

# PATSA 4 KIDS

**BI-ANNUAL NEWSLETTER** 



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## **SEEKING YOUR NEWS**

PATSA would love for this newsletter to be about YOU! The children and teens that have Tourette syndrome. We would like to include your stories, your struggles and your accomplishments to share with each other. You can share a picture, some artwork, or an award you received. You can write a poem, share a short story, or draw a picture of your favorite sport.

What hobby do you enjoy? Is there something that makes you feel excited? Is there something you want to share with others who have TS?

Something you decide to share could mean the world to someone else! It may make them try a new sport, write their own poem, or share a picture of themselves too.

Think of what you would like to share and then send it to to info@patsainc.org with subject line: Newsletter Submission! We can't wait to hear from you!



## **TELL IT LIKE IT IS**

#### INTERVIEW WITH LUCA RITORTO

#### 1. If you could tell your younger self something, what would it be?

Tourette's isn't the worst thing in the world. Sometimes it can be good and sometimes bad. Like at times I might make funny faces and then it is perceived as being funny, and I am seen as someone who makes people laugh. But, other times, it can be challenging as I have a hard time thinking before I act. So, I might say something I regret without meaning to do so.

#### 2. Can you name some of your tics?



Luca is 14 years old from Bucks County.

Some of my tics are random sayings that don't mean anything; getting mad for no reason; having OCD symptoms (that go along with having Tourette's); and when I feel bored, I constantly feel I need to do something.

3. Have PATSA programs and services helped you or your family?

The program helped me so people could know I had Tourette's, so people could understand more why I do things.

4. Has TS helped you in your education, employment or anything in your life?

Yes, it helped me to be the class clown. It helped me in getting extra ways to study in school, including using computer aides, getting extra study guides, and getting extra help from the teachers as I need it.

5. Anything else you want to share with other young people about TS or your experiences?

Yes, it is not a contagious thing and not a virus. It is basically something inside you that you are born with, but it doesn't define you. Don't get worried. It's not going to cause you to get sick.

The views of the interviewee do not reflect the views of the PATSA. Every individual experiences different tics, severity and co-morbid conditions.

The above article represents the views and experiences of the interviewee alone.

## **TS CAN'T HOLD US BACK**

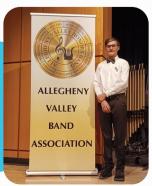


MALLORY RECEIVED A
POSITIVITY AWARD IN HER
FIRST MONTH IN
KINDERGARTEN!

Submit your stories and accomplishments for our next newsletter!
Send pic and info to sherrie@patsainc.org

WE CAN'T WAIT
TO SEE ALL THAT
YOU HAVE
ACCOMPLISHED!

KORBIN AUDITIONED AND WAS CHOSEN TO BE IN THE ALLEGHENY VALLEY HONORS BAND IN JANUARY 2025.

















### **MUSEUMS & ZOOS ONLINE**

VIRTUAL VISITS ARE A GREAT WAY TO VISIT A MUSEUM OR ZOO IN THE WINTER.

BELOW IS A LIST OF THE TOP 10 VIRTUAL TOURS IN THE USA!

#### Ages 3-7:

#### Ages 13 and Up:

#### San Diego Zoo

Features live animal cams and fun facts, allowing young children to see koalas, elephants, pandas, and more.

#### Georgia Aquarium

Offers live webcams of marine life such as beluga whales, sea otters, and fish in their Ocean Voyager exhibit.

#### Ages 8-12:

<u>Smithsonian Museum of Natural History</u>

Provides interactive, room-by-room tours of exhibits, including the Hall of Fossils and Ocean Hall.

#### Mystic Aquarium

Virtual programs include animal encounters, educational videos, and activities about marine biology.

#### Boston Children's Museum

Offers a virtual tour and a rich archive of hands-on activities to spark creativity and curiosity.

The Smithsonian on Google Arts & Culture
Explore various Smithsonian exhibits, from
space exploration to art and history,
through detailed virtual tours.

The Olympic Museum
Virtual tours allow teens to explore the
history of the Olympic Games.

National Women's History Museum
Features online exhibits that highlight
women's contributions to society, ideal for
exploring social studies topics.

Perot Museum of Nature and Science
The "Amaze Your Brain" series includes
experiments and activities that inspire teens
to explore science at home.

National Constitution Center
Offers virtual tours of exhibits and
interactive lessons about the U.S.
Constitution and its history.



### WHAT A MEMORY

I was first introduced to PATSA a long time ago, in 1990(I'm OLD I know!) to be exact, not long after I was diagnosed with this very strange condition. My mom tried and failed over and over to get me to come to a PATSA event or two. But I had this idea that Tourette's would be more real if I spent time with a bunch of kids that had tics also. And I wanted nothing more than to be "normal" so I told myself that I could hide my Tourette's if I stayed away from others who had it.

**Just a note:** One of my MANY tics was a shoulder shrug that I did so many times that the back of my earlobes had brush burns! I say that to say I obviously wasn't hiding anything! Except from the possibility of making incredible friends.

I do remember one time when my parents forced me to go to a Tourette's event. (Yeah don't you LOVE when they do that) Jim Eisenreich was a star on the team and he actually paid for the tickets for kids to go to a game! The thing was that I didn't know who he was, and I had already decided at the tender age of 12 that soccer was my sport, so you know, baseball was dumb. But my parents believed in the idea that "if it's free, it's for me" So I went kicking and screaming, and only partly because of my tics.

I can still see the ticket attendant pulling me and my family aside as we walked through the gates. And I can still feel the fear in my heart as security took us by a golf cart to a place unknown. My parents thought it would be more fun to keep the next part a surprise from me. (Don't you also LOVE when parents do that!) Arriving in the belly of Veterans stadium the security personnel directed us down a short hallway. For a moment I thought we were all going to sit in jail for some crime I didn't know I had committed, (You know because Anxiety + strong imagination = crazy possibilities!) 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 sitting on the floor. I wanted to run away but something very strange happened instead. As the group all looked at the late arrival and saw my tics starting to come out, I saw a relief grow in many of the other kids eyes. That same feeling of relief starting growing in me as well for the very first time. My tics told them they were still safe and theirs said the same to me. This was new and it felt so, so, good.

A few moments later I was sitting on the floor with them, admiring all of the "civilian clothes" as I called them, of the players currently on the field prepping for the game. Then Jim came out to speak to us for a few

### BY DERICK VALENCIK

minutes before he joined his teammates 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 of the room was something else as well! Up to that point I had never experienced positivity and hope when Tourette's was involved. It was always doctors and school meetings. BLAH!

To be very honest with you, I sort of believed that it wasn't possible to live a normal life with TS. But there was a Philadelphia Philie right in front of me shattering that self-limiting belief! It wasn't the end of doubt for me for sure, but it lost it's unbreakable grip on me that day.

I was 12 then, I just turned 40 this past June. 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. The common, unspoken bond was deep. I felt understood and could see that I was not the only one harboring these fears common to so many of us with TS. I knew that 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 as a teenager. I am proud of how I have handled many parts of my TS journey, but by rejecting the kindness and support of the TS community I took many opportunities for happiness and joy away from myself during the years when Tourette's was just brutal. 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. It's June 6th through the 8th and I would love to see you there. Heck, the entire PATSA team would love to see you there! Talk to your parents about it and let them know that you want to join us.

Let me finish with this. Whatever you choose regarding camp this year please, please, please take full advantage of the incredibly supportive TS community around you. The PATSA board, staff, and entire team of volunteers are all passionate about championing those who live with TS and their loved ones. There is no reason to do this alone. Reach out today and get connected, you will not regret it. And fingers crossed, I'll see you in June!

