



# THAT DARN TIC



## A NEWSLETTER BY AND FOR KIDS WITH TS

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**Marcus** (10 years old)  
Cremona, Alberta, Canada

Hi, my name is Marcus. I was diagnosed with TS and OCD when I was 4 years old. My tics right now are nodding my head and going "hmm, hmm" and clapping really loud. Sometimes my neck and my hands get sore from my tics. I hate them, but I live with them. Not very many of my friends

notice my tics. I don't want people to find out because they'll ask me questions. I love to play soccer. It's my favorite sport. Sometimes I play goalie. It gets really boring. I also play forward. I moved from Cochrane to Cremona. It was kinda hard to move. My sisters bug me a lot. I have a family of five: me, my mom, my dad and my two sisters. I have a golden retriever named Bruiser, a cat named CJ and a guinea pig called Cubby.



**Adam** (8 years old)  
Oxford, Pennsylvania



My name is Adam and I am 8 years old. I like to ride my bike, play baseball, do karate and to play with my friends. My favorite sport is baseball. I love to play on my Wii. I have had tics since I have been a baby, but the doctor diagnosed me with Tourette Syndrome when I was five. My dad has TS, also. Some of my tics are blinking hard, grinding my teeth, tightening my body, grasping my hands and spitting. My tics sometimes get on my nerves. The kids at school understand better now because I told them about TS. It is sometimes hard for me to concentrate when my tics are bad. I wish people around the world would understand TS better.

**Taylor** (10 years old)  
Aliso Viejo, California



Hi! I'm Taylor and I found out at the beginning of the fourth grade that I have TS. I'm glad I know what it is now because my friends questioned me a lot last year. Ever since I found out, I told all of my friends. I am currently working on a

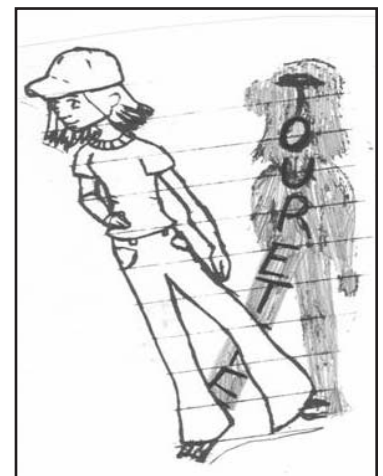
report about TS. I'm glad I have something to call it now. Before I was afraid that something was wrong with me, but now I know all about it. I am currently finding ways to help me reduce my tics. I found that reading and playing my violin help to distract me and to have fewer tics. My tics are tongue clicking, humming, eye blinking, jerking my head and making a funny sound with my mouth. Lastly, I have come a long way since I found out about my tics. Hopefully Tourette Syndrome will have a cure one day.



**Devon** (11 years old)  
Naples, New York

### Tourette

A lingering shadow  
Sometimes forgotten  
Always present  
Following  
Sometimes concealed  
Sometimes seen  
Always  
Part of me





**Holden** (9 years old)  
Weston, Connecticut

My name is Holden and I was diagnosed with TS when I was about three years old. I had a lot of different tics and other stuff that was in my head like singing a song before my tic and if I didn't do it right, I'd

have to do it again. I didn't like it.

My mom talked with a Macrobiotic Counselor and he told her to give me different foods to eat. Since May, I don't have any more tics or stuff in my head. I eat lots of different grains like brown rice, barley, quinoa, millet and whole grain sourdough bread, beans, fish, organic eggs, lots of organic green veggies and others. I have no sugar because that is the worst thing for my TS. I eat rice syrup, barley malt and raw honey. Also, raw milk seems to make a big change in me. It's different from pasteurized milk. Other things I am having are cod liver oil, coconut oil, olive oil and cultured butter. I can't have white flour, processed foods, preservatives, artificial anything or chemicals.

It might be hard for a lot of kids to change to this way of eating, but maybe it will help them, too. It was not hard for me because I have been eating a lot like this since I was born. My mother also cured me of an autoimmune disease when I was a baby called Systemic Rheumatoid Arthritis. The doctors said there was no cure and I could end up in a wheelchair! I'm fine now except I have trigger finger in both my thumbs from it. I hope you get better, too.



**Nicholas** (8 years old)  
Medina, New York



My name is Nicholas. I am 8 years old and I found out I had Tourette Syndrome last year (Summer 2007). For some years before that I went to doctors to be tested for asthma and allergies, but no one knew what was wrong. Then my mom and dad took me to a doctor who said I have Tourette's.

At the start of the school year (2nd grade) some of my friends picked on me and made up jokes about me. They would call me "twitchy" because I twitch my shoulders and arms a lot. My teacher would tell me to stop making noise and sit still. I also clear my throat a lot. When my mom and dad told my teacher about my tics, she made the kids stop and did not yell at me about it. I twitch a lot when I get upset and my dad says it is worse in the warmer seasons. I like to play my PlayStation. I love hockey - go Sabres! I am also a yellow stripe in Tae Kwon Do. My twitching seems to bother other people more than me.

**Jasper** (14 years old)  
Wilmington, North Carolina

**My Tourette Syndrome Youth Ambassador Experience**

In April, I went to my first TSA National Conference. There I learned how to be a Tourette Syndrome Youth Ambassador to help the world know more about TS. At first when I went to the meeting room, I was very excited, and when I saw everyone there, I knew that this was a great idea!



The first thing we all did was an activity to get to know each other. We all explained something about ourselves. All of us with TS got along really easily, almost like we knew each other before. It felt like there wasn't a pinch of dislike between us, and we all respected each other and liked each other a lot. I think it was because we understood each other. Everyone was so kind, including our trainer, Jennifer Zwilling. She was so well spoken, which was pretty cool because she was only 17 years old. She knew every question's answer and she explained it fully so everyone could understand perfectly. I really appreciate how much she had done to make this happen.

She gave the presentation and it was great. We were told that we were supposed to do it pretty much the same way so we don't give out the wrong information. It was only one day, but it was plenty of good information.

I appreciate all the work TSA had done to make this happen. I was so glad I would be able to teach as many people as I could about TS. Now I can help people understand about TS not only for me, but for all others who have TS, too, and have a hard time dealing with it.



**Brandi** (13 years old)  
Modesto, California

Hello! My name is Brandi and I was diagnosed with Tourette Syndrome when I was 11 years old. My tics are opening my mouth really wide and blinking my eyes a lot when I get nervous or scared. People at school used to tease me about it all the time, but not anymore because they are more understanding and respectful.

My Tourette's is like water in a river, because you can never control and it will never stop. And like a river, Tourette's can be scary looking sometimes.

**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>



**Emma Lynn** (10 years old)  
Vineland, New Jersey

When I was 9, I found out I had Tourette Syndrome. I learned with my family what it was and what I could do to help make my life work best for me. The next school year I entered fourth grade. I thought that it would be smart to tell my class about

Tourette Syndrome and how it made me feel. The year before I had a tough time with classmates not understanding me because they did not know what my tics were and why I did the things I did. If I taught my new classmates about Tourette Syndrome, my life would not be so tough and they would understand me and I would make friends.

So I stood in front of my fourth grade class and my teachers, and I told them that I had a neurological disorder and it was called Tourette's. Some things I do that might seem wrong are caused by my Tourette's. But I've learned that I have Tourette's, but Tourette's does not have me. The tics are not who I am. They are what I do to get out the energy and excitement that I have all built up. I was glad to have told my class and make them understand me and to be aware of Tourette's for any other people who have Tourette's that they may get to know.

I made lots of progress and friends this past year. I am glad that I took the lead to spread the word about Tourette Syndrome!



**Zach** (15 years old)  
Jacksonville, Florida

Hi, my name is Zach and I have TS. I love music, fashion, video games and guitar. But, making friends has been a challenge for me. I'm home schooled. I don't get a lot of time to have a social life, and with TS, it seems like I'm stuck in a world where everyone makes fun of me and

thinks I'm weird just because I have tics. But it's not their fault, they're just ignorant. That's why we should all teach them about Tourette's and why we are the way we are. I'm just saying, I've had a hard life since I was 9. It wasn't the best thing in the world when I began to twitch my neck and grunt. My teachers used to hate it. They used to yell at me to stop it and I said I couldn't. It just got harder and harder but when I got home I always felt better. I went to sit in a quiet place or played with my brother, Grayson, who is 10 years old. You just have to find something you love to do and just calm down. But mainly I've read the letters from other kids who have Tourette's in this newsletter and I was

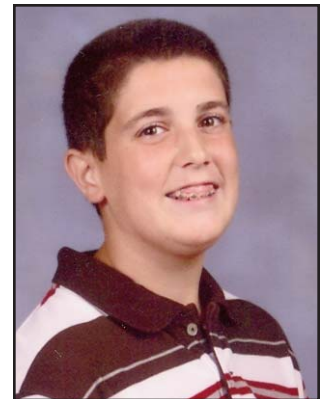
so touched by everyone's stories. I hope you guys enjoyed my letter and I hope to read more of yours.



**Nick** (14 years old)  
Little Egg Harbor, New Jersey

**Accomplish Much More**

My name is Nick and I was diagnosed with TS in about 3rd or 4th grade. TS has given me a lot of problems in school and at home. From what I can remember, one of my classmates in school asked, "Can't you stop making those noises?" At that point I didn't know what to say or do, because I really didn't know what TS was.



I have been going to a ton of doctors and they prescribed me medicine. One for TS and ADHD. When I was little my tics were bad. But then I was put on meds. It helped a lot, but not enough because I still have tics and they bother me a lot. Most of my friends and family are supportive of my TS. Sometimes my classmates ask if I can stop it. I tell them, "No, I can't stop it because I have TS!" I have learned that if you can't stick up for yourself then they will keep on laughing.

One of my closest friends is Zack. He also has TS. He and I are the best of friends. He is in the 8th grade. He and I go through a lot, especially at school. We, who have TS have to go through a lot more to accomplish things. I never let anything get in my way, like some cruel kid who wants to say something mean. I try not to worry about it because I have better things to do.

I like to play baseball and just hang out with friends. My mom and dad say that when you get older you will know who your true friends really are. And now that I am older I have figured out who they really are.

It's ok to have Tourette's, because it makes you a stronger person. Tourette's isn't the worst thing in the world, even though it seems like it.

One thing I want to do is be someone who talks to kids with TS. Now here is just a little poem I made up:

Roses are red  
Violets are blue  
I have Tourette's  
But it doesn't have me.

I believe overcoming this battle and continuing to fight has been my biggest accomplishment. Because if people are going to judge me on my movements and shrugs that are uncontrollable, then they are low themselves and they have nothing better to do.

So as I said before, accomplish much more and everything you can do, and stick up for what's right.

**Janet** (10 years old)  
Fall River, Massachusetts

### Who Am I?

I am a girl who has feelings just like all of you. I like to talk on the phone, I like to draw, I like to swim, I like to write, I like shopping, I like to have adventures, I like jewelry and nice clothes, I like to spend time with my friends and family, I like to watch *Hannah Montana* and other TV shows. I don't like doing my chores or getting up early, I don't like eating my carrots. I don't like it when people make fun of me.

So as you can see I am just like all of you. I am just a girl who likes to do the things most girls my age do. I have my own thoughts and feelings, likes and dislikes.

But I am different in some ways, too. I like to design and I can draw pretty good. I have hobbies and interests that not every one has. But we each have different interests and talents and our differences are what make each one of us special.

I am also different in another way. I have Tourette Syndrome. It is not something you catch, it is something you are born with. Tourette's is something in your brain that makes you move or make sounds even when you don't want to. Sometimes you don't even know you are doing them. Your brain tells you to breathe and to blink and do everything you do. Just like you can't stop blinking or breathing for more than a very short time, I cannot stop my tics for more than a short time. It is like when you have an itch, you can try not to scratch it, but it becomes all you can think of until you do scratch it.

Sometimes I wish I could stop, but I can't. Sometimes I feel different and weird especially when people laugh and make fun of me, it really hurts, and I wish I didn't have it. Sometimes I also feel special because God chose me to have this and maybe I am supposed to do something special because of it. I know that it is hard to be a kid with TS, I also know it is hard for all of you who don't have it to understand some of the things I do. But it is something I have and I can't change that. Just like you can't change the color of your eyes, how tall or short you are, or the color of your skin, I can't change having Tourette's. It is no different than the person who is blind or who cannot walk or any other of the many disabilities. Would you laugh at them for not being able to walk or to see or hear? Would you want to be laughed at for your height, the color of your eyes or hair or just who you are?

So as you can see we are all the same and yet we all have things that are different about us. So who am I?

I am Janet, a normal 5th grader. I know that I don't always understand Tourette's and I have it, so I know you don't understand it, either. If you don't understand some of the things I do, rather than make fun of me (because that hurts), you can ask me and I will try my best to answer your question.



**Desiree** (14 years old)  
Bennington, Vermont

Hey everyone, my name is Desiree and I have Tourette Syndrome. I was diagnosed with TS when I was in the third grade, but I have had my tics since I was 3 years old. Along with TS, I also have OCD and severe anxiety which doctors say may be why my tics are as bad as they are. My anxiety was so bad at one point that I was out of school for three months in the 7th grade. This definitely didn't help my tics or my self esteem.

My friends and family are very accepting of my tics and help me a lot with my TS. As I have gotten older, a lot of my tics have gone away, but the tics that I do still have, have gotten worse. I have been on many different medicines, but most of them haven't worked. At one point I was on a medicine that helped my tics, but it triggered my anxiety and made it really bad, therefore I had to be taken off of it. Since then, none of the medicines have worked without major side effects.

People in my school who know about my TS are very understanding. Every once in a while they will point out a new tic that they haven't noticed before, and then we will laugh about it, because I usually don't notice it until they point it out and when they mention it, I begin to notice it. When I see people in my school who know absolutely nothing about TS, they yell out a random swear word and then say, "Sorry, I have Tourette's." I get really annoyed. I don't have vocal tics at this time. What irritates me the most is that they know nothing about TS and that the people who do this have no idea that someone with TS is standing right in front of them. When people do this I usually laugh, not in a funny way, but in a "You're an idiot" way. When they say "What's your problem?" I just say, "Do some research" and walk away.

I am lucky, because most people don't notice my tics (or at least they don't say that they do), but when people do notice and are curious enough to ask why I do it, I just tell them that I have TS. I usually have to explain that it's not contagious and that there is more to TS than just swearing. One kid asked me if I had TS and he asked, "What do you say?" and I told him that I don't say anything, that I just twitch. To this day he still doesn't get that I don't say anything and he still asks me what I say or to do something, and I just tell him that I can't do things on command, they just happen randomly.

I have many tics. My worst consist of head jerking, muscle tightening and eye squinting. I used to have vocal tics, but they went away as I got older. I do them sometimes, but they are very rare. My tics tend to be worse when I think about them (so right now they are pretty bad), but when I'm not thinking about them, they're aren't as bad if I even have them at all. I am at a point right now where they are really bad for about a month now, but it will go away eventually. For people with TS, I would like to say, you are normal, you just have a few tics along the way. I know that I used to think that I wasn't normal, but I am, and I know that now. You may have Tourette's, but Tourette's doesn't have you.





**Shellz** (17 years old)  
Taft, California

Hey, my name is Shellz. I am 17 and I have had TS for as long as I can remember, but I was diagnosed in kindergarten. I have to deal with people asking me everyday why I make funny faces and noises, and it gets really old when kids look at you and make faces back at you. My friends are really understanding and know

what's going on and they help when I'm having a bad day, or when my tics just get a little out of control. We like to laugh and joke about it, but they know when somebody goes too far and they say something. It would be really hard if I didn't have friends who cared so much.

I'm always getting asked if I'm on medication for TS, but I don't want to take pills. I have worked for years and I can control the severe tics until I get home and relax. But the smaller facial tics I just let go, they're not that bad. It's a little easier because I'm not the only one in my house with TS. My dad and brother both have the condition, but out of everyone in my family with TS, I am the worst, but it's just a part of me that makes me unique and I wouldn't get rid of it if I had the chance.



**Asher** (14 years old)  
Tampa, Florida



Hey, my name is Asher, and I was diagnosed with TS when I was seven. Some of my tics include the thumb tic (twitching the thumb), the bite tic (basically making my teeth chomp down) and the neck tic (moving the neck). I also have many more annoying and often horrible tics, although I will not mention them all. Life with the tics has been extremely hard for me, especially when it comes to school work.

In school, I mainly enjoy band. I love playing percussion in my high school band and I enjoy being a part of the H.B. Plant marching band. My interests are video games, art, theatre, band, mythology, geography and most of all, writing. The reason I love writing so much is because I love to create, design and just think as I go. I have actually written and published a fantasy/adventure novel called *Adventure Land, The Strike of Lightening*. It is available on

Amazon. I am publishing book two in the summer or fall of this year, hopefully. I am working on book three. I will tie in lots of mythology into book three and future *Adventure Land* books. I love to study myths and religions. Buddhism is one of my favorites. I also am incredibly interested in Hinduism, Taoism and Shinto. I want to learn all about different world religions.

I will be going to China, Mongolia and Japan in the end of July 2009 or the beginning of August 2009. Good friends from Arizona have invited me on this fantastic trip to Asia, and I will be going with them. I can't wait to go!

I hope my TS will get better in years to come. My message to people with TS is that they can do anything they wish, and that they can go far! Well, I hope kids with TS will continue to thrive, and see ya!



**Hayley** (10 years old)  
Egg Harbor Township,  
New Jersey



Hi, my name is Hayley and I am 10 years old. I have a big house with a Persian cat named Crystal and I am in 5th grade. I really like to go outside and play with my friends who are Annie, Cierra, Jessica and

Tiffany. I do lots of activities such as: softball, basketball, Hip Hop, swimming and tennis. I have a really good teacher in school who is Mrs. Rosen. All my friends in school are Rikki, Sydni, Autumn, Erin and Kamryn. I do a really good job with my grades in school and always received Honor or Merit Roll. Last year in 4th grade, I received an award out of my entire class (which was 25 people) for perseverance. Then I got an award for friendship the next year.

As you probably know, I have TS. I have a bulging disc in my neck so when I tic it hurts real bad. I have many tics from my head to my toes. Even though my tics hurt me, I still push through. At school, I have some accommodations for my tics. This is somewhat funny: when I am ticing real bad my mom calls me a little trooper. If you have TS, then you should go to camp Bernie. They have lots of fun activities and they will supply the food for you, too! Above is a picture of me on a horse at camp Bernie.

Even though my tics can hurt really bad, I still manage to get through it. I am not going to let this disorder take over who I am. I still and forever will love me, myself and I, just the way I am.

### 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)



**Mayce** (11 years old)  
Holts Summit, Missouri

My name is Mayce. I am eleven years old and I live in Holts Summit, Missouri. I was diagnosed with Tourette Syndrome when I was eight years old. My tics are snorting like a pig, sometimes breathing weird, bumping things with my knees and elbows and doing and saying things until I get it just right.

Before I was diagnosed, my mom and dad would get upset with me for making the snorting sound. My second grade teacher told me that I sounded like a wild animal running through the classroom because of my snorting.

My friends and family don't mind my tics. I get frustrated with my tics because I try to stop and I can't. When I finally get use to one tic, I start doing a different one. I wish I didn't have tics, but that is just what I do and it makes me who I am.

I participate in cheerleading, dance and piano. My favorite things to do are e-mailing my friends, going shopping with my mom, my grandma and grandpa, my aunt and my cousins, and spending time with my best friend, Erin. When I grow up, I want to be a dentist.

## 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, 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. Submissions for the next issue are due by December 1, 2008.

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

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

or e-mail: [tracy.flynn@tsa-usa.org](mailto:tracy.flynn@tsa-usa.org)

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



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# Happy Fall!