

TSA Youth Ambassador 2010 Training Special Insert



Katelyn (16 years old)
Manlius, New York

My name is Katelyn, and I do not have TS, so being at the training with kids who have Tourette's was a really cool experience. My sister, Emily, who is 11 years old and has TS is the reason I became a TSA Ambassador. I loved

the training because it not only gave me a chance to learn more about TS, but it also gave me a chance to meet all kinds of new people from all over the place.

Another amazing part of this experience was the Trip to the Hill. I got a chance to meet with one of my Senators and for the others I got to meet their aides. At first I didn't really think I would be interested in speaking to such public figures, but I discovered that I really enjoyed it. I also got the chance to meet Elridge at the dinner the night before and the impact she had on me just from speaking with her for a few moments is incredible.

After I got back home I presented to my support group and then I presented to my sister's class. I was really nervous, but I afterwards I realized that I really enjoyed myself, and I really enjoyed educating people about a lesser known disorder that affects many people. I bug my mother everyday about when my next presentation is going to be. I truly enjoyed this opportunity, and everything that will follow!



Chris (15 years old)
Greenwell Springs, Louisiana

My name is Chris and I am from Louisiana, just outside of Baton Rouge. My dad, my brother and I all have TS. It hasn't been easy for any of us, but I've learned a lot about taking charge of my life since being accepted to represent Louisiana as a Youth Ambassador.



My experience in Washington D.C. at the YA Training in April was amazing. I know "amazing" is an over-used word, but in this case, it fits. It was great to meet other teens from all over the U.S. and not have to explain anything about myself to them. (Well, except maybe about stuff that people really do eat in Louisiana, like Tabasco on eggs.)

One thing that surprised me was how well everybody handled their tics during really long presentations. Some would throw their stress balls against the wall for a while, and others would just walk out into the hallway or outside if they needed to release loud vocal tics. The meetings with Senators and Representatives on Capitol Hill were really surprising to me. I experienced reactions that ranged from being sort of brushed off as a tourist by one Senator to actually sitting down and having a very personal conversation with another one. It was great to discover

that my views could matter to someone who helps shape our laws.

When I got back home, my training didn't "pay off" right away, because our school year runs from the beginning of August to the middle of May. There was a lot of end-of-the-year stuff I had to finish up, and just like many others with TS, school has NEVER been easy. I gave my first real YA presentation in June to a group of about 35 high school boys in a Sunday School class. It was kind of hard getting them to talk back to me, but overall, it was okay for a first time. I'll probably do at least 2 or 3 more church youth group presentations this summer, and then when school starts back in the fall, I hope to go into some classrooms. I think it's really important for me to try to be a voice for other people who have TS who might not ordinarily speak up for themselves. Everybody deserves to be treated fairly, and if I can help make life easier for even just a couple of people who have been picked on for being different, it will be worth it. I'm very grateful for the people who put together the YA program in D.C. It has made a big difference for me, and I hope that many other teens will have this same opportunity in the future.



Nathaniel (14 years old)
Orlando, Florida

I was excited to be selected as one of the Youth Ambassadors for Florida. I was excited, but also nervous, about attending the training in D.C. I am so glad that I attended the training. I learned new things about TS and learned how I could make a difference in the lives of others with Tourette's. One of my favorite experiences was the Trip to the Hill where we were able to meet with some of our legislators. I loved meeting and hearing Congressman Patrick Kennedy speak at the briefing. He inspired and challenged us to make a difference, no matter what our age is. Another one of my favorite experiences was just being with the other Youth Ambassadors. It's pretty cool to be in a room with 35 kids who tic, but no one looks to see where a noise or twitch is coming from!



The training has equipped me to tell others about TS. The props and cue cards are great visuals for my presentation to other groups. While I still get a little nervous about speaking, each time after I speak I am energized to go the extra mile and continue to tell others. People have understood and have been very supportive. I even had the opportunity to speak in front of 60 college students and they had some great questions after my presentation. Being a Youth Ambassador is stretching me out of my comfort zone, but I have already found that it is a rewarding experience.

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Tyler (13 years old)
Sugar Land, Texas

My name is Tyler and I have already used the YA training to my advantage. I have already given six talks to my school health classes. I thought the whole

experience of being trained to be a TSA Ambassador was great. I learned to talk to my peers and elders better, not only about TS, but in general.

I sent in an application and was surprised to get back a letter saying I had been accepted. I was very happy. It was great to learn things at this conference. I hope to go back next year. Being there this one time opened up a huge door for me. I could now talk about TS on a schedule and to a much bigger audience.

If you need reasons to do this, these are mine: do it for yourself; you will meet other people who have TS; you will get to talk about it to lots of people which will help you in society; you will learn a lot of things about TS that you didn't already know. Plus it was lots of fun. Well, have a good summer and I hope you send in an application next year.



Peter (14 years old)
Elkton, Maryland

Hi, my name is Peter and I was diagnosed with TS about 5 years ago. I started out with a cough and sniffing that we thought were just allergies, but none of the allergy meds were working. Then, I started repeating words. The doctors then diagnosed me with ADD, which I did have, but the meds for it didn't help. Finally, along the way, someone said that it could be tics, except for the fact that nobody believed it. After that, my neurologist said maybe these are tics and maybe he does have Tourette Syndrome, so I finally got diagnosed. Today we are still trying to find the best meds for me with a new doctor and a psychologist who will help me with CBIT.



I love to play football and it distracts me from my tics. I also like to play Runescape, an online adventure game. I have an awesome dog named Buddy who helps me a lot. I heard about the Youth Ambassador training through an email sent by TSA last year. I felt excited about the program because I knew God had given me the gift of speaking and I wanted to tell others about my disorder. So, here was my chance! When I applied and got the scholarship, I was even more excited!

When I went to the conference and training, I learned to stand up and be myself and to not be afraid to tell

others about my TS. Not only did I get great training and courage, I got to meet other kids who had the same disorder and I got advice from them. I made some great friends. I am now a TSA YA and I speak to schools about what TS is and how it affects kids like you who have it.

During my Trip to the Hill, I got to meet with Congressman Steny Hoyer, (who is in the photo with me) and Senators Cardin and Mikulski and Rep. Kratovil's office. I got to tell them my TS story and share my Peter Principle: suffering produces perseverance and perseverance develops character. They were all very encouraging to me. I believe that TS is a gift and I have many opportunities through the TSA YA program that other kids don't get. I mean, I got to meet with Steny Hoyer and all and that is just plain flat out amazing!



Daniel (14 years old)
New City, New York



In April, I visited Washington D.C. to attend the TSA Youth Ambassador training. The training started with some ice-breakers so we could get to know each other. For the first time, I was introduced to a lot of kids who are similar to me. The group I met that first morning was the group of people with whom I would hang out with for the rest of the trip. Not only did we hang out together in Washington, we still keep in touch.

During the training, we learned how to present about TS to people of all ages. They also gave us tips on how to be appropriate in our presentations, and gave us the materials for presenting. Those tips have been really helpful as I've made my first few presentations.

The finale of our training was the Trip to the Hill. I had never met a member of Congress before and was impressed that Rep. Nita Lowey took time to meet with us and listen to our stories about living with TS. I'm really glad I had the opportunity to take part in the TSA YA training.



Max (13 years old)
West Monroe, New York



In April I went to Washington D.C. to be trained as a TSA Youth Ambassador. I learned how to give presentations about Tourette Syndrome. Now I go into classrooms and teach kids about TS. I learned a lot and really enjoy giving presentations. I also went to meet my Congressman and I told him about Tourette Syndrome.

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Tanner (14 years old)
Loveland, Ohio

My name is Tanner and I was chosen to be the Youth Ambassador of Ohio. Traveling to Washington D.C. was an incredible experience for me because not only is it one of my most favorite places to visit, but this time it became the most memorable time of my life.

Attending the training for Youth Ambassadors gave me an opportunity to learn new ways to present myself and to speak confidently with others about TS. I gained a lot of self confidence by meeting other kids who I share similar experiences in life. We all had a lot in common, with the same focus and goals of educating others about TS and how to be more empathetic.

This group of YAs has become some of my best friends. I look forward to receiving their updates and seeing the difference they make in others' lives. They are truly inspiring people to me.

The most memorable experience for me was the Trip to the Hill. I met personally with Congresswoman Jean Schmidt. I shared my story with her and her aide. I was amazed at how down to earth and empathetic she is. She listened intently, and offered many suggestions and advice. This showed me that I have a voice and an opportunity of a lifetime to make a difference in my community. Sometimes kids just need to see someone making an effort and overcoming obstacles to know they can do it, too. I hope I can be that example.



Hayley Elizabeth (16 years old)
Altadena, California

When people watch me on stage, they see a funny actress. When people shake my hand, they meet a girl who talks too much. But when you become my friend you learn about a girl who struggled and overcame TS. In December, I became Southern California's TSA



Youth Ambassador. It opened so many windows and doors and opportunities for me to educate children about the neurological disorder I struggled with since the age of 8.

In April, I was lucky enough to be trained as a YA and to go to Capitol Hill to fight and lobby for more funds and bills to benefit people with TS. At the luncheon before we lobbied, I got to hear Congressman Patrick Kennedy tell of his support for TS. I was the first one up to meet him. I said, "You know what, I liked you from the minute you opened your mouth, because you talk loud just like me."

He couldn't stop laughing and almost dropped his award. Then he replied, "I like you too, especially because you have red hair and freckles just like me!"

While in Washington I met the other YAs who almost all had TS. After six years of intense medication, I finally have my tics under control, so while everyone was having tics, and I wasn't, I finally felt normal. At my high school, I never feel like the normal one, so it was nice for a change. Since the training, I have spoken to four schools and I am going to speak to my pediatrician and her colleagues to educate them on TS to help kids get diagnosed.



Megan (15 years old)
Fort Worth, Texas

When I was told I was selected to be a TSA Youth Ambassador, my initial reaction was not what you might expect. I was nervous that I wouldn't do my job well and that people wouldn't listen to the important things I wanted to say. After the first day of training in D.C., all the worries I had

disappeared because all of the other kids there were just like me.

The Ambassador training was so much fun because not only was I learning more about TS, I was making friends with some amazing people who I still talk to everyday! The Trip to the Hill was a great experience because it felt like the Senators that represent Texas truly care about what I had to say regarding TS. The other three Youth Ambassadors from Texas and I are all really great friends, and I love that we are some of the people who get to educate the great state of Texas about Tourette.

Even if presenting all over only helps one person, it is so worth it to me to make a difference in someone's life. I feel so blessed to be part of this amazing organization, and I can't wait to see where it takes me!

**You Can Become a
Tourette Syndrome
Youth Ambassador!**

TSA's Youth Ambassador Program trains kids and teens (ages 13 to 17) to talk about TS. The program gives young people with TS, their siblings, friends and classmates the preparation they need to speak about TS before their peers.

Learn more at:
<http://www.tsa-usa.org/People/kids/YouthAm.htm>

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Carolyn (16 years old)
Cedar, Michigan

Last April, I went with my mom to Washington D.C. to become a TSA Youth Ambassador and be able to talk to groups of people about Tourette's and what it's like to have it. It was a wonderful experience for me. Not only did I learn a lot, I also made lots of new friends as well. I live in a very small community, so I've never met anyone else who has TS. But that all changed when I took the trip to the nation's capitol. I clicked with lots of kids who have TS and continue to stay in touch with them today.

Also, by speaking to classrooms and publicizing the disorder, I've come in contact with several people of all ages in my area with Tourette's. My mom and I are planning to start a support group with all the people we met, because there currently isn't one around here. Working with the TSA has not only given me the courage to spread the word about TS, but it has also helped me to support others with the disorder.



Corey (16 years old)
Houston, Texas

The TSA Youth Ambassador experience was very powerful, and one that I will not forget. There were so many people with the same trials and tribulations; substitute teachers not understanding the situation and efforts to suppress tics but always failing were reoccurring themes. But we also had time to share how we deal with the different situations life throws at us. Some of the more helpful advice and information came from speakers such as Dr. John Walkup, Chair of the TSA Medical Advisory Board, who talked about some of the misdiagnoses of TS and many different ways to help subdue the tics, such as doing breathing exercises. Another speaker gave us a presentation on TS genetics, which was very informative and shed some light on the mysterious way I inherited this friendly anomaly.

Speaking to our representative's aides was also very surreal. I felt like I was helping push for a revolution in the way people view Tourette's. I felt like I had a voice in a matter that means so much to me. It was really cool seeing how the political process in this country works. Our representatives want our future votes, so they will listen to you and your concerns. After all, they aren't living in the community. They have a comfortable office in Washington D.C., and they don't always know what it's like out there in the neighborhood that they are representing, so it is our job to help.



Emily (14 years old)
Oradell, New Jersey

Sitting in a room in Washington D.C. with other children with TS was an example of my perfect world. At the TSA Youth Ambassador training program, I was finally comfortable in my own skin. I learned so much from not only the educators at the meeting, but also the other youth ambassadors.

The next day, we all boarded buses to go to the Capitol. You would think that we all sat with our parents, but as a matter of fact, all of the Youth Ambassadors piled into the back of the bus as if we had known each other for years. Meeting another person with TS gives you a special bond. Once we arrived at the Hill, Ethan and I made speeches, we all ate lunch, and then went off to meetings with our Congressmen. I am so thankful that my Congressmen were interested in learning about Tourette Syndrome education.

Obviously my thoughts on this experience are only positive. It was an unforgettable experience. And, I made special friendships that will last a lifetime.



Patrick (13 years old)
Locust Valley, New York

My experience being trained as a TSA Youth Ambassador was great. I enjoyed meeting many other teens who are affected by TS and learning about how it affects them and their lives. Even though the training was long, I obtained a lot of useful information that will help me be a good teen Youth Ambassador. I really liked the way Hunter described giving the presentation, and I found it helpful to break up into groups and practice answering questions that kids might ask about TS. I assisted Eric Zwilling at the end of the school year and helped him give two presentations at an elementary school in Hicksville. I thought it was a good experience and it will definitely help me feel more confident for my future presentations when I go out on my own or with my fellow Long Island TSA YA, Shoshana.

It was interesting meeting with the different congressional representatives. I found them to be very understanding and supportive. They wanted to hear what I had to say about living with TS. I told them all how having a presentation given to my classmates helped change my life for the better.



Read one more story from newly trained Youth Ambassador, Morgan, on the back cover!



Morgan (14 years old)
Draper, Utah

Orientation, meetings with congressmen, surrounded by people with TS. I have to admit that, at first, it was totally overwhelming. Little did I know the Youth Ambassador training would turn out to be one of the most incredible experiences of my life. I had the wonderful opportunity of being chosen as Utah's 2010 Youth Ambassador. In April, I was flown to D.C. to be trained on how to properly educate people about TS. There were teen Ambassadors from all over the country, and all but two had been diagnosed

with TS. I was one of those two and, for once, not having TS put me in the minority. Nearly everyone had been diagnosed, so it was OK to tic.

For two days we attended classes and learned how to become advocates for TS. We then met with our state's representatives. I had five meetings scheduled to talk with Utah's legislators. It was my job to share personal experiences about TS and help them realize that their votes and support do affect real people, that it really does make a difference, and my sister is living proof of that.

The conference was informative, the other YAs were incredible, and the Trip to the Hill gave me a chance to put into practice my training. Being a Youth Ambassador, your age slips away. It doesn't matter that I'm 14, that I'm still a child or that I'm only one person. I can make a difference, and with all the Youth Ambassadors, we can change the world.

That Darn Tic

That Darn Tic is TSA's newsletter by and for children up to 18 years old.

All submissions will be edited for length, grammar and content. Drawings and cartoons reproduce best when they are black and white on white paper. We may alter the size to fit the art on our pages. Submissions for the next issue are due by September 3, 2010.

Send your short stories, poems, essays, drawings and photos to:

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The next *That Darn Tic* issue will be coming your way soon!



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