



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

tourette syndrome association, inc.
42-40 bell boulevard
bayside, new york 11361
(718) 224-2999 ♦ fax: (718) 279-9596
e-mail: ts@tsa-usa.org ♦ website: <http://tsa-usa.org>

winter 2009

issue no. 29



Matthew (9 years old)
Allegan, Michigan

My name is Matthew and I was diagnosed with Tourette Syndrome when I was 7 years old. My friends and family don't mind my tics. School has been good. I have a great teacher, Mrs. Norland, who is very understanding

of many of my tics. I like to play sports, read and play video games in my free time. I love my Mom, Dad and brother, Lucas. I may have Tourette's, but Tourette's doesn't have me!



Samantha (14 years old)
Mandeville, Louisiana



Hey! My name is Samantha and I have had TS since I was 9 years old. My tics are grunting noises, eye twitching and sometimes I jerk my head. I have two friends, Amy and Mackenzie, who also have TS. Amy scrunches her nose and Mackenzie twitches her eyes. Mackenzie also has ADHD. Sometimes I ask myself, "If God loves me, why wouldn't he take this awful disease away?" Mackenzie told me God gave this to me because he loves me! My friend Sydney helps me a lot when I'm upset about my tics. She's always there for me.

I have a pretty good way of hiding my tics when I'm in school, although people have noticed them before. I close my eyes and breathe in through my mouth and out my nose. My mom says when I'm in my room reading, she doesn't hear me. I love reading "Twilight" books and playing volleyball. When I grow up, I'm hoping I can help find a cure for TS someday.

Lilian (9 years old)
Jakarta, Indonesia



Hi! I'm Lilian. I would like to tell my story about my Tourette Syndrome. You see, my TS started from tics. I had tics since I was 6 years old. They started with eye blinking. When I was 7 years old, my tic became neck jerking. When I was 8 years old, the tics faded away, but that was when

the TS started. The TS started with me making some peculiar noises with my mouth. Then I started uttering unacceptable (bad) words. First my friends thought I was saying the bad words on purpose. But later after my parents talked to the teachers, all that changed. My teacher explained that I have TS and I don't mean what I say. So they all understood why I say bad words. Until now, I still have TS and utter the bad words, but I also want to control it. Even though it is very, very, very hard, I still have to try my best. Sometimes if I concentrate a lot on one thing, it distracts me from saying bad words. It also involves reading, playing games (Nintendo DS for example) and doing extreme activities, like the activities in a school camp. My favorite is Flying Fox.

My hobbies are reading, drawing, playing games, watching TV and crafts (like making an HP pouch with a craft kit). I'm in Primary 4 now and my school is Singapore International School. I love making new friends. Whenever a new friend comes to school, I'm always the first one to say "Hi." My talents are doing magic tricks, singing, making crafts and making new friends. My motto about Tourette Syndrome: Tourette Syndrome is a part of me, which makes me different and special from the others. My other motto about TS (you know it!): I have Tourette Syndrome, but Tourette Syndrome doesn't have me! My usual motto: Nothing is impossible! And it's true! Before ending this, I would like to thank "That Darn Tic" for including my story about my TS.



Chase (11 years old)
Findlay, Illinois

My name is Chase. I live in a small town called Findlay, in the state of Illinois. I am 11 years old and have TS. It can be bothering sometimes. I didn't know how many people had TS until I read some of these newsletters. I get teased sometimes. My tics are noises and humming. Sometimes it's worse

than other times and I am still trying to get used to them. My mom and dad love me very much and try to help me calm down when it gets too bad.

I have had TS since the 5th grade and now I'm in the 6th grade. When my friend Ben comes over, it takes my mind off my TS. I do my tics a lot at school, but my mom talked with the principal who told the teachers about TS. I would like to show this newsletter to my teachers and maybe the class to help them learn more about TS. People who have TS sometimes can calm down by breathing deep, in and out. I take some pills that calm me down at night so I can sleep. I enjoy playing the piano, wrestling with my friends and playing with my dog, Izzy.

For all the kids that have TS, you never know what you can do, until you try.



Alyssa (9 1/2 years old)
Turlock, California



Hi, my name is Alyssa. I am currently in the 5th grade and I am learning to play the violin. I have TS, ADHD and some OCD. I was diagnosed when I was in second grade. My teacher's name was Mrs. Lewis and she was the best. She would e-mail my parents to let them know how I was doing in class. My hobbies are swimming, cheerleading and playing games. I wish I never had TS, ADHD and some OCD because it makes it hard for me to be nice.

When I grow up, I want to be a professional figure skater and an artist. Not all of my teachers were as helpful as Mrs. Lewis was. Some were kind of grouchy and did not want to help me. I wish I could have a friend who also has TS like me. She could understand my tics and other problems. I think I am the only one in my school who has TS and that makes it kind of lonely. And that's my story.

Curtis (11 years old)
Batvia, Illinois



Hi! My name is Curtis and I've been diagnosed with TS for about six years. I'm in 5th grade and my teacher is Mrs. Smith. Mrs. Smith told the class about my tics while I was gone because I felt nervous about what my class would think of me.

Some of my favorite things to do are play baseball and football and play on my travel soccer team. Some of my favorite sports teams are the Chicago Cubs and the Chicago Fire. I have a family of five: a brother named Evan, a sister named Alexa, a mom named Caron, a dad named Scott and two dogs named Morgan and Cosmo.

Some of my tics are repeating numerous words, grunting and sniffing and sometimes I turn my head at a ninety degree angle. I also have stomach spasms. People question me about my tics, but I just say, "I don't know," because I wonder what they will think of me. I also have OCD. When I practice trumpet or play baseball or soccer my tics float away and then come back when I'm done. Sometimes when I'm on the computer or watching TV, I realize that my tics go away and then when I realize that I haven't been doing them, I start going again. I feel different with my tics. I have tics, but tics don't have me.



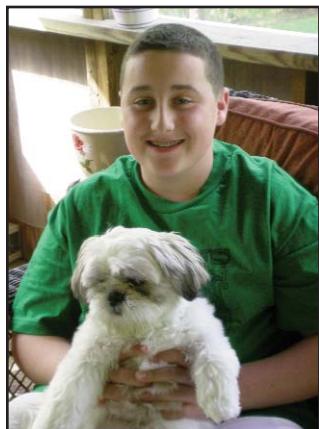
Max (11 years old)
Cicero, New York



My name is Max and I am 11 years old. In my free time I like to play outside. When it is rainy outside I will stay inside and watch TV. My favorite shows are "Forensic Files" and "Cold Case Files." When I grow up I want to be a homicide detective or a pilot. I have already taken a few flying lessons.

I have two tics. They are hitting my hand with a stick and moving my head up and down, which gives me a headache. I also have OCD, which makes me worry about things that won't happen.

In March 2009, I am running a 4.97 mile race for Team TSA. My mom and I have already raised \$2,800. We are going to Virginia Beach. My dad and sister are going to watch. My older sister is going to meet us there from New York City. With the money we raise, maybe TSA will find a cure someday.



Dylan (14 years old)
Stony Point, New York

Hi, my name is Dylan. I am 14 years old. I was diagnosed with TS in the 5th grade and it hasn't let up since. I enjoy playing baseball, basketball and football. I also love to play video games. TS is always a struggle every day from the minute I wake up to the minute I go to sleep. But I deal with it and I don't let it get me down

and I don't let it affect what I need to get done as much as I can.

My message to people who don't understand what TS It hurts us when we hear people making fun of us. Also, my message to people with TS is: keep your head up because the grass is hopefully greener on the other side. At least I pray for that every day. If I could thank anybody who helps me and always keeps my head on straight, it would be my Mom and Dad. Without them, I would be always "negative" every day. I hope one day that there will be a cure for TS and that this will all be over with!



Denny (13 years old)
Cinnaminson, New Jersey

My name is Denny. I am 13 years old and I was diagnosed with Tourette's at the age of 5 or 6. My Tourette's is super mild. Whenever my mom tells my teachers, they say, "Oh, I wouldn't have known if you hadn't told me."



The tics I basically have are blinking and sniffing. I believe I have more OCD. But don't think it was always easy. Some of them are a giggle to me now. For example, when I was younger, I used to slap my hands on my knees and jump up. Once in the first grade a girl said, " Why do you blink?" and I said, "Because you have to blink!" People used to make fun of me. I'm super shy around people I don't know. I also tend to stutter. I only do my tics when I am mad and anxious. I also move my jaw, which I think is a nervous habit. Here are some comebacks for you young kids. If someone says, "Stop it, that's annoying!" you can say, "Stop what? I don't notice anything." If someone says, "You're weird," you can say, "Thank you very much, I love hearing that."

Never let anyone get you down. Just think to yourself, I was born this way. I could be a totally different person if I didn't have Tourette's.

Christian (10 years old)
Pittsburgh, Pennsylvania



Hi! My name is Christian. I am ten years old and I'm in fourth grade. My favorite sport is football. I've been playing for four years. My team is the Cubs. I have played linebacker, center, kicker and played on special teams. My teammates are very nice to me.

I started having tics when I was very young. I don't like when I make noises in my throat because people who don't know tell me to be quiet and tell the teachers. That makes me feel mad and upset. My friends who know about my tics ignore the noises because they know I can't help it.

Sometimes they tell other people to leave me alone and tell them I can't help making noises. I try to ignore my noises. The noises sometimes hurt my throat and give me headaches. I wish I didn't have tics.

I have one sister. Sometimes she is nice. Sometimes we fight. She doesn't pay attention to my noises. My parents support me and take good care of me. My tics don't bother them. But my dog turns her head in a funny way when I make my noises. She is silly. My sister has a bird that chirps when it hears loud noises. We have four fish and a sucker in our fish tank. I love animals. I want to be a football player or a veterinarian when I grow up.

I kind of like school. As I get older I am hoping my tics go away. Some people don't understand why I move a lot or make a lot of noises, but the teachers try to tell them that some people can't help why they do things. They don't point to me or say my name, but I know they are talking about me when they tell the kids that people can't help what they do. They asked me if they could talk to other kids in my class and I said yes, but not to say my name.

There were two individuals at my school who really made a difference in my life during the school year. They helped the other kids understand without making me feel uncomfortable about my tics and why I do what I do. They are Amanda Carter and Lezlie DelVecchio-Marks. I feel they made it so much easier for me to cope with my tics during school. My close friends who really helped me out also and stood by me are, Matt, Carly and Christy.

Become a Tourette Syndrome Youth Ambassador!

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



Robert (13 years old)
Fairfield, Connecticut

Hi! My name is Robert and I have TS, ADD and OCD. I am 13 years old and was diagnosed in the 7th grade. Before that I was always in trouble in school, and was always getting kicked off my hockey teams. I am a travel level goalie. Some

of my tics have been grunting, spitting, twitching and looking up a lot. I have been made fun of by my sister's hockey team, my hockey team and even my friends. But I don't allow this to stop me from being a good hockey player. This doesn't stop me because I have parents supporting me and family. For example, I do not have good fine motor skills and I can't yet tie my own skates. Other people look at me strangely because all 13 year olds can tie their own skates. So to handle this, my dad and I get to the rink extra early so he can tie my skates and I still can join my teammates in getting dressed in the locker room.

I also have determination to be the best I can be. I am already looking forward to high school hockey. When I am not playing hockey, I am a circus performer. I go to circus camp every summer and learn to juggle and do other tricks. I felt uncomfortable at circus camp when the nurse would bring my meds to the table, but I got over it. I am still going strong and I will send you updates.



Priscilla (12 years old)
Tigard, Oregon

Hello there! I'm Priscilla. I have TS like other kids. My tics are jumping up and down on the chairs, making humming sounds and chewing on my sleeves. My tics started when I was 4 years old.

I have a big family. My Dad (Ed), my Mom (Kerry), my three brothers (Thad, Tom and Jimmy), and my two sisters (Tabby and JoJo). I'm a pretty good artist. I love drawing. I also love cats. I have three cats named Saffy, Smokey and Alfred.

I never want school to come. It's very hard going to a new school. I love bowling. Next year for my birthday I want to go bowling. Another thing I love is playing on the computer. I love playing Club Penguin and Webkinz. My Club Penguin name is Hollwen26. My Webkinz name is Kittpart. At night, I play 20 questions. Sometimes I sleep in the morning and wake up late. Life is fun, but I hate having brothers who tease me. When I grow up to be 20, I want to be a veterinarian to show how much I love animals. My favorite movie is, "The Brady Bunch."



I still have TS. But some of my friends ask why I do this stuff. I just tell them I have TS. But they still don't understand. I was going to eat something now, but instead I knew this would be my chance to write letter for this newsletter. I love to share or give stuff to people. If only I could be an explorer then I would look everywhere for wild cats, but that won't happen. God bless you all.



Adam (9 years old)
Elkhorn City, Kentucky



Hi! My name is Adam and I am 9 years old and I have TS. When I was around 7 years old, I started snorting. My mom and dad got mad at me, but when I started blinking my eyes and had a few more vocal tics, my mom knew something was wrong. After

going to lots of doctors, I was finally diagnosed with TS.

I feel pretty normal. The only thing that doesn't feel normal are the jerking and snorting that I do. I snort and gurgle a lot, but the only time I jerk is when I am sad or get nervous. I get headaches when I hold my tics in. I feel like a normal child at school because some kids accept me. But some don't, and that hurts my feelings. I am the only one that I know of with TS at my elementary school. No one understands TS there. Some people laugh and call me names, but my friends cheer me up. My teacher is nice. She understands me and all of this. She always gives me toys to take on my trips.

Right now I'm experiencing more motor tics and I need medicine, but I'm doing really good with this because my mom and dad and three brothers and sisters understand me and love me.



Taneisha (15 years old)
Kingman, Arizona



Hi! My name is Taneisha and I have Tourette's. I have had tics for a very long time. I still do my tics. My tics are blinking, saying words, mumbling under my breath and yanking my neck. I just got this newsletter from my mom. It is really cool to see that I'm not the only kid who has Tourette's. I used to cry and not like the fact that I have TS. I just started to get the fact that I have TS. Since I got older, I still do my tics, but I can just control them sometimes now. All my friends know I have TS. They actually don't say anything bad about it because now they know. My favorite sports are football, basketball and track. TS doesn't stop me from doing what I want to do even though I have it. I still keep my goals and someday I want to become a dancer.



Davis (11 years old)
Delta, BC Canada

Hi everyone! I wrote this article for my school newsletter. I hope you enjoy it!

Tourette Syndrome is a disorder where people can't control some movements their body does. I am talking

about this because I want to tell kids about TS, because I have different tics. Since I was four, I have had different tics at different times, like eye blinking, shoulder shrugging and head-shaking, hopping while I walked and shaking my hands.

At the beginning of my last school year, I started to miss lots of school because my legs started to tic really badly. Just before Christmas 2006, Dr. Freeman from Children's Hospital, diagnosed me with TS. Most of my tics are simple motor tics. I also make some noises with my lips when I am just sitting quietly, like watching TV and riding in the car.

There are two types of tics - simple and complex. In these two categories there are motor and vocal tics. The simple tics are more common. Motor tics could be eye blinking, head jerking, shoulder shrugging and facial grimacing. Vocal tics could be throat clearing, yelping and other noises, like sniffing and tongue clicking. Complex tics are not as common. Motor tics could be jumping, touching other people or things, smelling or twirling around. Vocal tics could be saying ordinary words or phrases, repeating a sound, word or phrase just heard, and in rare cases, saying unacceptable words. Some people find it hard to believe that we can't control it.

The cause of TS has not been figured out yet, but I hope they will find out what causes it. I have TS tics that get worse when I have to sit still at school or get nervous. Sometimes TS can cause problems with sleeping or school. For me it was both. Here are some ways to make a person feel better:

1. Not Teasing. People who have TS feel better when they are not teased.
2. Not Staring. When I get stared at, I get all nervous and I tic harder.
3. When you see someone getting teased, go to the person who is teasing and tell him or her to stop.

There isn't anything to make TS stop yet, but I hope they find something. TS will not always be bad all the time. The tics get better when you get older. After I read about other kids with TS, I knew I wasn't alone.

Evan (13 years old)
Ocala, Florida

Hi, my name is Evan. I am 13 years old and when I was four years old I was diagnosed with TS, Bipolar, OCD, ADHD and Asperger's. It is a big diagnosis for one person. I wish someone would find a cure. I have no friends. My school did not follow my IEP, so now I am home schooled.



I am lucky to have good, loving parents and brothers. We have a lot of fun together. I wish someone would help me.



Lauren (7 years old)
Newport News, Virginia



My name is Lauren Emily. I was first diagnosed with TS when I was 7 years old. Sometimes I blink my eyes and move my neck weirdly, and move my nose weirdly, too. I really want to stop, but I was born with it. It was so nice when my sister, Erin, helped me calm down. Erin is my twin

sister, just so you know. She is very nice, but she can be tough and if anyone makes fun of my tics, she will probably beat them up.

I like to play soccer and sometimes play with the Wii and sometimes I like to play basketball. But sometimes during those sports I get worried because of my breathing. But my mom tells me that I am fine. It was scary at first to have TS, but now I know it's really no big deal.

Did You Know?

**You can read this issue
(and all past issues of "That Darn Tic")
on the TSA website
by going to this direct link:**

**[http://www.tsa-usa.org/
Publications/ChildrensNewsletter/
that_darn_tic.html](http://www.tsa-usa.org/Publications/ChildrensNewsletter/that_darn_tic.html)**

Riley (7 years old)
Lakeland, Florida



Hi! My name is Riley. My tics are stretching my mouth, stretching my chin, raising my eyes and doing a "huh" sound.

My tics bother me. My friends still like me. I have had my tics since I was 4 years old.

To see Riley's drawing in color, go to the TSA website, www.tsa-usa.org and click on the Newsletters tab, then click on this issue of "That Darn Tic."

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. 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 March 15, 2009.

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

TSA
That Darn Tic
42-40 Bell Boulevard, Suite 205
Bayside, NY 11361

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

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



tourette syndrome association, inc.

42-40 bell boulevard ♦ bayside, new york ♦ 11361-2820

Non-Profit Org.
U.S. POSTAGE
PAID
Tourette Syndrome
Assoc. Inc.

Please be sure to tell your doctor about TSA's upcoming 5th International Scientific Symposium on Tourette Syndrome to be held June 12 and 13 in New York City!

The program includes an expert faculty that will present on genetics, neuroimaging, neuropathology, clinical trials (medication and non-medication), epidemiology, neurophysiology, neuroimmunology and descriptive/diagnostic clinical science. The Symposium will set the agenda for future TS research efforts and improved clinical care. Send interested physicians to:
<http://www.tsa-usa.org/sympos5.html>.