's empowering for the children to talk about learning abilities or being bullied/harrassed to finally being able to live life because of the help PATSA has given them in the classroom and home.

My other favorite event is the all new Fall/Winter Tic Connections that serve families that may not be able to travel across the commonwealth for big activities to get together with other families and just be themselves while learning from each other.

**3) What do you find rewarding about volunteering for PATSA?** Seeing struggling families with nowhere else to go breathe a sigh of relief when they first find PATSA and learn we are there for them every step of the way. Many families say PATSA is the only dedicated lifeline in the Commonwealth for Tourette's Syndrome. Just seeing one more family get the help they need to navigate the rough seas with our helping hand advocating in schools for their children is beyond enough for me. I love nothing more than seeing a child be comfortable with who they are and in their environment with a feeling of purpose is like liquid gold. No child should ever have to endure the stereotypes and discipline many of us in the Tourette's community face because of a lack of knowledge/understanding by onlookers. This is the reason PATSA exists.

## IN THE TRENCHES WITH PATSA CONSULTANTS

Recently, we helped a family feel safe enrolling their daughter in public school. Their adorable daughter was set to enter Kindergarten in August and the parent reached out to the school in June to share information and request a meeting before school started. She wanted to make sure that the school would be a safe place for her daughter--so that she wouldn't be disciplined for tics or be misunderstood for some of her other actions.

The school's polite answer during a phone meeting? "She's not our student until the first day of school. So we will meet with you then."

Umm--what? That's not how it's done for other students! Imagine if the child was in a wheelchair or had seizures and the family wanted to make sure that everything was set up for their child within the school. They would have had more than one meeting to prepare!

With PATSA's intervention--we not only met with key members of the school team prior to the first day, but we also got a 504 accommodation plan set up AND a full school evaluation started! Since then we have had not just one, but three meetings with the school. These meetings have been positive and productive. The parent is happy with the communication she has developed with the school and everyone is becoming part of a team in support of her daughter!

Even with all that progress, there is still more to do to help this one student. The school has not yet scheduled our FREE training for their staff, although we have been able to train their classroom peers. We continue to request these services and know that they will also make a difference for her and for her classmates. Happily, the child is adjusting, supported and successful in Kindergarten so far--and they all have PATSA on their side to assist!



# SPRING EVENTS!



## CAN'T SIT STILL RUN/WALK

**SUNDAY,  
APRIL 28, 2024  
9:00 AM**



**\$30 5K  
\$20 ONE MILE  
INCLUDES T-SHIRT**

Beautiful, measured, professionally timed 5K course in Carnegie, PA.

8:00-8:45am Check In  
9:00am 5K Run/Walk  
9:15am One Mile Run/Walk

Registration Deadline (to guarantee T-shirt): April 8, 2024

Awards for 5K top-3 male & female finishers.  
Certificates for top male & female finishers in decade age categories.

Go here: <https://bit.ly/3ShqoHd>

See our webpage for more information.

**Runners,  
Sponsors, and  
Fundraising Teams  
are needed!**



## Day at the Capital

**ADVOCATE FOR TOURETTE SYNDROME  
in Harrisburg on Tuesday, April 30, 2023**

Volunteers are needed to share their stories with local legislators during our advocacy day. This annual activity is vital and helps the legislators understand why funding for TS is so important to YOU! Learn more and register at:

<https://bit.ly/DAC24>



## Light it up Teal

**Tuesday, May , 2024**

Our PR Committee and other volunteers are seeking buildings, bridges and other places to Light up Teal for TS Awareness Month! More information available by email and at this link:

<https://patsainc.org/events/awareness-activities/>





# TS Family Camp 2024

**Our 18th Annual TS Family Camp Weekend is scheduled for June 7-9, 2024**

Held at Black Rock Retreat in Quarryville, PA -- they offer almost everything we need in one large space, Their Marantha Lodge includes a large meeting room, break-out rooms, gym, dining room and 60 private, hotel-like rooms so each family can have their own space!

If you have never attended, put this amazing event on your calendar!

Scholarships are available if cost is an issue for your family.

"Watching my child meet new friends and feel like she is not alone has been such a beautiful gift. I am so sad we haven't come to camp sooner."

"For the first time, we were able to attend events and discussions without worry about our kids -- they were understood and accepted and helped when struggling -- what a feeling of relief and acceptance!"

"My son came home with a whole new confidence level that I have never seen before! It is truly amazing!"

<https://patsainc.org/events/ts-family-camp/>

The PA Tourette Syndrome Alliance continues to seek 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 businesses and organizations that are within your social network!

Bring your leads to [sherrie@patsainc.org](mailto:sherrie@patsainc.org).

Alex van Ruler received a doubled donation from his employer to support our Pumpkin Run! Thank you to Johnson & Johnson and Alex for his support!



**Who do you know?**

**Who can you connect us to?**

## FINDING CONNECTIONS:

Dave Kiefer nominated PATSA for support through his employer, FedEx Ground. This will provide \$2,500 for TS Family Camp!

Patty John, Jamie Roach & Mark Weishner were able to double their donations with their employer Baird through the Baird Foundation!

# OUR GENEROUS DONORS



## Teal Advocate \$5,001-\$10,000

Robert & Joan Dircks Foundation

## Leader \$1,001-\$5,000

Pfizer Community Foundation

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West Manheim Township Lions Club

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**Richard Kramer by** Nathalie Anolik

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**Morton Wolpert by** Rachel Ezekiel-Fishbein

PATSA thanks all of our donors!

We can only serve people, because of YOU!

If we have missed your donation on p, 5, 6, or 7 for Aug 1, 2023- Jan 31, 2024 please let us know. We want to acknowledge ALL donors.

# DONATIONS IN HONOR

**Melissa Anne** by Jamie McGee

**Eoin Connor** by Becky Anne, Michelle Baum Stehman, Michelle Connor, Janet Klinger, Dorothy Perez, & Lori Renne

**My Family** by Scott Lederman

**Rachel Ezekiel-Fishbein** by Margalete Ezekiel, Aaron Ezekiel, Rachel Ezekiel-Fishbein, Tamar Granor, Kelly Green, Bridget John, Julie Liedman, Emily Lowe, Liz McKenzie, Naomi Reses, Martin Schmid, Sally Silverman, & Kenny Winneg

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**BFE Consulting Group, LLC**

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**JACK DOES WHATEVER**

**James P. Reaver**



**The Chambersburg Club**



Like a Clock,  
I keep on ticcing!

Nacho Average  
Cheesehead

Defying the  
Ticcing Odds



Return address:

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**Callum De Quevedo**

Student  
Lackawanna County

The logo for PATSA (Pennsylvania Tourette Syndrome Alliance) features the acronym "PATSA" in a white, sans-serif font. The letters are arranged in a slightly curved, overlapping manner within a blue oval shape. The background of the logo area consists of several overlapping circles in shades of blue and green.

1-800-990-3300  
WWW.PATSAINC.ORG