

MEGAN TOY

is a Peaceable Schools Coordinator in the Washington, D.C. school system. She is also an accomplished tri-athlete and member of TEAM TSA.



TSA: What do you do when you're not participating in Ironman events?

Megan: I work for the D.C. public schools in a special position — Peaceable Schools Coordinator. I teach alternatives to violence and bully prevention in kindergarten through sixth grade classes, train peer mediators and run training workshops for adults who work with kids in the D.C. public schools. As part of it I share my personal experiences. I can really say 'I've been there' and they appreciate those stories.

TSA: How long have you been doing this?

Megan: It'll be five years in March. I have a Masters in International Peace and Conflict Resolution from American University in Washington, D.C.

TSA: How did you become involved in TEAM TSA?

Megan: When I was diagnosed with TS, my family joined our local chapter in Rochester, New York. My mom still gets information and newsletters from them. I was visiting home and saw something from TSA in the mail and asked my mom if I could open it. It was the publication about TEAM TSA. It was fortuitous that I was the one to open it. My mom would not have had a use for it. I took it home with me and went to the website. I was very pleased with how easy it was to set up a web page and that you didn't have to do one of the selected races as I'd already had my race calendar for the year.

TSA: You're obviously a very serious athlete. How did you get into triathlons?

Megan: When I was in college I was on the crew team and after school I took a hiatus from athletics. Then I had a life-changing experience. I ended an engagement and for the first time I was completely on my own. I started looking for challenges

and setting goals for myself. The first was running a 10K every month. Then a friend told me about triathlons. I didn't even own a bike. I had to buy one to start training. Later that year I did my first Ironman.

TSA: When were you diagnosed with TS? And how did you react to the diagnosis?

Megan: I started to get symptoms when I was nine but I wasn't diagnosed until I was 15 and a sophomore in high school. Like a lot of kids I tried to hide it and suppress it as much as I could. Eventually I got sick of it and my mom was worried about me getting teased. I told her I really couldn't stop it. It was time to go to a doctor. Just to know that it had a name, that other people had it, was a huge relief.

TSA: How did your family cope with your TS?

Megan: I think it was a relief to my mom but it also made her worry. The diagnosis opened up new questions. Now that we knew what it was, would it get worse or better? I tried medications but they didn't work out for me. By my junior year of high school I gave up on them.

I have an incredibly supportive family. They've been there for me whatever I've needed. My brother is four years younger than me and I remember walking by his room and hearing one of his friends asking him, 'what's wrong with your sister?' and hearing him explain TS. It felt good knowing that my little brother was standing up for me. He's a unique and special guy.

TSA: Does your brother or another family member have TS?

Megan: My brother doesn't have it, but an aunt by marriage does. It's funny but when I was diagnosed they asked about my family and I told them that when we're watching TV at night my mom clears her throat. She didn't even know she was doing it. We think that she may have a mild form.

TSA: TS has been in the media a great deal recently. What do you think of the media's role in disseminating information about TS and the quality of that information?

Megan: I haven't seen much except for Oprah. I'm happy when they focus on real people and real experiences and not on coprolalia because it seems to be the biggest misconception about TS.

TSA: Stress has a particularly negative impact on people with TS. It seems like you'd use exercise to help cope, anything else?

Megan: Yes, I do use exercise but I think that because of my profession and my studies in crisis management and conflict resolution that I keep my stress levels low. I use the techniques I teach to help me so I don't get as riled up as I could. I'm self-aware and do a good job at not worrying.

TSA: Do you have anything you'd like to say to kids with TS and their parents?

Megan: I'd like to share what made a huge difference in the amount of harassment and bullying I experienced in high school. With the help of another girl with TS from TSA, I got excused from school for one full day and we sat in the health room and taught every health class that day. For the first 20 minutes I talked about what TS was and then I let them ask me any questions for the rest of the class. The questions were very personal but I answered them, with the girl from TSA to support me. They asked if TS was contagious, if it hurt, etc.

By the end of the day I had created 250 allies. They started to stick up for me. There was a night and day difference because the bullies weren't getting any support. The next year, my senior year, I would go to other schools and support other kids and answer questions.

