VOLUME 43 // ISSUE 2



PATSA NEWSLETTER

SUMMER 2024



2024 TS AWARENESS MONTH

Teal Tuesdays, Light Your Town Teal and Social Media Outreach made for an exciting TS Awareness Month in 2024.

PATSA's PR Committee recruited the help of volunteers to expand this outreach. Johnstown, Pottstown, Harrisburg & Scranton joined Pittsburgh and Philadelphia to Light Up Teal this year! Several publications picked up our Press Release too. Examples here:

- a. Article: https://www.tribdem.com/news/stone-bridge-to-be-lit-teal-in-recognition-of-tourette-syndrome-awareness-month/
 article 6219e948-144d-11ef-9395-4bb9cb404a36.html
- $b.\ TV: \underline{https://www.wpxi.com/news/local/several-pittsburgh-buildings-light-\underline{up-teal-tourette-syndrome-awareness-month/}$

IA2H4DCZONHE3OL5I2HAMALQDY/

c. Online article: https://theflashnews.co/news/several-pittsburgh-buildings-lit-up-in-teal-for-to-664de38c6f580329464df174

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Western PA Consultant Brandi Cooper brandi@patsainc.org

Eastern PA Consultant Nicole Wesner nicole@patsainc.org

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 info@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!

Donors and Corporate Sponsors Invest in PATSA's SERVICES!

None of our services could happen without our donors, grant funders and corporate sponsors! During the first half of 2024 a total of \$59,814 was provided to ensure we could continue <u>all of our services</u> and the following events:

Virtual Retreat
TS Awareness at the Capital
18th Annual TS Family Camp

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 <u>WWW.PATSAINC.ORG</u> TODAY!

INTERVIEW WITH VOLUNTEER: DAN BAUER

Dan is 37 years old, has been volunteering with PATSA since 2016. He works as a Food Service Manager, overseeing two surgical hospitals in Allentown.

1. What inspired you to volunteer for PATSA?

What inspired me to be a volunteer, really is a "who". That would be Lindsay, my girlfriend at the time. When we first met, she told me about it after our second date. I had no idea what Tourette Syndrome was or anyone who has it. After dating for several months, she said she



Lindsay & Dan Bauer

volunteers at this PATSA camp. She asked if I wanted to come and help and volunteer. I wanted to support her and get to know the group she called her "second family". It was a great experience getting to meet and see other people with tics and understanding more about it. After the first year of being a mentor, I wanted to keep supporting her and helping the PATSA family. Years later we are still together and have been married now for three years.

2. What is your favorite PATSA activity or event?

My favorite PATSA event is TS Family Camp and my favorite activities at camp would be pool time, laser tag and dodgeball. I enjoy being on the camp committee and seeing everything come together when we are in person for the event. I enjoy reconnecting with families that I have met over the years.

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

Being there for the kids, running around with them makes me feel like a kid again. Teaching them how to make pasta and soft pretzels on the online virtual retreat was also fun. Giving back to a nonprofit organization that serves a misunderstood disorder is the best experience.

IN THE TRENCHES WITH PATSA CONSULTANTS

Last fall we had the opportunity to provide our Family Training in an interesting way. A couple with one child who is diagnosed with Tourette syndrome were in the middle of a divorce and custudy arrangement. The father, who had not been involved in many of the doctor appointments and school meetings, was having a difficult time understanding Tourette syndrome and his son's specific needs. This was creating a huge disagreement between the parents in order to obtain a settlement and custody arrangement.

Often when people don't understand TS, they focus on the wrong things and sometimes even discipline them for repetitive symptoms. It is often hard to understand that these symptoms are real, especially when they can be suppressed at times.

Divorces can be contentious at times, and this was no exception. Because the mother had support from one of our consultants, she had learned a great deal about her son's needs, but his father didn't necessarily believe her point of view.

This is where PATSA was able to help! Because the mother and her lawyer wanted both households to be on the same page where the child's needs were concerned, they got information about our Family Training and asked the court to order the father receive our training. They felt this would help him to understand TS and how to support his son.

The judge did order the father to have the training and it was held within 2 weeks of the request. Our training was held via Zoom and since this consultant had been involved with the school meetings, she knew a great deal about this specific child's needs. She was able to answer questions for the father and really help him to understand that tics are real and can't be fully controlled, even if a child may want to try.

Through this training, the father has a better understanding and is better able to have successful parenting time with his son. If you ever need a training for someone in your family, extended family, or your child's school, please contact us!

FALL EVENTS!



RUN FOR TOURETTE SYNDROME AWARENESS

<u>Pumpkin Run</u>

See our webpage for more info
Runners,
Sponsors, and
Fundraising Teams
are needed!

Info online here: https://patsainc.org/events/pumpkin-run/



Tic Connections

Eastern Tic Connection

Saturday, Sept 21, 2024, from 4:00 - 10 pm. Join us at the Lehigh Valley Iron Pigs ballgame, 1050 Ironpigs Way, Allentown. Tail gait with us in the parking lot 4-6, enjoy the ballgame at 6:30 and stay for fireworks after the game. Cost of \$15 provides ticket, food, drinks (tail gait) and a parking. Hosted by Nicole Wesner our Eastern PA

Consultant.

Pre-registration is required.



Info for All Events here:

https://patsainc.org/events/tic-connections/



Central Tic Connection

Sunday, Sept 22, 2024 from 1-3. Join us at the Carlisle Sports Emporium, 29 S Middlesex Rd, Carlisle where we will play mini golf, arcade games and enjoy pizza & drinks in a private room. Cost of \$16 provides food, mini golf & \$10 in game card. Hosted by Sherrie Wivell our Executive Director.

Pre-registration is required.



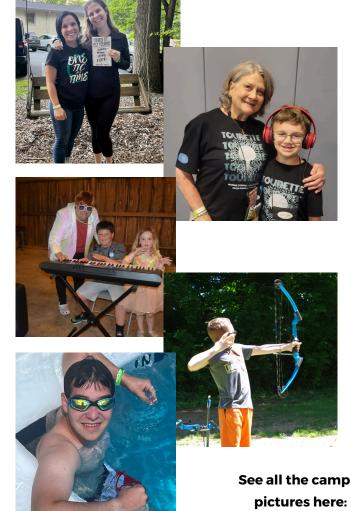
Western Tic Connection

Sunday, October 6, 2024 from 11-1. Join us at the Fun Slides Carpet Skate Park, 1130 Perry Highway, Pittsburgh for a private party with other families affected by Tourette. For \$15 per person, you will enjoy skating, mini golf, pizza, chips, cookies and drinks. Hosted by Brandi Cooper our Western PA Consultant.

Pre-registration is required.

Our 18th Annual TS Family Camp Weekend was held June 7-9, 2024





https://eu.zonerama.com/TSFamilyCamp2022/ Album/11485447



Our Silent Auction raised over \$1200 from the following donors:

AACA Museum Inc. Adams County Winery Adventure Sports in Hershey Allegro Winery Altoona Curve ASCEND Pittsburgh Barb Ruschak Boiling Springs Pool & Waterpark Carnegie Science Center Chanticleer Foundation / Garden Delgrosso's Amusement Park Dorney Park & Wildwater Kingdom Fun Fore All George & Gail Counihan Grandpa Joe's Candy Shop Harrisburg Senators Hickory Falls Family Entertainment Center Hope Nunemaker John Heinz History Center Kreider Farms Farm Tour Lake Tobias Widlife Park Lancaster Barnstormers Landis Valley Museum Lehigh Valley Zoo Lincoln Caverns & Whispering Rocks Lindsday Bauer Living Treasures Wild Animal Park Longwood Gardens Martins Chips Mercer Museum & Fonthill Castle Mister Car Wash Museum of Illusions Philly Oasis Family Fun Center Office Max Old Jail Museum Oriental Trading Company Pam Bernet Penn Brewery Philadelphia's Magic Gardens Pittsburgh Botanic Gardens Pittsburgh Steelers Reading Fightin Phils Shady Maple Smorgasboard Six Flags Great Adventure SSW Crafts Stauffer's of Kissel Hill Trindle Bowl Washington Wild Things William & Carol Stiefel Williamsport Crosscutters

OUR GENEROUS DONORS

From Feb 1 - June 30, 2024

Teal Visionary \$15,000-\$30,000

Anonymous donor family

Steward \$1,000-\$2,499

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DONATIONS IN HONOR

Alexander Rubbo by Sharon Rubbo

Harrison Smith by Mandy Heron

Stephanie Dissen by Ken Cummings

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 Feb 1, 2024 - June 30, 2024 please let us know. We want to acknowledge ALL donors. 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 a business or organization within your social network!

Send your leads to sherrie@patsainc.org.

Hope Nunemaker reached out to the Valley Grange organization and Stauffer's Biscuit Co and landed \$6,000 in sponsors for camp!



Our Spring Run Committee and fundraisers engaged all the sponsors below to help support our programs!

Who do you

know?

Who can you connect us to?

HELP? Jason Cooper requested physorship from his employer

CAN YOU

Jason Cooper requested sponsorship from his employer and received sponsorship for both our Can't Sit Still Run and TS Family Camp from Grandpa Joe's Candy Shop!

CAN'T SIT STILL RUN/WALK



\$30 5K \$20 ONE MILE

The Patty John and
Jamie Roach Group

SPONSORS:









Expert care from people who care.

was raised!















Steel Point Opportunities



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Patty John KORBIN COOPER

Bob & Jana Grimm

PA Tourette Syndrome Alliance, Inc 18 High St. #68 Hanover, PA 17331



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