



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Logan (9 years old)
Cat Island, The Bahamas

My name is Logan, I am 9 years old and I am in the fourth grade. I live in the Bahamas and I have TS. My mom's name is Ginger and my dad's name is Rob. I have a really nice Labrador dog and his name is Happy. My tics make my head go up and down and I say,

"hmmm hmmm" and "uh-uh." When I do my tics it feels good, but when I hold them in, it gets worse. I live beside a creek and like playing with my dog and playing video games. I also like to play Monopoly Aviation. My best friend is Adam and we play video games together as much as we can. We also like tubing and swimming and building sand castles on the beach. TS makes my breathing harder sometimes. It is nice other people treat me the same instead of differently.



Cody (12 years old)
Marydel, Maryland

Hi, my name is Cody. I hate my tics. They make me blink my eyes, shake my hand, tic my head back and forth and make noises with my mouth. I'm also very hyper.

I like wrestling. I'm on the wrestling team at school. I like playing video games. I like music, too. I live with my sister, mom, poppop and mommom. I love them all. I have four cats named Smokey, Tiger, Snowball and Stripes. I love them all, too. I know I will get over my TS with the help of my family.



Torrie (10 years old)
Jasper, New York

My name is Torrie and I was diagnosed with TS when I was 9. Sometimes when I get teased I want to cry because it's not my fault. My teacher, Mrs. Wyant, will notice my tics once in a while. My tics are eye twitching, vocal tics and moving my nose weirdly. My doctor calls it "the bunny nose."

When I grow up I want to find a cure for people with Tourette's.



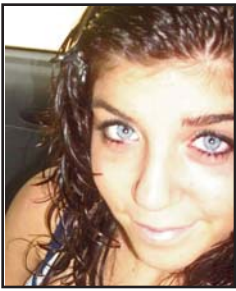
Matthew (7 years old)
Ludlow, Massachusetts

Hi! My name is Matthew and I was diagnosed with TS and OCD when I was 6 years old. Some of my tics are eye blinking, throat clearing, saying bad words and clapping. My friends and family don't mind my tics. I wish I knew other kids who have TS so that I don't feel so



alone. My teacher has been great. Her name is Miss Zina and she understands me and helps me through the day. I have a special pass to use when my tics get real bad. I try not to use it unless I have to.

My hobbies are playing the drums, soccer, playing games on the Wii and building things with Legos. I find that when I am doing these activities they distract me from my tics, I have a family of four: a brother named Anthony, a mom named Sherry and a dad named Ken. My family loves me and they help me to find ways to relax when my tics are bad. I don't understand why I was born with tics, but my mom says that I'll probably be a better person and learn to help others with TS because of it.



Sarah (17 years old)
Louisville, Kentucky

**My Monster is a Beast
Like Tic Tic**

My monster menacingly moves
Drastically disturbing every living
Creature crawling in the distance
Rumbling rapidly and at random
It claims not only I
As its very victim

Some striking words to describe him are
Shakes and shivers but
Not the slightest bit of stillness.

Great grieving and embarrassing episodes
Torments, tangents and
Too many freak attacks.

My monster is the tenacious tormenting Tic.
His bouncy being is not bug-like at all
Slowly but surely he evolved

With his mother being terrible Tourette's herself.
He never had the slightest
Chance of having his victims

Play peacefully on the purple playground.
His very important victims are

Taken ransom at random
He is so super sneaky
No! You will never know
When he decides to slowly
Slip into your system

His booming beastly body
Then thrives and tears tyrannously at your insides.

But he is consistent at caring for life.
He is keenly not the killing type.

50 frantic years from now

My morose monster will still put up
Several aggressive and angry attacks
My monster will master all medications
The Tic will be become tremendous!

He will still be really rancid
On really random people.

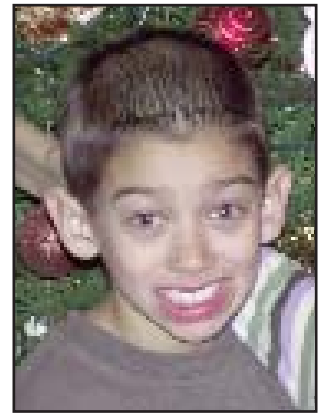
Frantically fooling with the fresh flesh and
The big strong bones of its victims.
Not one cynical clue will come.

Very vexed victims and soon to be victims
Will fear the dark, dreary, discoloration
That the Tic in time

Will bring to any luscious life lucky enough.
The tyrannical trembles and torments
That make up my monster, the Tic.

The everlasting and extremely evil Tic
Along with his absolutely arrogant mother Tourette's
Will terribly tear and trickle through
All the solemn souls
Seriously surprising so many people.

Connor (11 years old)
West Richland, Washington



Hi! I'm Connor and like everyone else in this newsletter I have TS. I have OCD, LD and more, too. I have a great family. They all help me to stay calm. Our family all started Tae Kwon Do last summer and we really like it. We are all working to get our Black Belts and we are over half way there. Breaking boards is awesome!

My mom is the co-leader of our local TS support group. It is not real big, but we have fun. We all go bowling have pot lucks and other fun stuff.

My mom and I also raised \$10,000 for a new puppet (for the "Count Me In" puppets program). She volunteers at the Arc of Tri-Cities, where the puppets are housed and she is a puppeteer, too! They are puppets that go to schools and do skits about disabilities. They didn't have a skit or puppet about TS. The PACER Center in Minnesota where the puppets are made, asked if they could name the puppet after me. Pretty cool, huh? It's the only puppet named or modeled after a real person. They even made the puppet look and do things that I do. But the best part is that now the puppet is out there for everyone. It has already helped other kids like us around the states put awareness into the community. I feel great now that all the kids in my school have seen the puppet performance for TS and now understand a lot better about why I do some of those odd things. The puppets go to local and surrounding area schools to help teach kids that everyone wants to be "counted in!"

Next year is middle school, which means more students and teachers to educate about TS. My mom and I are now working on getting the TSA Youth Ambassador Program in all the middle schools and high schools. You should check it out at www.tsa-usa.org. This would be great if all of us became ambassadors! Do you think my mom cares? Ha, ha! She is the BEST!

You Can 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>



Jenny (14 years old)
Somers, New York

"A Lesson Never Forgotten"

Sitting in that blue metal chair in 7th grade English class, I fought the urges to tic and do rituals. It was exhausting. I kept thinking that I could do it. Then out of nowhere, my hand came up to my face uncontrollably, and I hit myself on the forehead. Darn! I was doing so well before, holding that urge back!

Then, as usual, I heard two girls in the back of the class, giggling because they saw what I did. I wished everyone would just lay off and just leave me alone. So I'm a little different. I know that. But why would someone be so cruel? Why couldn't they just accept my differences? I walked out of the classroom feeling hurt. On the way to reading class, I couldn't stop ticcing. My head was racing with thoughts. It was like there was someone in my brain controlling every movement. It was like that person wanted me to suffer and be embarrassed. Touch that door three times! Touch the floor! Make mouse noises! Don't stop, and whatever you do, do not step on those cracks in the tile! Great, now I was going to be late for reading class, because of all these "setbacks."

That was my school life. I was teased and embarrassed everyday. However, our local TSA Chapter really helped me get through my hard times by introducing me to Adam and Alexa. They are a year older than me and they also have TS. Adam said that I should tell my class that I have TS, so they would understand and be more compassionate toward me. So, that's what I did.

My school developed a program called, A Walk in My Shoes, about all sorts of disorders and syndromes, and I "jumped" at the opportunity to speak to my science class. When the day finally came, I was nervous, but I was also excited. Maybe after this speech people would get my message. I started off by telling them that, "I have Tourette Syndrome, and this is what it is." All eyes were on me for those 5 or 10 minutes. Everyone listened to what I had to say, and they all looked like they cared. When I was finished, there were questions and comments. A hand shot up in the air. "I have asthma," he said. Another hand went up. "I have ADHD," she said. I was shocked. All of the sudden, everyone was sharing their disorders and conditions. Did I really influence everyone in this room to share what "issues" they have? I felt proud, and accomplished. Ever since that day, no one really teased me anymore. I got my wish; everyone gave me a break, and they didn't make fun of me for being different anymore. Being able to walk around the hallways of the school, ticcing and doing rituals, and having no one bother me about it made me feel like I was "normal."

Because of all my success, I was invited back to speak to every single seventh grade class during their A Walk in My Shoes program. I came into each class and basically did the same thing that I did the year before. I told them that, "just because people are different, that it doesn't mean

it's OK to make fun of others because they act different, or do strange things, or rituals." This experience has taught me so many things, and I will never, ever forget them. So I'm a little different, I know. I will never be ashamed of my condition. At least I know one thing - it's OK to be different.



Tali (17 years old)
Rancho Santa Fe, California



My name is Tali and I have had Tourette Syndrome since age 3. I'm the oldest of four, and believe it or not, we ALL have Tourette's! You couldn't imagine what it sounds like at our dinner table! I never really knew what TS was when I was in elementary school. I knew that my Mom would always hold meetings with my teachers before I even got to meet them myself. She would tell them that I wore glasses and needed to sit toward the front of the class and about the tics that I had: jerking my neck, rolling my eyes, humming softly and jerking my shoulders, just to name a few. I didn't really care that I was different, as I made friends easily and kids didn't really ask about the odd movements I was making. Besides the occasional, "please stop humming," I was naive and carefree.

It wasn't until 7th grade that my tics got worse and I realized why my mom had all those conversations with my teachers. I started wishing that I were "normal" like every other kid at my school. Eighth grade was probably one of the worst years of my life, trying to accept myself for who I was and the hardships that came along with them. High school has been a whole new world for me, including new tics (banging hard things with my elbows, wrists and knuckles, and raising my eyebrows up and down). I've made a bunch of friends who, even though they notice my tics, accept them and don't let them get in the way of our friendship. I've made the varsity softball team three years in a row now and I'm involved in choir.

I've always loved singing. Be it musical theatre, a choir, or on the way home from softball practice, I love to sing! I've been playing piano for many years and two years ago taught myself how to play guitar. It wasn't until recently that I really started writing music. I wrote a song about my TS called, "Let It Out!" You can hear it on my website: www.talirappaport.com. It's been a dream of mine to become a singer/songwriter, but as a hobby it's ok, too.

Having TS has taught me that the most important thing is to just be myself, because that's what really shows through to others and matters most. Yes, TS is a challenging thing to deal with at times, but I have found that it has taught me a lot about being patient, compassionate, and most of all, accepting of other people's differences.



Benji (18 years old)
Albany, California

Barley

I opened a text message to find that my friend had misspelled the word “barely.” She had transposed the “e” and had written “barley” instead. After saying the word “barley” to myself over and over, I realized how much I liked the

sound of it. So much so that I knew it would be indelibly stuck in my head for the next several hours. My Tourette Syndrome often causes me to become obsessed with specific words. With my obsession comes a strong desire to say aloud the word infecting my mind at the time. Although I don’t absolutely have to, I sometimes indulge this impulse. I knew that if I summoned every ounce of self-control I could stop saying “barley,” but I knew it would drive me crazy.

The word continued to run through my head as I was sitting on the bleachers in the Albany High School gym, waiting for my wrestling match. After my coach ordered me to put my cell phone away, I turned and looked at my teammate and said, “barley” without any introduction or explanation. Used to my idiosyncrasies, he gave me a slightly puzzled look, didn’t ask any questions, and returned to warming up for his match.

He was running in place with an intimidating facial expression. In my experience, almost all wrestlers warm up this same way. I don’t. I let go of my inhibitions and let my personality—Tourette’s included—out in the open. I warm up this way in part because my syndrome compels me, but also because I’ve learned it can be useful. My unorthodox method can be confusing and intimidating to opponents. I cavorted around the gym singing songs at the top of my lungs with every lyric replaced with the word “barley.”

But I haven’t always been competitive and uninhibited. In fact, just a few years ago I was in remedial P.E., unable to keep up physically with anyone my age. Even today, I still have impaired fine motor abilities; I’m glad that slip-on shoes are in style. Throughout elementary school I was always the last one chosen for any team sports, if I was included at all. I would withdraw into my own thoughts and had little positive interaction with my classmates. This might have continued if I hadn’t joined the middle school wrestling team where I slowly learned that I could be physically competitive, have fun tumbling around with other kids, and have a group of friends. I went from being withdrawn and practically unable to run to being able to play and win at a sport. At this same time I was excelling academically and began to realize that I could accomplish almost anything, despite my obstacles. While I still have to accept some limitations, I try to get some fun out of them.

For example, when I attempt to play basketball with my friends and miss a shot that I should have made, I just joke about my ineptitude instead of being embarrassed. My match began. As I grappled with my opponent, I was distracted by the need to disguise my compulsive “barley” repetition as heavy breathing so as not to get a penalty for talking. After the whistle ended the first period of my match, I glanced furtively at the scoreboard. I was winning. This in itself was not that surprising; my opponent was not from the toughest school and I often win matches, but in the context of my life it was amazing.

As the referee held my hand up in victory I heard a muffled chant of “barley, barley” through my headgear. I dragged my taxed body off the mat, glowing with happiness, not from the victory alone, nor from the mere presence of cheers, but because my friends and teammates in the audience were all shouting my word, a symptom of my disability, in excitement and praise.

I have never been a normal kid, and I have fought to be accepted. It wasn’t until recently that more than just a few people would associate themselves with me. I never had an instruction manual for how to use my personality, yet I’ve gradually figured out how to make it work. I don’t fight against my quirky personality, I know it’s what makes me who I am; I just wrestle with its implications.



Brandon (11 years old)
North English, Iowa

Hi! I’m Brandon. I have just been diagnosed with TS in March of 2009. I have had tics since I was in first grade. I didn’t realize that I had them, and they didn’t bother my parents. Now I am in fifth grade, and since my classmates started to tease me and make fun of me, my parents took me to

a doctor. My mom and I went to my school and told my classmates and teachers about TS. Now they don’t tease me anymore. I think I am a lot happier now, too.

My first tic was just moving my nose up and down. Then it went to moving my fingers back and forth. But now I do them both and move my eyes from side to side and stretch my mouth real wide. Most of the time I don’t even know that I am doing them.

I like to draw a lot, play video games and stuff on the computer. I am in 4H, I show rabbits and a bucket calf. I also volunteer at our local pet shelter, working with the cats. I like going there. The cats don’t ever make fun of me or tease me.

I am glad that my mom found the TSA. I am planning to get more involved with them so I can educate my teachers, family and friends.



Caleb (12 years old)
Jackson, Tennessee

Hi! My name is Caleb and I am 12 years old. I was diagnosed with TS in 2008. My tics are tensing my body, making noises with my mouth and nose and jerking my leg. I am a huge WWE fan and my favorite wrestlers are John Cena and Jeff Hardy. I never miss a show unless I am just too tired.

My tics make me tired very often. I take medication for my tics, but it doesn't control them completely. I sometimes still get upset because kids at school stare at me, but I try real hard not to let it get me down. I also enjoy my PlayStation. My favorite games are any wrestling games and Guitar Hero or Rock Band. Playing games helps me to relax. I also enjoy fishing and hope to take a hunter's safety course this summer so I can start hunting.

I would like to meet other kids from my home state who have TS. Maybe we could write letters to each other and become friends. Who knows, maybe we can be a support system for each other, I may have TS, but it will never have me!



Caitlin (16 years old)
Jackson, Tennessee



Hi! My name is Caitlin and I am from Tennessee. I do not have TS, but my little brother does. His name is Caleb (see his story above). He is 12 years old and is in the 6th grade. Caleb was diagnosed with TS at the age of

11. Before they diagnosed him with TS, he would always ask us what was wrong. Of course my mother knew what it was, but he didn't. He would come home very upset because the children at school were making fun of him. He even had a problem with a teacher making remarks about him. Seeing my brother go through this was very difficult. Sometimes I would sit in my room at night and cry because Caleb was so afraid of going to school or being out in public. His tics are very different. He has them when he is excited, scared, sad or angry. He usually jumps or kicks. My mother and I have grown quite used to it. Still, sometimes when we are out in public, people stare. Caleb doesn't pay attention to it like he used to. I'm very proud of him. My mother shared this newsletter with both of us. Caleb was very happy to see that people actually take the time out to take notice of kids with TS. He doesn't know that I'm writing you this letter. We want him to know how proud we are that he is making wonderful progress and that no matter what, we will always be there for him.

Shayna (12 years old)
West Sacramento, California



Hi! My name is Shayna. I am 12 years old and I live in West Sacramento, California. I have a twin brother named Landon, a mom and a dad who love me very much, a grandma who is the best, and a pug named Sasha and a six month old Chocolate Labrador Retriever named Otis. As you probably know, I have Tourette's and it is very hard coping with it. My twin brother, Landon, was diagnosed with Asperger's Autism at the age of two, and he has had it very hard as well. My older brother, Ryan, died at the age of 18 of non-Hodgkin's Lymphoma on December 1, 2007 and my family misses him very much. So you can say it has been very hard for me and my family.

Having Tourette's tops it all. My life has had a few bumps, although I have accomplished so many things. I act, sing, dance, play flute and saxophone and I am very smart. This year in 7th grade I got straight A's in all of my classes. I did a play at Sacramento City College called "Mr. Toad's Christmas Carol." I had so much fun playing a French field mouse.

At the age of 6, my mom started seeing signs of tic symptoms. Now at the age of 12, I know that I have TS. My dad has TS as well. My tics are moving my eyes at the corner of my eyes and cocking my neck to my shoulders. Having Tourette's isn't going to stop me from living out my dreams, though. Right now, I am going to Sacramento City College to take French, so that way I can go to France when I am 16. Also, I want to be in a Broadway show to sing and dance. I want to become a singer or an actress. I will most definitely be going to college, that is for sure! I hope that whoever reads this will be inspired to achieve your dreams even though you have "That Darn Tic."

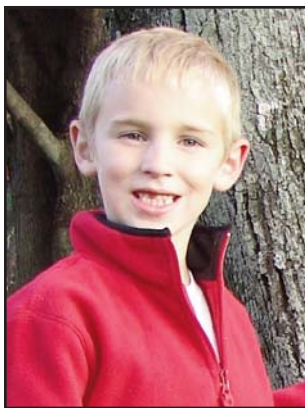
"That Darn Tic" Poem

Go away tics, go away
I cannot have you today!
I have places to explore things to do
Oh, I can name more!
I am going to be somebody, somewhere, someday
So go away tics, go away!

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)



Austin (7 years old)
Muskegon, Michigan

My name is Austin. I am 7 years old. I was told that I have Tourette Syndrome. I don't like to talk about it much. I also have AD/HD and OCD. I don't like to wear stripes or things that scratch my skin like the tags in my shirt. I don't like my food to touch and I stand when I eat. I just started to wear jeans again. I was only wearing wind pants or

basketball pants because they didn't bother my legs.

My body tics a lot at school and at home. I sometimes growl, snort or scream like a fire siren. My teacher and friends at school are nice to me. They do not tease me or make fun of me. I have a lot of friends. I like to play soccer and have a lot of fun when I get to play. I've been swimming since I was 4. I really love the water.

Sometimes I have good days and sometimes I have bad days. When I don't like to talk about it, on a bad day, I growl instead of answering people. I like to watch the Discovery Channel and listen to my MP3 player. When I grow up I want to either be a veterinarian and work with animals or an engineer. I'm really good with computers. My mom said that I can be anything I want to be!

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 June 1, 2009.

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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Help Spread the Word!

Contact Your Local Chapter for
Events Planned in your Area!