

Are you “ticcing” more than your clock?

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The Challenges of Tourette Syndrome

Feature Editor:
Sharon Noel, 17
Massachusetts

Do you ever feel eyes staring at you? Or that you can't do anything without being watched? Girls with Tourette Syndrome (TS, Tourette's) feel this way all the time. Tourette's is a disorder which causes uncontrollable gestures called tics. How do girls come to terms with Tourette's? And how can others understand it? Teen Voices explores Tourette's through the stories of teen girls who live with it. Learn how to help spread support for this often misunderstood disorder.

2:06 AM

Loren Packer-Hopke
New York

I sit up late at night
and wonder why.
I hug my pillow tight
as I start to cry.
Why do I always feel
that I let people down?
What I think isn't real.
I feel like I'm gonna drown.
I think in my mind
I'm not good enough.
Even though I know I'm kind--
so why can't I act tough?
People do like me
for who I am.
But what they can't see
they would never understand.

Loren struggled with Tourette's through her teenage years. She recently began a doctoral program in school and community psychology. Loren says that what she went through as a teen only increased her resolve to help teen girls with this disorder.

Teen Helps Other Teens Squash Stereotypes

Jennifer Zwillling, 18
New York

When I was seven, I was diagnosed with Tourette Syndrome, a lifelong neurobiological* disorder characterized by tics which are rapid, sudden movements or vocalizations* that occur repeatedly. Although my mom and I attempted to educate my school, I found that people were not as tolerant, understanding, or knowledgeable regarding TS as one would hope. I was thrown out of science class for one of my tics and my peers frequently asked questions—some with taunting undertones. I even saw physicians who lacked accurate information on this very misunderstood disorder.

As I got older, I experienced horrifying portrayals of TS in the media. Upon joining the local TS chapter and meeting other families living with TS, it seemed everyone's stories paralleled mine: TS was generally misconceived, and the results for people living with the disorder were, at times, inconceivable.

Through my personal experiences, I decided that something must be done to educate those who affect the lives of children with TS. Since my diagnosis, I had met with my teachers every year to discuss the implications of TS, and how it affected my life. I knew that I was comfortable talking about living with TS to teachers and students, since I had previously educated classmates. I was aware that some other children with TS might not be as comfortable doing this. Since I already had outlined a program that I used to educate my community, I could definitely help other children provide the people in their lives with accurate information. Moreover, since I have TS, I would be able to answer questions and offer a perspective that most educators could not.

When I was 12, I first began offering to help Long Island families of children with TS advocate for themselves. I received an overwhelming number of requests to speak in schools. Families were always extremely appreciative, and school staff always seemed to be very grateful for having an “expert” educate their students. Through word of mouth in the TS community, I was asked to present my program in New York, Virginia, Washington, D.C., and North Carolina.

As I perceived the receptiveness of schools to my program, I realized that I could not do this alone, and if I could train other teens to present my program, then they could learn to advocate for themselves within their communities as well, which could extend my program nationwide!

I founded the Youth Ambassador Program for the national Tourette Syndrome Association (TSA). The Program trains teens to raise awareness about TS; to advocate for themselves and others; to educate peers and younger children with accurate information; and to teach understanding, sensitivity and tolerance of TS, while displacing the myths and stereotypes often attributed to and associated with this misunderstood and misdiagnosed disorder.

To date, the Youth Ambassador Program has equipped over 3,000 students, teachers, and advisors with accurate information through presentations in classrooms, health fairs, and after-school clubs. The program helps students be more understanding of all differences, and is an

effective anti-bullying program as well. The Youth Ambassador Program is succeeding in changing general attitudes about TS.

I am now a senior in high school and will be attending Duke University in the fall. I will always be involved with national TSA and continue my mission of raising awareness about TS.

Jen's video about her program can be seen at <http://tsa-usa.org/People/kids/YouthAm.htm>

***Neurobiological disorder:** disorder that affects the nervous system and is caused by genetic, metabolic, or other biological factors.

***Vocalizations:** people with TS often make sudden sounds with their voice without meaning to.