VOLUME 42 // ISSUE 2



PATSA NEWSLETTER

SUMMER 2023



2022-23 DONOR IMPACT:

PATSA's Board of Directors made a significant investment in programs by adding 1040 service hours for our two Consultants. Resulting in:

- A 68% increase in Educator Trainings.
- Doubling the number of Peer Trainings.
- A 700% increase in Health Related Trainings.
- A 63% increase in the number of families supported.
- Tripled the number of state-wide conferences to make more groups aware of our programs and support.
- The Executive Director was able to focus on grant writing and individual donations, which raised an additional \$48,429 for services compared to other years.

This additional 1040 hours for programs will continue through this school year. We continue to look for more ways to impact the TS Community.

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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!

Individual Donors and Corporate Sponsors are needed to invest in PATSA's future!



By investing in our services last year, a total of 56 trainings were held to help teachers, nurses and peers better understand students with Tourette syndrome. This was **DOUBLE** the number of trainings from the previous year, meaning double the number of children helped!

Training school staff is **proactive** and reduces the need for our consultants to frequently meet with school teams to ensure they are following educational plans. These trainings **develop empathy** and understanding from teachers, especially when they "experience" a 2-minute writing activity while being interrupted by a tic. This experience **opens their eyes** to the struggles of their student like no other part of our training! This simulation often results in more support for the student, especially in allowing extra time for writing or reducing writing tasks. **Will you help us provide these necessary services for more students?**

JOIN OUR TEAL INNER CIRCLE DONORS BY
INVESTING \$1,000 OR MORE FOR TOURETTE SERVICES

(CONTACT SHERRIE WIVELL FOR MORE INFO)

INTERVIEW WITH VOLUNTEER: LORI HARVEY

Lori Harvey, MEd, MBA, MHA, LBS is a PATSA Board Member, previous Secretary of the Board & parent of two children diagnosed with TS.

- 1. How long have you been volunteering for PATSA? I have been proudly dedicating my time to volunteering with PATSA since 2015, and my commitment to their mission has only grown stronger over the years. With each passing year, I find myself more passionate about supporting PATSA's endeavors to make a positive impact in the lives of those affected by Tourette syndrome.
- 2. In what capacity do you volunteer, and how did you get started? My journey with PATSA began when my youngest daughter was diagnosed with Tourette syndrome at the tender age of 3. As our family navigated the challenges of this condition, we were fortunate to discover PATSA, a treasure trove of support and resources. To contribute and give back, I started volunteering by assisting with summer camp activities and actively participating in fundraising efforts. Our initial experience with the summer camp program was nothing short of transformative, leaving us with an enduring desire to extend its duration for even more meaningful connections.
- 3. What inspired you to volunteer for PATSA? The inspiration to volunteer for PATSA arose directly from witnessing my youngest daughter's struggles with Tourette syndrome at such a young age. Her painful and debilitating tics motivated me to seek guidance and help, which led us to PATSA—a beacon of hope and support for our entire family. PATSA not only provided crucial information about Tourette but also offered assistance with the co-occurring challenges she faced. Recognizing the vital role of family support, I became determined to comprehend the best ways to cater to her comprehensive needs.
- 4. What is your favorite PATSA activity or event? Among the multitude of meaningful activities organized by PATSA, my absolute favorite is the summer camp program. This exceptional event brings together families from all corners of Pennsylvania and beyond, creating a compassionate and understanding community where individuals with Tourette, their families, and siblings can come together and share experiences. The emotional impact of this camp, coupled with the formation of lasting friendships and connections, is truly heartwarming. It provides a safe haven where everyone genuinely understands each other's journey and fosters a sense of belonging that is simply unforgettable.
- 5. Do you encourage others to volunteer, and if so, why? Absolutely, I wholeheartedly encourage others to volunteer with PATSA. This incredible organization offers an array of services to individuals with Tourette and their support networks. From providing invaluable in-services at schools for administrators, teachers, and peers to assisting with IEP and 504 plans, PATSA plays a pivotal role in the lives of those affected by Tourette. Their support groups serve as a crucial source of comfort and guidance for families and individuals alike. Being part of PATSA means contributing to a growing and impactful cause that helps dispel the misconceptions surrounding Tourette syndrome while promoting understanding and support for those living with it.
- 6. What successes have you seen with PATSA since you started volunteering? The successes of PATSA are numerous, and personally, I cannot emphasize enough how instrumental they have been in supporting my family throughout the years. PATSA's dedication to providing necessary support and services has been a game-changer for my children, particularly in their education. Their confidence and resilience have been nurtured through the services and programs that PATSA offers. Since my children's early years, PATSA has been a steadfast partner as we navigate life with Tourette syndrome, and their positive influence is evident in every aspect of our lives.
- 7. What are your aspirations for PATSA moving forward? PATSA's uniqueness lies in the comprehensive support and services it brings to Pennsylvania—an unparalleled resource for those dealing with Tourette syndrome. Looking ahead, my hope for PATSA is to expand its reach and touch the lives of even more individuals in need. Reducing the stigma surrounding Tourette through educational initiatives is essential, and I am confident that PATSA will continue to be a trailblazer in this endeavor. As Tourette is a highly individualized condition, PATSA's adaptability and readiness to cater to each person's unique journey are commendable. My aspirations for PATSA involve seeing it flourish as a model organization, enabling more individuals to receive timely diagnoses and the unwavering support they deserve.

FALL EVENTS!

Pumpkin Run

2023 PUMPKIN RUN **5K AND ONE MILE** \$30 for 5K (includes T-shirt & single attractions SUNDAY OCT 29

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

RUN **FOR**

TOURETTE SYNDROME

https://patsainc.org/ev ents/pumpkin-run/

See our webpage for more information.

Runners.

Sponsors, and

Fundraising Teams

are needed!

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:











MEET US AT THE ZOO on Sunday, September 24, 2023

Donors have made it possible for PATSA to have 3 zoo events for families FREE of charge! We have 3 locations where you can meet other families affected by TS for some informal fun at our fall Tic Connections! Located in Pittsburgh, Halifax (above Harrisburg) and Norristown. Learn more and register by searching for "Tic Connections" on our website.



Virtual Retreat

Saturday, Feb. 10, 2024

Our TS Family Retreat will be held virtual again this year. Designed as a family event, there are "small groups" for the children & parents--in break out rooms during the virtual event. More information available on the dedicated webpage: https://patsainc.org/events/ts-family-retreat/



FINDING CONNECTIONS:

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.

A volunteer, employed at Pfizer, sent us information about their Community Grant Programs.

PATSA submitted a grant proposal and was awarded \$4,000 to support trainings!

Thank you, Becky!

Jordan Galing held a Farm Fundraiser to meet the animals in April which raised \$502! Thank you to all who

attended this awesome event!

Sixteen year old Hope Nunemaker, presented info about Tourette, PATSA and TS Camp to Valley Grange just outside of Harrisburg. The members voted to provide \$5,000 for TS Family Camp!



Tina & Till Flohr did a month long fundraiser on Instagram to educate about TS and PATSA--this brought in \$2,000 to support vital

programs!

Who do you know?

Who can you connect us to?

TS Family Camp Sponsors & Donors:

In honor of Hope Nunemaker & Family







West Manheim Township









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Trindle Bowl
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Washington Wild Things
Zone 28

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Innovating Worthy Programs Foundation

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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 Feb 1, 2023- Jul 31, 2023 please let us know.

We want to acknowledge ALL donors.

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