



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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winter 2007

issue no. 21



Leah (8 1/2 years old)
Wantagh, New York

Hi! My name is Leah and I have Tourette Syndrome and OCD. I have happy tics. I have a giggle tic and a jumping tic, and I blink a lot.

I like my tics, they are a part of me and they make me who I am and what I will be.

When I grow up want to be either an actress, a model, a dancer, a meteorologist, a doctor or a crossing guard.

I love school. I think having TS actually makes me smarter. I love my teachers and they are very understanding about my tics. I know my tics can interrupt the class sometimes.

I don't know anyone else with TS and would like to meet someone else with it.

I haven't told any of my friends about my TS yet, and they are starting to notice it now and even though I don't mind it, and even like it, I don't want them to think I'm weird. I don't know how to tell them but I will soon.



Will (8 1/2 years old)
Sioux City, Iowa

Hi! My name is Will and I have TS. Sometimes I can't focus on my school work. I made my First Communion this past year. Sometimes I wake up and find myself in the doctor's office.

I hate when I tic. My teacher is Mrs. Bengford and she likes when I tic. I love sports as well, especially football. It's my favorite sport ever. I hope there's a good cure for TS.



Garrett (12 years old)
Piedmont, California

Hi! My name is Garrett, I am 12 years old and I have TS. I was diagnosed in the fourth grade, when I moved to California from New York. My family has been very supportive of me.

My worst tic is snorting. In elementary school kids would tease me about it. At the beginning of fourth grade my absolute worst tic was blowing spit. Although over the past couple of years I have gotten over it and luckily for me now I take medicine for it. Also now no one really bothers me about it. So the kids who used to tease me about it have gotten over it, and so have I. And only one kid has been mean to me about it, and the meanest thing he says to me is, "What is your current tic?"

In conclusion, if you have Tourette's, believe in yourself and sooner or later other people will, too.



Colette (9 years old)
Batavia, Illinois

I have had TS since I was 2 years old, but I was diagnosed when I was age 7. Some of my tics are cracking my neck, clanking my teeth and blinking. Here is a poem I wrote about TS.



I really hate my tics
They make me scratch
They make me twitch.
I wish that I could throw them away
But they happen everyday.
My tics will come my tics will go
Making new ones as I grow.

Rosario (15 years old)
Metepec, México

Tourette Syndrome, I have to admit, is an everyday challenge. When I wake up I put in my mind everything is going to be alright; that my friends will understand why I have to do my "routines" and that my relatives won't call me crazy because I act "weird" as they sometimes say.

But I have to say that it is not their fault, they just misunderstand the situation. Media and the government don't always spread information about how to treat children with TS at school in order to better comprehend our disorder. Children with TS are as intelligent and smart as a "common" kid. Our neurological disorder has nothing to do with our abilities and who we are.

But to make this clearer I would like to write my story, for you to understand more about me.

Nowadays schools all over the world only want to have "perfect children" and just care about the children's grades. During 8th grade, my average was over A-. One time I got a B- and my teacher called my mom. I felt like a criminal; I thought that I was a bad person, so I studied harder and harder. I focused more on my studies and I didn't spend a second of the day playing. So when my quizzes came, I was so tired I couldn't keep my eyes open. I was very nervous and I started noticing that both my hands were shaking, my mouth produced more and more saliva and my eyes were winking faster and faster, and when I started writing, something in my head told me to erase it and write it again four times or something bad would happen. I remember I didn't know why that made me feel better and I couldn't stop doing it; but when the time came to give our exams in, I begged the teacher to give me a second chance to redo my exam another day because I was not feeling well, but she decided to take my exam. Fortunately I managed to answer correctly (thanks to my hours of study) almost all the exam's questions even though it took me four times to write and erase each one of the questions!

Months kept passing, and my tics got bigger and bigger, but one day my mother started noticing the changes in my conduct. I no longer wanted to be with my friends, I didn't want to eat my food if it was mixed, also my friends told me that I was getting cranky.

My mother decided to take me to a shrink (actually to eight different ones). Some said that I had schizophrenia, some said that I had dementia. They gave me lots and lots of medicines, but they just made me feel tired and weak, and because of that I didn't eat so I lost a lot of weight in two months. I was totally hopeless, because I heard the best for me was to be admitted in a psychiatric hospital.

So my mom decided to take a last shot. She started looking for books and on the internet about mental disorders. She even wrote all the symptoms that she read about and found they all match TS. So she took me to see a neurologist, Dr. Matilde Ruiz, and yes, she confirmed it; I have TS. She also told me that the discharges in the left side of my brain were higher than in the right, and that I

didn't have to worry that everything would be fine. I was very happy, believe it or not, because I didn't know the name of the disorder I was fighting, and with that information I finally had the guns to fight against it. At that moment I finally saw a little light at the end of the tunnel.

Now I am being treated and I am feeling great! And I also have to say that I am not ashamed of who I am. What I have doesn't make me less or more than others, I am just another kid in the world who wants to grow up and become a productive member of our society.

Yes, TS is an everyday challenge, but it is also a challenge I beat everyday!



Joey (16 years old)
East Meadow, New York

I have TS and OCD. I have been living with it since I was 8 years old. My TS is mild and mainly consists of eye blinking and vocal tics. I am lucky I have friends who accept my disorders and do not make fun of me. I like Jim Eisenreich, who was a professional baseball player with Tourette's who works with kids with TS. I love to play XBOX 360 and my favorite game is Oblivion. I'm a junior and I am taking the SATs soon. My favorite sport to play is football. My favorite teams are the New York Yankees and the Minnesota Vikings. My OCD is not about dirt and neatness, but about numbers and counting. Hopefully there will be a cure soon. I am an honors student and a member of the National Honor Society, despite my TS and OCD. While TS may be a pain, hard work and perseverance allow a person to do anything they set their mind to.

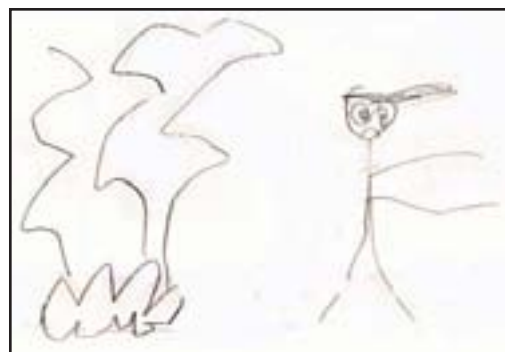


Andrew (9 years old)
Townsend, Delaware



Here is Andrew's drawing, titled:

How do you make a bomb tic?
Give it a Syndrome!





Zachary (14 years old)
Chappaqua, New York

I have had many experiences in my life where I have made discoveries about how the world works; many times I have gotten responses from people that I did not expect. I have chosen to talk about something that is very personal to me. I have Tourette Syndrome. The "tic" that comes from my Tourette's is a cough. It's very loud and many people mistake it for a sneeze.

People have responded to me in ignorant ways. The first few times it happened, the responses hurt my feelings. Then I realized that I shouldn't be embarrassed. It was the people who responded to me negatively who should be embarrassed.

One time I was in a restaurant and my tics were really bad. I was coughing loudly so many of the people in the restaurant were turning and looking at me. To make it worse, the people sitting right next to us kept looking over at me with disgust every time I ticced. Not once did they stop to think that I might not be able to control what was happening. Finally they asked the waiter to move them to another table, away from me.

I have had many different experiences where I've seen first hand how people react differently from what I would expect. They don't think how their response might affect me. They don't realize that everyone isn't the same and that each person has unique qualities that make him or her different in some way.

While many people get annoyed from my ticcing, there are just as many who are nice about it. Some strangers might think I'm having a really bad sneezing attack and will tell me, "God Bless You." I realize they are just trying to be polite and do the right thing.

My tics change from time to time. Sometimes my eyes roll around too much which makes it hard for me to read, or sometimes I might sniffle loudly. I can even have all those things happen one right after the other.

I just wish that all people would try and put themselves in someone else's shoes every once in a while. If they understood, they might react differently and not get annoyed.

Sometimes other kids at school will tell me that I can stop ticcing when I can't. I try to explain, but they just don't want to listen. It hurts my feelings because I'm just like any other teenager except that I have Tourette Syndrome.

If more people took time to think about how other people feel, the world would be a nicer place.

Did You Know... That you can read this issue (and all past issues of *That Darn Tic*) on the TSA website? Just go to the TSA homepage, www.tsa-usa.org and look under Newsletters.

David (11 years old)
Garden City, Kansas



I have had TS since I was 2 years old so that's pretty much all I know. My parents didn't know what it was until I was 6 years old. I was put on medication when I was six because I had rubbed blisters on my fingers. My tics change all the time.

After reading "That Darn Tic," I feel like my TS is mild. Maybe it's because of my medication. My mom wanted me to write so I could share how I deal with TS in school. At the beginning of the year I talk to the class about TS. The school nurse and the counselor help me. I ask the kids if they have any questions, and sometimes they do. I even showed the DVD, "I Have Tourette's but Tourette's Doesn't Have Me" to the class. It educates people and they don't stare and wonder so much. We make sure everyone who teaches and helps me at school knows what I have. This year I get to use the Alpha Smart because I have trouble writing.

My worst tics are in my wrists right now. I am in the fifth grade and love to draw. I have two cats, two rabbits and two hermit crabs.

I would like to see the TSA logo on Tony Stewart's and Kurt Busch's race cars someday. We even wrote a letter to Tony. He has so many fans write that he probably hasn't read it yet, but wouldn't that be neat? If anyone knows him personally they should ask him. It would bring a lot of attention to TSA.

I wish everyone with TS a bright future.



Taylor (9 years old)
West Haven, Utah



My name is Taylor and I am in the fourth grade. I have Tourette Syndrome with ADHD and a little OCD. Some of my tics are licking my lips and winking. I play soccer. I like to play basketball and video games. My favorite movie is "Cars." I want a Hudson when I grow

up. I like to play with Legos and Mega Blocks. My pets are a lizard, a dog and a goldfish. I am a big fan of Grievous from "Star Wars." I go to cub scouts and I'm a bear. My favorite animal is a monkey. I am reading "A Series of Unfortunate Events" right now.

Tics stink! I hate tics, but I deal with them and I have a lot of friends who don't care if I tic. It is not fun to have Tourette Syndrome. I have a few friends with TS. That is my life.



Nathaniel (14 years old)
Bismarck, North Dakota

My name is Nathaniel and I am in the ninth grade. This story is about me getting diagnosed with TS. This paper was for school, but I thought you might like to read it even though it is a little long. I like this newsletter and hearing the stories that other kids have to tell.

MY STORY WITH TOURETTE SYNDROME

Tourette Syndrome is a disorder that I can live without. I was diagnosed with TS when I was in first grade. TS is not an ordinary disorder because it can stay with you the rest of your life, and it's not contagious, it is genetic. It consists of motor and physical tics, "tics" being the movements or sounds a person with TS makes. Everybody with TS has different tics.

I seem fine about it now, but when I younger, I was scared. It began when I was in pre-school and about 3 years old. When I was 3, I began to do strange things that I would now call tics: for example, I would stretch out my neck or roll my eyes around and I would hold onto an action figure and make exploding and gunshot noises. My teachers would reassure my mom by saying that lots of kids do crazy things, if she asked if I was doing anything strange. Once she asked me if I couldn't control the things I did. I got mad. I sat straight up in bed and said, "Mom, you just take care of your own self." (Hey, I was only four years old at that time.)

Pre-school was only a half a day, so it wasn't such a big deal. When I went into first grade, everything changed, mostly because first grade was all day. It was okay in the very beginning, except I cried a lot. Things went that way for a while. Three weeks into the school year, there was a parent-teacher night. When my mom sat down in my desk, my teacher, Mrs. Reglman, broke off a conversation with some other parents and said to my mom, "We have to talk."

After the whole thing was over, my teacher said to my mom that I was still crying after three weeks of school. She said that I wanted to go home because I thought my mom and sister Veronica were in trouble and I just had to go home. My mom thought that she (my mom) was being funny when she suggested maybe that it was TS. Instead of laughing, my teacher's face was still serious-looking. She thought that it was indeed TS. Then my mom got angry with her for giving her little "analysis." The next day, she called a friend and told her everything that happened. When my mom's friend said that she thought it might be TS, my mom got annoyed with her friend, too. Then she decided to look Tourette Syndrome up in my dad's Merck Manual, a book that is like an encyclopedia of diseases. My sister was playing in a big pool of sunlight that was flowing into the room as my mom cried because she was relieved that she finally knew what I had.

That night as I was reading books with my mom, she told me that there was a name for what I had. After she told me, I told her everything that I was going through at school. But when I told her about the voices that I was hearing, she

got scared again because hearing voices did not come with TS. The next day after I went to school, my mom called the pediatric neurologist and said that we had an appointment with them in a couple of weeks and asked if we could get an appointment sooner. She was crying a lot. Eventually, after she told them that I was hearing voices, we got an appointment (even though we think they did some canceling of appointments so that I could get in). When we saw the doctor, she said everything except the voices seemed like Tourette Syndrome. She put me on medication that would help my tics. I was a little disappointed because I thought it would make my tics go away forever. But she referred me to Dr. Schnee, a child psychologist. Eventually, he found out that the voices ("like school" and "hate school" and "two robots") were things that I made up to help me with my tics, so I wasn't really hearing voices.

Things got better after that. Time passed, and after I got used to having TS, I could explain what I did to people if they didn't know what it was. If you are in situations like mine, rely on family to help you through. My mom helped me a lot in that time. So just let family help you through.



BJ (10 years old)
Apple Valley, California

My name is BJ and when I did an assembly for the fifth and sixth grade classes (about 200 kids), I was scared that the kids would laugh. But now I feel good that every kid I know knows that I have TS.

I like so many kinds of ballgames like nationball, dodgeball and so many others. I have an interest in nature, dinosaurs and science. I would like to talk with other kids who have TS like me and become pen pals with them.

There are so many things I want to do to help kids with TS. I'm like the only kid in my school who has TS. I have a friend who stutters, but I really don't care that he stutters, he's just like anybody else. I don't know why, but some people stare at people who have disabilities; people who twitch or do any other thing. Oh yeah, I almost forgot about my sister. Between you and me she gets pretty bossy. Don't tell anyone.

**Simon and Sally
Hit the Road for TS Awareness**

Simon and Sally, characters from TSA's own series of children's storybooks, are leaving the confines of their stories as part of a child-centric awareness campaign. Images of the characters are available for download and children are encouraged to take them to soccer games, ballet recitals, scout meetings, camp and everywhere children gather. The children are then urged to take photos of Sally or Simon at these events and send them to the new Sally and Simon online scrapbook, sallyandsimon@tsa-usa.org. Simon and Sally books are available from TSA

Become a TS Youth Ambassador!



Jenn (16 years old)
Brookville, New York

When I was 13 years old I developed a program with the help of my sister, Amanda and brother, Eric, where the three of us would go into schools and to teen groups to educate others about TS. My dream was for this program to be presented nationwide so that our

generation would grow up understanding TS. The goal is to inform others about TS, which is such a widely misunderstood disorder, so that our generation becomes more tolerant and sensitive to the issues facing their peers diagnosed with TS. The program is also designed to help others understand that the stereotypes that are commonly believed about TS are not necessarily accurate and true.

With much help, support and collaboration from the wonderful staff at the national Tourette Syndrome Association, the program evolved and is now officially called the TSA Youth Ambassador Program.

Last April, my dream became a reality at the National TSA Conference in Washington, D.C. when teens from all over the country were trained to bring the program back to their own communities.

The Tourette Syndrome Youth Ambassador Training Program is well underway and has been presented or is currently being presented in New York, North Carolina, Hawaii, Virginia and California! More volunteers are always needed to help educate others.

I know that it can be intimidating to stand up in front of a group and speak about anything, especially TS. So all the information and materials that you need to present the program, to understand what the program is, and how you can get involved, are available on the TSA website,

www.tsa-usa.org, or you can email me at ts@tsa-usa.org.

If you still feel a bit insecure about presenting the program you can actually just use the video of me speaking to a class that is available on the National TSA website and then supplement the presentation with the hand-outs that are available. Additionally, for younger children you should also check out the programs using Simon and Sally that are on the website as well.

It's a really great thing to be become a TSA Youth Ambassador whether you have TS or not. Having the opportunity to educate others while advocating for yourself or someone you know, is one of the most rewarding things in the world.

If you are already using the program and we haven't been in touch, please e-mail me so I can add you to the Youth Ambassador list and we can add your state or city to the list of communities that are being impacted by the TSA Youth Ambassadors!

We are following the motto "think globally, act locally" and I know that we can make a difference...so be in touch! I look forward to hearing from you!

TSA's Youth Ambassador Program trains kids and teens 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 at school, sports leagues, scout troops, camps and after school programs. At the TSA website, all the resources you need are there!

You can watch in streaming video the Youth Ambassador video, or download the video/and or audio to your iPod; printout a peer presentation outline and slide show, and a one-page handout for the class and visual aids.

Nicole (9 years old)
Bradenton, Florida



Hi, my name is Nicole and I have a mild case of TS. What TS makes me do is blink my eyes, jerk my neck and crack my wrists and ankles. I'm in the third grade and I'm lucky that I go to a small school where I'm not teased about having TS. If someone does ask me about why I blink my eyes, I explain that I have TS.

My interests include Kung Fu. I have earned five belts in Kung Fu, and I only need six more to get my black belt. I have my assistant instructor patch and help teach forms to the new students.

I also enjoy playing soccer. I'm on a boys' team called

the StingRays and I play both offense and defense. I'm on the dance team at school and sing and act in a church musical twice a year. What I like about doing activities is that I get so involved that hardly no one nor I notice my tics.

I have a 6-year-old sister, Madeline, and three older brothers and an older sister who no longer live at home. I have a cocker spaniel named Molly May and two cats, named Toby and Annie, who are very annoying and who wake me up every morning. I like fishing and golfing and playing chess with my Dad.

Having TS is no big deal because I know that God made me special and that He loves me and cares for me. I appreciate that He made all people different and some people happen to have TS. God made you special, too, and He loves and cares for all of you.



Olivia (9 years old)
East Stroudsburg, Pennsylvania

My brother Zachary has Tourette Syndrome. When we go to stores he makes faces and people stare at him. I feel bad for him. People at school used to make fun of him. I felt bad. So I said, "Leave my brother alone, he has Tourette's! He can't help it!" And then they would walk away.

When he was diagnosed with TS he would say curse words. People would stare so I would say, "God Bless You." So it would sound like he was sneezing and people would go along with it. It actually worked! The people stopped staring!

Even though my brother has TS, I still love him more than the world!

In this issue, it was great to read a story from Rosario, who lives in Mexico. If you live outside the United States, we want to hear from you too! Send us your stories or drawings and we will do our best to publish them!

That Darn Tic

That Darn Tic is TSA's newsletter by and for children up to 17 years old.

All submissions will be edited for length, grammar and content. Please don't send us your only copy. Drawings, photos 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. We will publish as many as we can fit—so send us your best and we'll do the rest! Submissions for the next issue are due by March 1, 2007.

Please send your short stories, poems, essays, drawings, riddles, cartoons and jokes to:

TSA

That Darn Tic

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or e-mail: tracy.flynn@tsa-usa.org

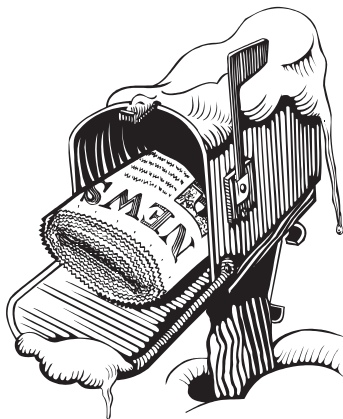
The next *That Darn Tic* issue will be coming your way soon!



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