

PATSA 4 KIDS

BI-ANNUAL NEWSLETTER



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ONE IN 50?

BY SHERRIE M. WIVELL

Wow! Have you heard this new statistic? Recent research shows that one in every **50** students has a tic disorder or Tourette syndrome.

This is a lot more people than we thought before. I am pretty sure lots of you know more than 100 people but don't know two other people at your school who have tics or Tourette syndrome.

It could be that some people are hiding their symptoms. They might be trying to not let other people see their tics. They might have something as small as rapid blinking or they might mumble a word quietly, even though they feel like they have to do it.

This is one reason it is so important to spread the word that having tics and Tourette syndrome is OK! Tics are common. And it's ok to let them out! The more people who know about it, the less people will feel they have to hide it.

What can you do to help people let it out??

TELL IT LIKE IT IS

INTERVIEW WITH CALLUM DEQUEVEDO

- **1.What is the hardest part of having TS?** The self injurious tics are the hardest part for me. They can hurt so much.
- 2. If you could tell your younger self something, what would it be? It will get better. Things don't stay bad all the time. Keep working to do things to help yourself. Don't give up.
- **3. What is something good about having TS?** It offers for me to be part of the Tourette community. I have gotten to go to some really awesome events and places and connect with people who are like me. This fall I met Tourette Cop, Craig Elgin and David Begnaud, Lead National News Correspondent for CBS News. They both have TS and even though we are all different, we share many similarities with TS!
- **4. Can you name some of your tics?** I have a couple of punching tics, a breathing tic, shoulder shrugging, copralalia, echolalia, palilalia, head banging, toe flicking, neck cracking, knuckle cracking, lots of vocal tics, laughing tic, grunting. There are more but it's hard to count them all! Many are complex tics.
- **5. How do you tell people about your TS?** I try to get straight to the point and say, I have tourette syndrome. I try to explain some of my more complex tics so that they don't think I'm behaving badly or awkwardly.
- **6.** Have PATSA programs and services helped you or your family? They came to my school and helped to advocate for me and explained about Tourette Syndrome to all of the teachers at my school. Nicole Wesner has accompanied my parents to IEP meetings and answered many of our questions.
- 7. How are you involved with PATSA and why do you think others should get involved? I am a youth presenter and have done many presentations in my school and local community. I've attended several PA-TSA events and made some good friends through those experiences. This has given me the opportunity to connect with others with TS.
- **8.** What else would you like to say about TS, your school/employment or anything? Due to the severity of my tics, I am not currently attending my local school. Instead I am attending school online but would really like to go back to school to be with my friends.

Callum is a high school junior from Lackawanna county.



Callum pictured with Tourette Cop

Callum attended the TAA Gala

I work a few hours a week at Hollister in a local mall. I'm lucky that my manager and coworkers are very understanding of my TS. It can be tough sometimes to work when I'm not feeling well or my tics are more severe.

In December 2022, I had Deep Brain Stimulation surgery at Mount Sinai Hospital in New York City. My first programming appointment was January 5th. I'm hoping this helps relieve some of the more serious tics that I have and allows me to return to school. My surgery and journey are being documented by David Begnaud of CBS News. He interviewed me on Instagram Live back in November and we saw him again on January 5th. I'm happy to have this opportunity to share my experience with the world so that more people can learn about TS and treatments available. (CBS Morning News aired the story about Callum on January 19, 2023)





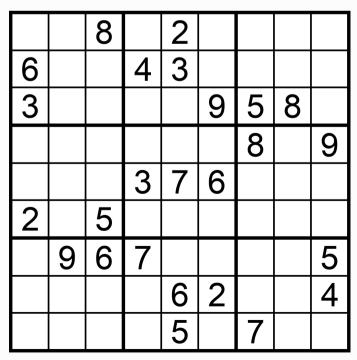
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ACCEPTANCE

Acceptance is an important part of life. It's a feeling of being valued, respected and accepted for who you are. Acceptance can be really important for children and teens, as you are still figuring out who you are and how you fit into the world.

Acceptance for yourself begins with self-love. This means liking yourself for who you are, even if you don't fit into the same mold as everyone else. You are special and unique, and it's important to recognize that. Self-acceptance allows you to be comfortable with who you are and have confidence in yourself. Acceptance can help to create a sense of belonging and purpose. Knowing that you are accepted for who you are can give you the confidence to try new things and take risks. This can open up new opportunities and experiences that will help you to grow and develop.

Acceptance is also important for other people. It means understanding, respecting and being kind to others, even if they are different from you. This means embracing the things that make someone unique, even if they are different from you. It's important to remember that everyone is special in their own way and that it's okay to be different.

When a person learns to accept themselves and others, it can help them form strong, meaningful relationships. Acceptance also means being open-minded and willing to learn. Everyone has something to offer, and it's important to be open and willing to learn from others. This can help you grow and develop as a person.

Our motto here at PATSA is "Accept Me"—and that means EVERYONE!



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"Acceptance is the road to all change" Bryant McGill