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PATSA NEWSLETTER

WINTER 2022

TOGETHER AGAIN

BY SHERRIE M. WIVELL

"Together Again" was the theme for our 2021 TS Family Retreat held on October 23-24. Held at the beautiful Refreshing Mountain in Stevens, PA, it could not have been a more perfect setting in the wonderful fall weather. We hosted almost 75 people at the event and our families enjoyed the outdoors and lots of fun activities.

The kids met animals, some climbed the tower or did the "Giant Swing", got to play Gaga ball and do some arts & crafts! We had great fun with Family Dodge Ball and so many shared their talents in the annual Talent Show!

A special thanks to our volunteers who helped us with all aspects of this event! From planning, set up/tear down, helping the kids groups, taking pictures, registration, to volunteers who jump in wherever they are needed. There is a place for EVERY Volunteer, so keep that in mind for our next event!

We had an amazing time and were so glad to be "Together Again!"

Our Volunteers:

CONTENTS

Retreat 2021 - 1

Disclaimer - 2

Volunteer Interview - 3

Upcoming Events - 4

Teal Inner Circle - 5

Our Donors - 6

Memorial & Honorary Gifts - 7

Mailing addresses:
PATSA
18 High St. #68
Hanover, PA 17331
Or
PATSA
700 Washington Ave. #456
Bridgeville, PA 15017

Phone
1-800-990-3300
717-337-1134

Website
www.patsainc.org
info@patsainc.org

STAFF
Administrator/Consultant:
Sherrie Myers Wivell
Phone ext. 2
sherrie@patsainc.org

Outreach & Volunteer Administrator:
Sara Woolf
Phone ext. 1
saraw@patsainc.org

Western PA Consultant
Brandi Cooper
Phone ext. 4
brandi@patsainc.org

Eastern PA Consultant
Nicole Wesner
Phone ext. 3
nicole@patsainc.org

Volunteer Opportunities:

Volunteers are needed in a variety of positions both large and small! Recorded trainings are available for some positions. To start the process, just let us know what program you might be interested in by completing a volunteer application online or requesting the application by calling or emailing Sara Woolf. (sara@patsainc.org or 1-800-990-3300 x1)

Committee Member – Volunteer your time to provide support and guidance on one of our active committees. These committees meet by phone conference 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 more members at this time.

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.

Support Group Leader – start a local support group in your area or help with an online group.

TS Family Camp and Retreat – A variety of volunteer positions are needed at Camp and Retreat, some of which are paid.

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).

While we will attempt to respond to all mail, we are not able to answer medical questions. The PATSA, Inc. does not endorse products, services, or manufacturers. Such names appear only as information for our members. PATSA assumes no liability whatsoever for information about 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 Pennsylvania Tourette Syndrome Alliance.

INTERVIEW WITH VOLUNTEER: ANN FICKE

Ann is 50 years old and married to John. Together they have a 12 year old son with TS. Ann is a licensed Social Worker but currently works part time at Wegman's. She likes to cook and watch movies with her family.

❝

1. How long have you been volunteering for PA-TSA? A little over a year.

2. In what capacity do you volunteer & how did you get started? I co-lead an online support group for parents with children who have TS. About a year and a half ago, during an online PA-TSA retreat I met another mom with a son who has TS, and we hit it off. Very quickly, we talked about and agreed to help PA-TSA start an online group for parents in Eastern PA. With the pandemic on, it made sense to do it virtually and now we see it's so much more convenient for parents who don't have to get a babysitter. It's also great for people who don't want to drive an hour for another meeting. We had to take a break last summer and its taken a little time, but the group is starting to take off. We have also opened up the enrollment to anyone with TS or has a loved one with TS. The more people we can support the better.

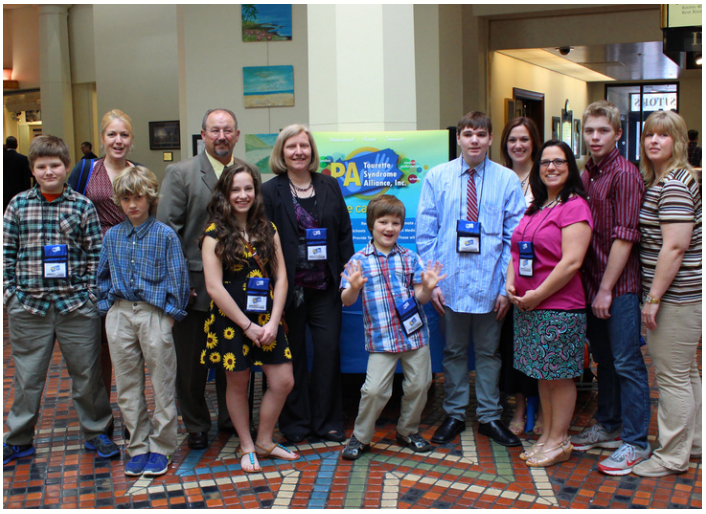
3. What inspired you to volunteer for PA-TSA? When my son was first diagnosed, I was given PA-TSA's info. They were a life line to understanding, living with and thriving with TS. I have met some of the most wonderful people both working for PA-TSA and through events at PA-TSA. The time spent at events never seemed long enough. It was an easy decision to help expand the support and start a monthly group meeting.

4. What is your favorite PA-TSA activity or event? I have to say the retreats. They are always well organized and fun for all of us.

5. Do you encourage others to volunteer, if so, why? I encourage anyone connected to TS to reach out and support PA-TSA in whatever way they can. Everyone's lives are so crazy, anything a person can do is helpful. They can donate, or volunteer or just spread the word about all the great work PA-TSA does.

6. What successes have you seen with PA-TSA since you started volunteering? All of the work done in schools, and getting IEP's and 504 plans for students. So many families struggle to ensure their children get the support they need to have a full education in school settings. PA-TSA is relentless when it comes to making sure kids with TS get all the benefits they need and deserve. With the pandemic it was even more challenging but they never stopped working to advocate for kids. I also think the retreats are such a huge success. It's great to have a place where people understand what you and your loved ones go through. Kids meeting other kids who have the same struggles and can support each other is awesome!

7. What are your aspirations for PA-TSA moving forward? I would love to see even more outreach to the community just to make people aware of PA-TSA. I was lucky that the neurologist who diagnosed my son knew of PA-TSA and gave me their info. I wish every Doctor's office knew about PA-TSA.



SPRING EVENTS!

TS Family Camp

Our 2022 Annual TS Family Camp will be at Black Rock Retreat in beautiful Quarryville, PA, Lancaster County!

Dates: June 10-12, 2022

Workshops for parents, group fun for kids and family activities. It's a dedicated time for you to meet others, gain support and have fun together.

Every attendee will receive materials, giveaways and t-shirts to commemorate the fun. Cost is $160 for adults and $130 for kids under 12. Scholarship funds are available for Camp as well. For more information and to register go to: https://patsainc.org/events/ts-family-camp/

TS Awareness at the Capital

Nothing is more important in the preservation of PATSA services than our yearly Day at the Capital event! This is where we get to talk with State Legislators to make sure they keep Tourette syndrome in the State Budget! This funding pays for over 60% of our services and they need to hear from YOU!

Parents and students make your voice heard! Let the Legislators know how much you need support from PATSA and that these services should continue.
To register go to www.patsainc.org and search for Day at Capital.

Highmark Walk

Our teams and individual walkers raise funds to support our TS Family Camp! This event can't happen without your help!
Join us in-person or raise funds as a virtual walker or team! You may even win prizes!
We plan to raise $8,000 to support FREE services between the two locations:

Harrisburg Location: HACC--Harrisburg Campus
Date: May 21, 2022 at 9:00 am

Register/Donate here: hcf.convio.net/patsa-harr

Lehigh Valley: DeSales University
Date: June 4, 2022

Register/Donate here: hcf.convio.net/patsa-lehigh

> IF IT DOESN'T CHALLENGE YOU, IT WON'T CHANGE YOU.
> - Fred DeVito

Mary Lou Reaver had big dreams! Her dream grew into the PA Tourette Syndrome Alliance from a phone support line in her house! Just like Tourette's, our organization has "waxed and waned" over the years but PATSA is definitely on the upswing now!

Together, we are working towards building a new dream! We need to continue our current services but do them better and for more people! There is a need for more support, more school trainings, more friendships fostered, and more outreach to the general public! We dream of a day when **no one in Pennsylvania** says: "Tourette's? I have never heard of that!"

Each year we train more schools, provide more families with the tools to understand Tourette, and reach more doctors, but at our current rate, it will take 240 years to reach all of the Educators in Pennsylvania! That sounds daunting but we are not giving up. We are focused on finding investors that can help us make a difference...NOW! People who can help us insure that every child, every family and every school is served--not in 30 years, not in 20 years--but NOW!

With this in mind we are launching our Teal Inner Circle (TIC) Major Donor Campaign to find those individuals who want to invest in PATSA's future and help us make a huge difference! Look for more information and invitations coming soon. If you want to learn more go to page "Teal Inner Circle" of our website or reach out directly to Sherrie Wivell at sherrie@patsainc.org.

Wondering what to do with your Required Minimum Distribution (RMD)?

Consider a Qualified Charitable Distribution (QCD) to PATSA. If you are 70 ½ or older, you can transfer up to $100,000 from your IRA each year to a Qualified Charitable organization and exempt it from your income.

Generally, distributions from a traditional IRA are subject to federal income tax. However, if the IRA owner meets certain requirements, he or she may be able to transfer funds directly from the IRA to a qualified charity and consequently exclude the withdrawal from taxable income. There are benefits to a direct transfer to charity from an IRA, (as compared to an ordinary, direct donation)

- The QCD will not increase your Adjusted Gross Income (which may affect Medicare Part B costs)
- If you are not eligible to itemize – a QCD may be a better option

If you think this might be an option you'd like to discuss further, contact your financial advisor or tax consultant.

OUR GENEROUS DONORS

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Patty John & Hefren-Tillotson, Inc.

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> "NO ACT OF KINDNESS, NO MATTER HOW SMALL, IS EVER WASTED.
>
> - Aesop

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

If we have missed your donation July 1-Jan 31, please let us know. We want to acknowledge ALL donors.

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Thanks to our Pumpkin Run 2021 Sponsors

ShocktoberFest
Pennsylvania's Premier Haunted Scream Park

West — By your side for a healthier world™

Wawa

Run for Tourette Syndrome Awareness

Held October 31, 2021
Stay tuned for event at Halloween 2022

Philadelphia Rock Gym
The McLoughlin Family— supporting Jack Finn
JJ's Tic or Treat Team
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Check out race results and pictures from our Pumpkin Run website page.

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PATSA

18 HIGH ST. #68
HANOVER, PA 17331

700 WASHINGTON AVE. #456
BRIDGEVILLE, PA 15017

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