



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Karlene (10 years old)
Nashville, North Carolina

Following is a letter I wrote to my "companion," Tourette Syndrome.

Dear Tourette's,

You are very mean! I feel like Jello because of my shaking. It feels weird in my stomach, like I have to shake, and that feels bad to me. You are exhausting. You make me fall out of chairs. It is

harder for me to make friends because of you. People don't know why I'm doing it and sometimes I have to tell them. Even though it helps for me to tell them, I wish I didn't have you so that I didn't have to tell them about you. You make me a little worried about my nephew because he copies what I do – like my shaking and my head jerking and the noises that I make. I don't want him to keep doing this for the rest of his life.

I wish I could go to my Grandma's house and put you in her burn pile. I would love to put you on fire and make you go away forever. Not just for me, but for everyone else who has you too! I would let those other people with Tourette's help me make you go away.

I don't know when this will happen, but I am sure that someday my Tourette's will go away. It might be a long time from now, but hopefully it will go away forever, and nobody else will ever have you again! I hope that someone will find a cure for Tourette's.

You have been bothering me for almost my entire life. For a long time, I didn't know what was wrong. I want to learn more about you so I can get rid of you! I'm happy I now know what you are, but I'm sad that I have you. It's sad that other people have you, too.

You make life hard lots of times. It hurts in two ways. It hurts mentally and physically. It hurts my feelings when people make fun of my Tourette's and it hurts my body when I fall out of chairs and other things like that. Even

though the medicine helps some, it doesn't help for long. The shaking stops, but it still feels like it needs to get out from inside my body. And sometimes when I shake, the bad feeling still stays in there. It's like you can't help it; kind of like hiccups of the brain.

When I shake in the car, you make the whole car shake. You make me feel weird when people stare at me when I do my shaking. And sometimes when people do things sort of like my Tourette's, I shake. It's like when my nephew copies what I do, it makes me shake even worse, then he does it even more, then I do it, like we're having a competition. He thinks it's hilarious. It hurts my feelings a little bit, but I know he doesn't know what I'm doing because of you.

I can't wait for the day when I get to shake you! Boo Tourette's and yea for all the kids with Tourette's!



Liam (6 years old)
Round Rock, Texas



I was reading this newsletter on the TSA website, and I wanted to tell you about my own TS because the other kids did. My TS started in about March of 2006, I think. I don't have many tics when I'm at school, though. But sometimes, I make them at school and I'm able to control my TS. I like to do computer time and watch TV. I also like to play with my friends. When they're at my house, it's really fun. I control the tics when I'm with my friends, too.

I like this newsletter. I hope that more kids will send things in for the newsletter so I can learn more about kids with TS. I like music, too. My favorite music is by D'vorak.

I want to be a conductor when I grow up because I like music so much. I also hope that when I'm all grown up and am a conductor, that you and some other kids with TS come to my show.



Jacob (8 years old)
Greenfield, Indiana

My name is Jacob and I have TS with OCD. I was diagnosed in March 2005 and I am in the third grade.

I am interested in Karate and I am currently a Green Belt. I also like custom cars, showing swine, riding my BMX bike and playing video games. When I grow up I want to

work for the ATF (Alcohol, Tobacco and Firearms).

I have tried dozens of medications, but they have all failed me. I am on a new medicine that helps a little. When I tic I feel tired and I feel like I am going crazy. My tics started when I was 6 years old. I have facial tics that cause pain. School is difficult because of not being able to focus.

I don't know anyone with TS where I live, but I would like to.



David (7 years old)
Long Branch, New Jersey

Hi! My name is David and I have TS. I make vocal noises, facial twitches and bend my body. It makes me sad sometimes when kids make fun of me at school when I tic. I try to tell them I have TS, but they do not understand. When I tic hard, it sometimes hurts and is uncomfortable. My doctor has prescribed medication to lessen the tics and it helps.



TS does not stop me from things I enjoy doing. I enjoy playing baseball, sports, guitar, drums and spending time with my family and friends.



Stephanie (17 years old)
Stewartsville, New Jersey

I am a senior in high school and I've had Tourette Syndrome for almost three years now. My arms and eyes twitch. It gets annoying, but my medicine helps calm it down. I am glad that no one makes fun of me for it. If they did my life would be a lot worse. Even though it is hard living with TS, I make it through.

One tip for living with TS is to not let it get to you. Live your life as if any normal person would. You are as smart and as creative as anyone else in the world.

You have Tourette's, but Tourette's doesn't have you!

Jaylen (5 years old)
Lakeland, Florida



My mom recently joined the TSA and we think it is great! So far, I think I am the youngest person I know of diagnosed with TS. I have had verbal and motor tics since I was 3 years old.

I started with eye blinking, twitching and facial grimaces. I say "un-na" all day long which is turning into a throat grunt (because I am trying to control it). My parents tell me to let them out, but, I want to control it. This week I started yelling out "Na-Na-Na." I hope this one doesn't last long because I am starting kindergarten soon.

I can go three months with decreased activity, but, when I have tics, I really have them. I jerk my neck, twitch my legs, bite on my shirt at home, and put my fingers in my mouth. I also have OCD. I have to "wipe" everything – especially if someone touches or taps something. It drives me crazy. I have trouble getting to sleep at night a lot, so my mom helps soothe me and relax me. The doctors thought I was having seizures, but I was not. I just have so many tics at once throughout my body. The doctors here say kids with TS are really smart because my IQ was pretty high. My three-year-old sister Nina is great. My tics don't bother her and she really seems to understand them. She tells people, "that is his tic so leave him alone!"

I don't want to get made fun of in school like I've read, so my parents send me to a school where nine kids with TS go. Maybe it won't be so bad. My mom is still going to show them the tape we bought from TSA called "After the Diagnosis." I am going to take karate there too because I am obsessed with karate and when I do it, I don't have any tics. When people ask me what is wrong with me, I just say, "Jesus made me special and if you ignore it, I won't be nervous and I will do it less."

I really want a Game Boy, but when I play with them, my tics get 100 times worse. Does anyone know of any video games that don't make you tic? I want one so bad, but, Mom took mine back. I want to play video games like other kids.

Sometimes, I just want to be regular like other kids that can sit still and be quiet with no tics.

Did You Know...
you can read this issue (and all past issues of *That Darn Tic*) on the TSA website? Just go to www.tsa-usa.org and click on **For Young People** on the left hand menu.



Sean (14 years old)
Murrieta, California

Hi, my name is Sean and I was diagnosed with TS, OCD and ADHD when I was 9-years-old. Some of my tics are eye blinking, shoulder shrugging and I tug on my clothes. Sometimes I have to touch other people or repeat what they say. All of my tics slowed

down once I got on the right medication. Eating healthy foods, getting lots of sleep every night and exercising helps, too. I also have a counselor who has taught me some things so that I can be more relaxed in social situations.

My parents help me a lot and encourage me to do lots of different things even though I get afraid that I'll fail, or that other kids will tease me. My dad and I started fishing together when I was six-years-old and now I'm pretty good at it. I earned a Black Belt in Tae Kwan Do when I was 11-years-old. The past two years I played football and basketball on community leagues. I might take dance lessons so that when I start eighth grade, I'll enjoy the school dances more.

One time I went to a Dodgers game with the TSA and I met Jim Eisenreich. He used to play for the Dodgers and he has TS. Now he has a Foundation that sends him around the country to teach people about TS. When I was in fifth grade, I did a report on him because he was someone I looked up to.

I have a white German Shepherd named Jesse, a yellow Lab named Dawson, a chocolate Lab named Kai, a Chinese Water Dragon named Cooper and two Golden Skinks named Jake and Zack. I've had a hard time making many friends, but I've come to learn that I really only need one or two good ones. Besides, my pets are about the best friends I could have.



Amanda (13 years old)
Ontario, Canada

Even though I have TS and OCD, I still lead a normal fun life! Seven months ago I found a stray kitten and we kept her and saved her life. She is now a cute, happy, healthy cat that loves to sleep in my bed and eat cat treats.

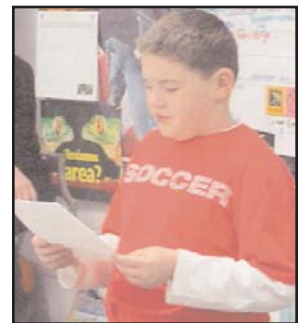


I have joined Air Cadets and attend it every week for three hours in my uniform. I also do weekend Air Cadet stuff, like going up in a glider airplane, marching in a Vimy Ridge Parade and going on a Survival Training Weekend in the woods. I also went laser tagging with my church youth group. I like hanging out with my friends at my house or at their house. I also like biking to the park and jumping on the trampoline.

Thank you for taking the time to read this. Like a guy in this movie that I watched once said, "Life is short, if you don't stop and look around once and a while you're gonna miss it."

Eli (10 years old)
Bexley, Ohio

Recently, I spoke in front of 50 fourth graders in my class and showed them the HBO-TSA documentary, "I Have Tourette's but Tourette's Doesn't Have Me." Following is the presentation I made about TS:



Tourette Syndrome is a disorder that makes me do movements I can't control and make noises like whistling or sometimes do things that are annoying like being too fidgety. At first we didn't know why I always made this face that my family called "the scream face" and we thought it was kind of funny. But, then we realized that I couldn't stop doing the face.

So how did I get TS? It is a disorder that involves my central nervous system, so nerves and the brain play a big role in TS. The faces that I make are called tics. Tics are the most noticeable part of having TS. A tic is a physical movement that people with TS do and they have no control over it. I know there are kids in my class who think I can stop ticcing whenever I want, but I can't. Most people who get TS are between 5 and 8-years-old and it might go away by the time I'm in high school, but the doctors are not sure.

Tics are not fun and definitely not funny. When you see the movie, you will see kids that do a lot of different kinds of tics. It will seem funny but it's really not because they can't help it. People with TS cannot help the tics; they just have to do them. Imagine trying to not blink; after a while, you would just have to do it.

It's really hurtful to me when kids in the class make fun of me and tell me that they think I can stop doing this, because I can't. I hate when people stare at me waiting for me to do the face because it makes me really self conscious and I can't eat lunch or enjoy my friends at recess. This has made fourth grade a little hard for me.

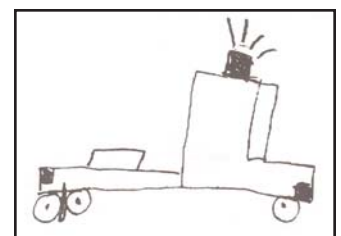
What is important to understand is that you can't catch TS. It's not contagious. Just because I tic doesn't mean I'm not smart or that I can't do things like sports, schoolwork or play and be like everyone else.

So I hope that when you watch this movie, you will be able to show some empathy for my Tourette's and not make fun of me anymore and understand what it's all about. If anyone has any questions about Tourette's after the movie, I can answer them.



Bradley (10 years old)
Blackstone, Virginia

I like drawing, but sometimes it is hard with my tics, so it takes me time to do it. I am good at soccer, too.





Tanner (9 years old)
South Berwick, Maine

Hi! I was diagnosed with TS when I was seven-years-old. I get a lot of headaches because of my head tics. I hate having TS because of my tics, but I am still a normal kid.

Sometimes people ask questions and make fun of my TS. It hurts my feelings. I talk to myself and ask why do I have these stupid tics. I talked to my class, and read a book about my tics. It stinks, but you'll live. It is not like it will take over your life or anything.

I can't control any of my tics. Even though I have TS I can still play sports and do a lot of other things. I feel sad a lot when I should feel happy. Some other things that I hate about TS is wiggling, shaking, spasms and stretching. Once you are first diagnosed with TS it can be really hard, but the symptoms may last a few months, a few years, or maybe the rest of your life. but it's okay. You'll be fine. It can be scary at first, but then you'll get used to it.



Zach (12 years old)
Haiku, Hawaii

Hi! I live on the island of Maui in Hawaii and I was diagnosed with TS when I was seven-years-old, but my parents started noticing my tics when I was around the age of four. My tics are nodding my head, cracking my knuckles, twitching my

right eye, shrugging my shoulders, sniffing and rolling my eyes. I also drum on things all the time, so my parents finally bought me an actual drum set. I love it. I also have OCD. Because of this I have to make things even, walk on each foot the same amount of times, touch things the same amount of times with each hand, and a few other things.

Sometimes my tics get overwhelming like when my eyes are blinking so much that they get super tired and I can barely hold them open to concentrate. Sometimes my head is shaking so much that it feels like my brain is being bounced around in my head and it's hard to go to sleep because I have to sit up when my head shakes.

When people notice my tics, I tell them that I have a Complex Neurological Disorder. I then tell them that it's called Tourette Syndrome and what it is. I think that it's important to educate others about TS because most people don't really know what it is and it lets them understand why some people tic. I feel lucky because no one at school ever teases me about my tics. They don't seem to mind me ticcing at all.

I just saw "I Have Tourette's but Tourette's Doesn't Have Me." Seeing it was great because I don't know anyone else with TS and I got to see that there are other kids who are just like me. I'm going to show it to my school this fall and do a talk on TS.

I love windsurfing and skiing. The problem is that I only get to go skiing once a year for a week. But I get to go windsurfing whenever I want to because I live right next to the beach. When I am windsurfing or skiing it makes me feel detached from the real world and I don't think about having TS at all.

Having TS makes me feel closer to people who have disabilities because I know what it's like to be different and have people stare at you. I volunteer with a program that raises and trains service dogs for people in Hawaii who are disabled. I won the Hawaii Middle School 2006 Prudential Spirit of Community Award because of all the volunteer work that I do. I think it's important to do volunteer work because it makes the world a better place. I hope to inspire other kids to do volunteer work, too. Here is a poem I wrote about having TS:

My Tourette's

A ship bobs violently
up and down in
rough waters,
I can't stop.
Thin ice cracks
under a small boy's hand,
I can't stop.
Large boulders roll
down a tan mountain
freckled in brown,
I can't stop.
Two oars shrug around
in endless circles,
I can't stop.
Never could
never will
be able to
just stop.



Andrew (13 years old)
Baldwin, Wisconsin

Hey! My name is Andrew and I have a mild case of TS. TS really isn't too much of my life, even though it can be a problem for me. Basically all my tics are facial movements, shaking my hands and rarely making vocal noises. It doesn't really happen during school, but it has, can and will in the future. Most kids will repeat my tics at school or just ignore them.

Some of my interests are watching storms and tornadoes, chatting on MSN Messenger and on my cell, knitting and crocheting, biking and walking, I love to show goats at fairs, play with cats and play with Buddy (my grandparent's dog).

Now more about my TS. I used to get acupuncture to help make my TS better; it worked well too. At school, some kids recognize me for my TS, and know and even tease me for it. It really doesn't bother me because it's not that important to me – let kids think what they want. It can't get into the way of things – it's part of people's lives. God made us all different, so that can be a good thing about TS.

Nathan (9 years old)
Taunton, Massachusetts

I have TS, OCD and ADHD. I can only wear really soft shirts and pants and don't really like tags. I like to make my bed nice and neat, but not all the time. I love to draw, build and play with BIONICLES, Legos and other stuff. My favorite thing right now is my Red Mystic Force Power Ranger.



Me with my mom and Congressman Barney Frank

I am homeschooled with my two younger brothers and sister and go on fieldtrips with other kids. I was in a public school for two years for kindergarten and first grade where I got picked on by the other kids for my tics and the teachers didn't really

understand. Other kids would call me a pig for a snorting tic I had. Now I don't really get picked on for my tics anymore from my friends in my homeschool group.



My drawing of a BIONICLE

In May 2006 my mom and I met Congressman Barney Frank. We talked about a lot of stuff, like how he was trying to help get a law into effect to help kids with TS, from getting harassed. (*The IDEA recently included TS under Other Health Impaired*).



Colten (15 years old)
San Angelo, Texas

My name is Colten and I have TS. This summer, I attended the North Texas Buckskin Brigade. This is a wildlife leadership camp designed to empower high school youth with the skills and knowledge in wildlife, habitat conservation, land

stewardship, team-building, communication and leadership to become ambassadors for conservation in order to ensure a sustained wildlife legacy for future generations.

At this camp we learned about every aspect of the whitetail deer. We learned about habitat evaluation, plant identification and how to age and score deer. The amazing thing was that I didn't tic while I was at this camp. It was great. I guess when you are doing something you love there is no reason to tic. Hunting is my passion. It is also my escape.

TS has always tried to hold me back. But I persevere and do the things I love. Don't let TS hold you back. It's not worth it. I have Tourette's but Tourette's doesn't have me.

Raffi (9 years old)
Melrose, New York

My name is Raffi and I have TS – that's short for Tourette Syndrome. I have two brothers and a dog named Spot. I am the only one in my family with TS. My parents found out when I was seven-years-old after a terrible year of tics, but my first tic was when I was five-years-old.



Sometimes when my tics were bad, kids teased me and called me names. But, after we found out it was TS, I learned all about it and now I tell other kids when they say anything. Educating people is the best way. I tell them I can't control my body; it's controlling me. I like to help other kids with disabilities, too, because I can't stand to see anybody teased for anything they have no control over. Other kids don't know what that's like. I have lots of friends now, some are even girls. They all understand much better. I also like to play basketball, too. To my friends I'm just Raffi.



Jessica (9 years old)
Bradenton, Florida



Hi! My name is Jessica and my birthday is on May 1 and I'm cool, intelligent and fun! I have Tourette's. It is some sort of syndrome that I don't like. It annoys me so much it's unbelievable! I take medicine for it thanks to my mommy. Here is a story I wrote.

The Evil Ghost

One day in the park, someone saw a ghost. She thought a minute to make sure it was a ghost. She thought and thought and then she noticed it was coming after her!

She yelled, "Evil Ghost! Evil Ghost!" all over town. When everyone heard her say "Evil Ghost" they all ran and screamed.

The ghost followed everybody around town. It was scary. They called an exterminator, but the ghost scared him so bad he ran away.

The girl named Molly, who was the one who saw the ghost first, said to everybody, "We need your help to destroy the ghost." Everybody was in. So they got scary masks on to see if they could scare the ghost. After a little while the ghost was gone, thanks to Molly and her idea.

James (7 years old)
Center, Texas

Hi! My name is James and I have TS and ADHD. I love the outdoors. I love hunting, fishing and baseball. I am going into the third grade this year. My tics right now are grunting, nose twitching, smelling hands and eye blinking. They come and go and change. I like to build stuff. I have a dog, a chicken and three cats.



Jamie (11 years old)
Hillsborough, California

Hi! My name is Jamie and I have TS. Tourette's makes me rotate my neck a lot, sniffle, blink and get angry quickly.

My mom says I don't need to take medicine for it unless I want to. I told my mom I wanted to take medicine. I was afraid someone would ask me why I was doing that movement and make fun of me. I don't really care about having TS because I was just born that way.

I don't know how I got TS. No one in my family has it.

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 15, 2006.

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

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



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