



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Destiny (8 years old)
Hermitage, Tennessee

Hi! My name is Destiny. I'm 8 years old and I have had TS and ADHD since I was 4 years old. I'm going to be in third grade this school year.

Ever since I got diagnosed with TS my whole family has been great. They looked up everything about it and helped me understand what's going on with my body. Sometimes I

still cry when I do the tics that really hurt me, like clearing my throat.

But I don't let it stop me from doing things I like to do. I play softball in the summer and I also play in the fall. I'm taking medicine for my TS and I gained weight from it, which I get sad about, too. But it really helps me control my TS and ADHD. I know that when I get older I can do anything I want to do knowing that my TS won't stop me.



Kyle (8 years old)
Loganville, Georgia

My name is Kyle and I am 8 years old. I am going into the third grade. I live in Georgia with my Mom, Dad, Dory, my dog (a Sheltie), Belle, my cat and Hermione, my hamster. I have Tourette's that causes me to tic. My tics include sniffing, snorting, blinking, hocking noise and spitting. Kids at school make fun of me and tell me to stop, and so does my teacher. Can you believe that? I yell



at them and tell them "I can't stop," but it doesn't help. My tics don't bother me, but it is annoying to others. What's annoying is when others make fun of me and tell me to stop. I don't take medicine for it at the moment because the one I tried made me feel weird. I realize that all people are different and this is only one of many things that make me different, so it's ok!



Ethan (10 years old)
Queens, New York

Hi! My name is Ethan. In February while I was in the fourth grade, my school had a "No-Name Calling Week" contest. I decided to enter my poem about having Tourette's. I was very surprised and ecstatic to find out that I won the contest for the fourth grade. I hope you all like as well.

Tourette's

My name is Ethan, some of you know me at very best, but not many know that what I have is called Tourette's.

When I make sounds and move about,
some people stare with grim faces.

I turn and say I'm just a boy who has Tourette's.
When kids laugh and call me names it's very hurtful,
I just might say.

I never feel sad or down, I look far and up ahead
because my future will be the very best.

I thank my teachers, family and good friends.

They do their best to understand that
what I have is called Tourette's.

I learn to have a lot of respect, for all those people who
may not know that I am just kid
with a tic that's called Tourette's.



Alyssa (10 years old)
Raleigh, North Carolina

My name is Alyssa, I'm 10 years old and just finishing 5th grade. I was diagnosed with Tourette Syndrome when I was 5 1/2 years old. Since I was adopted from China, we don't know if my birth mother or birth father have TS. Some of my tics are arm and leg jerking, which happen at the same time,

shoulder crunching, which really hurts my shoulder joint, and shouting in the middle of a sentence. In school, I have a lot of difficulty with writing because of my TS, so I was given a portable keyboard to help me. This school year I developed coprolalia, and sometimes I use a pillow in school when the vocal tics become very loud. I also have OCD. There are situations where I feel like I have to trace vertical lines over and over, that's my compulsion. I went to a doctor who teaches kids "tricks" to help them with their OCD. He taught me to think of my compulsion as a bully, and taught me how to be stronger than my bully so I could stop tracing lines. My other doctor is a neurologist who gives me medications to help me with my tics.

Some techniques I use when I get stressed or my tics get overwhelming are to take deep breaths or scrunch all of my muscles really tight and then let go. I also had seizures when I was younger. Those are really scary to have!

Some activities I love to do, and am good at, are swimming, singing in my school choir, and Tae Kwon Do. Swimming helps me relax, and I don't have any tics when I'm in the water. Through my whole life so far, I've been taking medication, and probably will have to take medicine for a long time.

Tourette Syndrome is not fun to live with and I don't like TS, but I hope it will make me a stronger person because it is part of me.



Shellz (16 years old)
Taft, California

Don't Let Go

Please grab my hand don't let go.
I'm waiting in the rain for you to let me know.
Pondering long and hard.
But still waiting in the silence of ignorant bliss.
You come at last and take my hand.
Only to tell me goodbye.
You leave me in the rain once more.
I can feel the tears underneath the rain.
But they can't dull the sound of my screaming pain.
Again there I stand alone.
Only to realize.
I've been waiting in vain.

Nathan (8 years old)
Hawthorne, California



Me and My Tics

My name is Nathan. I am 8 years old and I am in second grade.

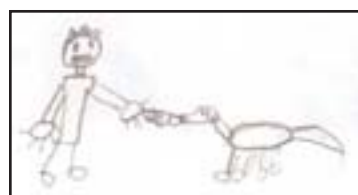
There are four people in my family. My mom, dad, me and my sister. My sister's name is Jenna and she is 4 years old. When Jenna and I are not fighting, we usually play pretend.

I also have a dog named Max. Max is a very active black lab. Max and I really, really like to play tug-of-war.

I really like to play with legos and mega blocks. I also like to do art. I like to draw, paint and color. Some sports

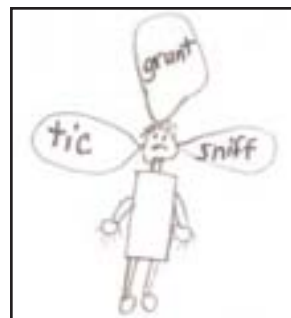
I do are basketball, ice skating and swimming. I really want to learn Karate.

I was 5 years old when I started making noises. My mom and dad thought it was allergies. I took



allergy medicine, but it didn't work. I kept grunting and my parents said to stop. It really annoyed them and they told me to breathe in an unhappy voice. When they yelled at me, it made me feel sad because I couldn't control the noises that I made.

My mom took me to a doctor called a neurologist and we found out I have Tourette Syndrome. TS is when your body moves when you don't want it to. It can be a shoulder shrug, an eye blink, a facial twitch or a grunt. The doctor said my tics may get worse at puberty, but after puberty my tics may go away. It makes me feel really happy that my tics might go away.



Every now and then I go to see a nice lady named Dr. Carlson. She is a psychiatrist. Her office is in a tall, tall building on the eighth floor. She talks to me about my tics and she gives me medicine. I like to go to her office.

I have a lot of friends who really make me happy. Some friends don't even notice my tics, but sometimes some people ask, "Why are you making those noises?" When they say that, I really feel bad because it annoys them.

I want people to learn something from this story.



One thing I want people to learn is TS is something that I can't stop. I also want people to know that I'm like all other kids. One last thing I want people to learn is to just get use to my tics and ignore them. Me and my tics are now part of life!



William (16 years old)
Sharpsburg, Georgia

I have Tourette Syndrome and have recently written a poem about how it makes me feel. I have been prompted by my Lit teacher to submit this poem to "That Darn Tic" in the hopes of it helping someone else who has TS. Even with more awareness out about TS, it is still hard to communicate how it actually makes you feel.

The Puppet

My body is a marionette,
Pulled and tugged with strings unseen,
By the puppeteer deep inside my mind,
His dark bidding unleashed upon my body,
His wicked games begin,
body moves, yet I do not will it,
His restlessness sings my soul,
I cry out in agony and pull against my strings,
But it is in vain, for the pressure only cuts me more,
The puppeteer is in control, and all my efforts useless,
I succumb to his twitches and jerks,
And loathe his very being.
My efforts come in pills and procedures,
But he laughs as they do more harm than good,
And as I look up through my tears and frustration,
A curtain opens and the lights are upon me,
I see others like me, yet they have no strings,
No puppeteer to own their core,
They sit in their seats and laugh
And point as if I am on show,
"Why does he jerk, why does he twitch?"
"Is it a joke, is it a trick?"
A string jerks once more and my eyes snap shut in pain,
The crowd erupts in laughs and jests,
Confusion, questions, the onslaught doesn't rest.
My anger builds for them as well,
For why are they without the strings,
That make me do these horrible things?
Why do they get to sit in rest,
Without this fire inside their breast?
lunge at them in fits of rage,
But I'm thrown back again, beast in a cage,
The strings cut me - deep into my skin,
And prick me with their tiny pins.
I scream and cry and wince in pain,
But the puppeteer keeps up his games,
I look around in jealousy,
And through my tears I clearly see,
Another just as strung as me.
He fights against his beasts and stands,
And brings together both his hands,
He starts to clap and starts to cheer,
But that only I can hear,

He says, "I know how it is to be set on stage,
The laughs, the hurt, the tears, the rage,
But that is what will keep you there,
The object of their heartless stare.
Those are strings, they are not chains,
Grip them tight like Clydesdale's reigns,
And ride this out, for it's your show,
And how it's played only you know."
His words of comfort touched me deep,
And my eyes have since ceased to weep,
For I've realized this is a part of me,
And though the puppet master named Tourette's
Will remain with me 'till'm put to rest,
It's still my show, it's still my play,
Here's to the encore for another day.



Danae (13 years old)
Tacoma, Washington

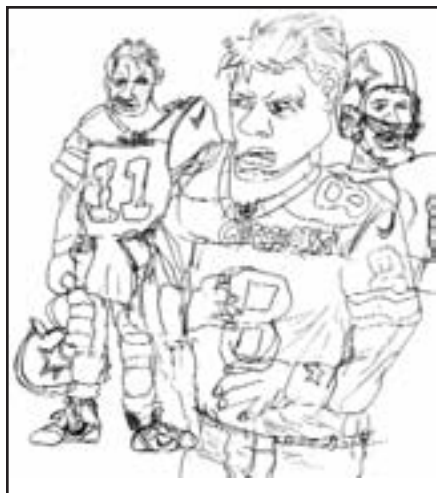
I just watched the TSA-HBO documentary, "I Have Tourette's but Tourette's Doesn't Have Me." I think both kids who have TS and kids who don't have TS should watch this movie so that kids who don't have TS can learn about it and not make fun of kids who have TS.



Tyler (11 years old)
Pensacola, Florida

My name is Tyler and I was diagnosed with TS in 2002. I have a lot of school friends and they never really tease me. My parents told my teachers about my tics and the teacher explained them to the class and they were OK with that.

I feel God has blessed me



with a loving family who support me and God has also blessed me with the talent to draw. It relaxes me when I draw and prayer really helps my tics. Here is my drawing of football players Drew Bledsoe, Troy Aikman and Roger Staubach.



Emma (9 years old)
Cary, North Carolina

Hi, my name is Emma and I've had TS since I was 5 years old. It is a horrible thing, but I can still do things if I focus hard. I do ballet, lyrical, tap, clogging, jazz, hip-hop and something called Odessy of the Mind. I love Webkinz, too. I've had TS for almost 5 years now. My first tic was coughing. Then I started to squat, roll my head, jerk my arms,

tighten my arms, tighten my legs and tighten my butt. I also clear my throat and many other things. It's so hard to keep up with them! I go to my school counselor and a therapist. I also have OCD. Every year, my school counselor has to explain to my class what Tourette Syndrome is.

I danced for the 95th Annual Cherry Blossom Festival in Washington, D.C. When I'm dancing, my tics go away. I have two pets, a dog and a brother. My brother is annoying but the dog is nice. I have TS but TS doesn't have me! I love to read. I used to have a tic that would make reading harder, but now I don't have that tic anymore. Whenever I explain TS, people think I have bugs everywhere! My TS is worse at night. I've started this thing where if I do one of my relaxation techniques, I get a dollar. One of my friends, Megan (my BFF) is the most understanding friend in the world!

She understands TS. My two best friends forever are Megan and Samantha. Megan has ADD and Samantha has asthma. I always get 4s and 3s in school. 4s are the highest. Samantha, Megan and I have a band. I do the keyboard and I design the clothes. I absolutely love to sing! I've never had lessons though but my friends say I'm still awesome at it. My tics don't really affect it.



This is what my tic looks like; it has a mind control gadget, it has furry green hair, big teeth and claws.

It's so hard to explain to people who do not understand. Sometimes they say, "Stop that!" or "What in the world are you doing?" or "Why do you keep doing that movement?" I try to explain but it is so hard. In our school we do something called town meeting. Our grades meet in a large area that we call the town meeting area. We have to sit down all scrunched up in that place. I have to stand up in the back because one of my tics is straightening my legs and if I do that, I will hit the person in front of me. When I stand in the back, kids say, "Sit down!"

My teacher is Miss Ortiz. I am the fastest typer in my class. I'm in AG (academically gifted). I love school and I want to be an author one day. Some people say I have a sickness. One of my neighbors picks on me and says mean things to me. She is like an arrow and I am her target. In jazz, there is one girl who physically pushes me around. I will not mention their names. I am in fourth grade

and my neighbor is in third. She doesn't really know what TS is. She is very tall and says I'm as short as a second grader. Her brother picks on me, too. Sometimes I stand up to them.

Life with TS is so hard sometimes. I kind of like being different sometimes, but sometimes I don't.

That is me and my TS.



Connor (10 years old)
Attleboro, Massachusetts

Hi, my name is Connor. I enjoy playing baseball, video games, and the piano (which I write my own music for). I'm also a brown belt in karate. When I was 6 years old my Mom noticed I was making strange hooting sounds and other noises. After speaking with my pediatrician, I had to go to see a specialist in a hospital. The doctors at the hospital

diagnosed me with Tourette Syndrome, ADHD and dyslexia. The hospital gave me medicine to help control my tics due to the Tourette's. I can't stand it because I hate to swallow pills, but it does help regulate my tics at times. Although there are times when the medicine doesn't work so well and I feel like jumping out of my skin. I try really hard during those times to hold my tics in because they can be very loud and I don't want to hurt people's ears. It's really stressful to have to worry about that all day. Holding my tics in also makes it extremely difficult for me to concentrate during school.

The worst thing about TS is when people look at me funny for my tics. Sometimes they tell me to stop it. I try to explain to them that I can't help it. Most of the time people don't believe me and think I'm doing it purposely. A lot of people don't understand what TS is and I've found it helpful to educate them about the symptoms of TS.

Next year I'm moving to a new school for 5th grade. I'm a little nervous because I have good friends in my class now and great teachers who understand and help me feel comfortable with my tics. I'm worried next year students and teachers won't be so helpful and understanding. Due to these concerns I'm creating a transition plan with the help of my school's psychologist and teachers. I hope this plan will be used not just by me, but by any other student who comes through my school system with TS. Part of the transition plan is to educate the staff at my new school about Tourette's and also create a method of teaching the students in my class about TS. In the long run this plan will benefit not just me, but other kids like me. I hope it makes their move from elementary school to middle school less stressful than mine was. Also, hopefully, it will teach people that although at times Tourette's might make me look or sound strange, I'm really just a nice guy.



Alexis (16 years old)
Moreno Valley, California

I was diagnosed with Tourette Syndrome and OCD on Monday, February 4, 2007. My tic consists of my head jerking to my right side. One of my most noticeable OCD symptoms is if someone touches their nose, I have to touch mine. Before I was diagnosed, my friends used to joke and say that it was Tourette's. I personally thought that it was epilepsy because it runs

strong in my family. My older brother has it. When I found out what my condition really was, I felt relieved because it wasn't epilepsy. At the same time I was sort of sad because I have to live with this forever.

Most people notice that I have it. For the most part, I am perfectly fine with it. If people who don't know ask 'What's up with you?' I just simply say "Nothing, my ear itched" or "I got the chills." If they guess that it is Tourette's then I tell them the truth because I feel that there is no point in trying to hide something that is a huge part of me. They liked me before they figured it out and if they decide not to like me because I'm different, then they really didn't like me to start with!

Some people laugh when they see it for the first time. Others think that it is "cool" or "cute" (I don't see how). As for my OCD, let's just say that there are many cruel people in this world who don't know when they are hurting someone. I have had four major breakdowns to where I could not handle it anymore. But my family and friends are always there to support me through my rough patches. My mommy is the most helpful. She knows just what to say when I am really down.

Most days I don't let my condition stop me from doing what I want to do. I've been cheerleading since I was 5 years old. The only thing that made me upset was the fact that I couldn't do it anymore because I was always the flyer and it could be dangerous if I tic in the air and injure others. I've decided to get into Drama instead.

I have never actually met someone with tics, but there was this one time that the ADT people came to install our security system. I was in my room listening to music and my brother came in and said "Alexis, the ADT guy has Tourette's." (My brother knew that I felt alone.) I could not believe it so I went downstairs. The man had face grimaces. I was so amazed that I just stared at him. I wasn't trying to be rude. My mom kept telling me to go upstairs. When he had left, we told my mom and she said that she didn't even notice. That night I was so happy because I felt like I wasn't the only "freak." I've learned to come to terms with my condition and whenever I am feeling down, I just go online and read other people's stories. It helps me to know that I am not alone with this.

Lee Ching (17 years old)
Malaysia



I Bet

I bet when you first see me twitch
You will start to think I am a freak.
Of course, you will think I am that geek
Who can only manage a squeak.
I bet the second time you see me twitch
Your hand will start to itch.
It will itch so hard
That you'll swear to dump me into that ditch.
When I twitch for the third time
You'll stare at me like I'm committing a crime.
But can't you see that I'm the victim
And you are tormenting me all the time.
You start screaming and yelling
As my twitches and tics get ever annoying.
You start picking on me
Ignorant of the pain you are causing me.
But if I tell you I've Tourette's
Do I still need to hide in my silhouette
Away from all those I fear to upset
And live like a fish trapped in a net?
Well, let me tell you this
I will survive all this
I am no weirdo or geek
For I am indeed unique.

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,
<http://tsa-usa.org>
and look under Publications.



Robert (12 years old)
Northumberland, England

Hi! My name is Robert and I live in Northumberland, the part of England that is on the border with Scotland. I have had TS for one year now and I read every issue of "That Darn Tic."

I am interested in music. I play electric guitar and I take lessons. I like playing golf and football (soccer), and I am learning how to snowboard. I live near the sea, and the city of Newcastle. I like going to Newcastle to shop and look at clothes.

I go to Middle School in Morpeth, a historic market town near our village. I am in all the regular classes, but I have help in Math because I have a bit of ADD. I cope pretty well at school. The other kids understand about my TS. I have no brothers or sisters.

My family and I are members of the TSA in the UK, and I have met other people in England with TS. I am going to the national conference in Coventry later this year.

I would like to have a pen friend in the USA who I can e-mail to talk about TS and other things. I would like someone my own age, either a boy or a girl.

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 December 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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**HAVE
YOU PARTICIPATED IN A
TEAM TSA MARATHON
PROGRAM EVENT?**

**We are working on a special issue of
That Darn Tic, featuring stories from kids
who have walked, run or biked on behalf
of TSA in our TEAM TSA Marathon
Program. Send us your stories
and photos today!**