



# THAT DARN TIC



## A NEWSLETTER BY AND FOR KIDS WITH TS

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**Becky Nesel** (8 years old)  
Red Hook, New York

Hi, my name is Becky. I want to tell you a little about my Tourette Syndrome. I found out when my mom and dad told me one night. I was interested in it so I listened carefully. They showed me this newsletter. No one calls me any names because I tell them about it. I tell them

that I have TS and I explain it, too. I also had an MRI. An MRI is when I go in a little tunnel and a technician takes a couple pictures of my brain. I was really scared at first, but when I got used to it, it was fine. There was a mirror to let me look at my mom if I got scared. I was in there for 30 minutes! I forgot to say that I had to stay still for the whole time! I make the "K" sound, the "STT" sound, I make weird faces, I kinda laugh too, and I move around like crazy!!! Tourette doesn't ruin my life though it's a part of my life!



**Arthur C. DiNardo** (12 years old)  
Dover, Delaware

My name is Arthur and I am 12 years old. A few years ago I was diagnosed with TS. My mom would get on me for my tics. At the time we didn't know what they were. My mom took me to the Air Force doctor while we were stationed at Aviano AB, in Italy. My neck was hurting from my tics. Mom thought it was from playing video games. I like your newsletter for kids. It's nice to know I'm not the only one. Although at school I am.



**Alex Yue** (12 years old)  
Fountain Valley, California

Since my writing is so messy, I decided to type this letter instead. I've been taking Tae Kwon Do for the past year. I am now a green belt which is the fourth belt. Tae Kwon Do is helping me with my balance and flexibility. It is making me stronger. It will give me more confidence.



**Haley Houchens** (11 years old)  
Tampa, Florida



My name is Haley and I have had multiple tics most of my life starting with winking then the tics just kept coming! Every time one tic stopped, another came in its place. I have lots of hobbies including playing my violin, reading, writing, swimming, acting, and dreaming about horses. Ever since I went horseback riding with girl scouts, I couldn't stop thinking about them.

I am going to play my violin in the Tampa Fine Arts Festival. It's like an orchestra, and nobody in my violin class has tics, but I do better than anybody! Since I am homeschooled, nobody ever makes fun of me, even when I was in school, nobody said one thing about it, and if they did, I probably wouldn't even know what they are talking about, because I can't tell when I'm ticcing! For example, I would be pulling out my hair while I was on the computer, and my mom would say, "Haley, why are you pulling out your hair?" And I would just sit there, wondering how I could not know I was doing it

Tics may be hard to live with, but I am in good hands, because I do not know I am doing it. But for you kids that can tell, try to not think about it, and if you can't keep your mind off of it, God made you for a reason, and your tics are how God made wonderful you!



**Ethan Drew Doitteau** (9 years old)  
Windsor, California

My name is Ethan and I am going into the third grade. I was diagnosed with TS and OCD last year when I was in second grade, but my doctor thought I might have TS when I was three years old. I used to blink my eyes all of the time.

My mom took me to the doctor and he said it could be TS, but later the eye doctor said I had eye allergies so we forgot that I might have TS. In kindergarten and first grade my teachers and my mom could figure out why I was "different."

I have lots of physical and verbal tics. Some come and go, others always are there. I twist my arms around to my back and sometimes I flap my arms and often flap my hands at my wrists. I always twist and cross my fingers, and I smell my hands all day long. Sometimes I repeat what my mom says very quietly as she is talking to me, and I sometimes walk like a spider or I walk around the border of the rug over and over. Lately I twirl into or out of the room and sometimes if there is a long hallway, I twirl all the way to where we are going to.

It is tiring to have so many tics and sometimes I cannot help arguing and correcting my brothers. I get very angry super fast, like all of a sudden, and I can't stop myself. Sometimes before I know what happened I have pushed or hit my little brother. It makes me feel very, very frustrated and sad inside.

I want to be like Tim Howard of Manchester United. He knows that with God and with faith we can do anything. He said in an interview that I watched with my family on TV that TS is not a disability for him, it does not keep him from having and chasing after his dreams. I dream of being a marine veterinarian when I grow up so I can help sick animals.

I don't have very many friends, but the ones that I have know me and it's okay with them that I make noises and do funny things. It's even okay that I am so sensitive and sometimes want to see my mom. I like reading the things that other kids with TS write in "That Darn Tic" because it makes me feel like they are like me and I am not alone.

**"My Tics"**

I twirl and swirl and shrug my neck,  
I can't sit still  
Not for a sec.  
I hum and blink,  
I grunt and wink,  
I wonder what my classmates think.  
I echo you,  
I flap my hands,  
I feel like no one understands.  
Since now I know it has a name,  
I don't see things quite the same.  
Now I know it's not my fault,  
It even happens to adults.  
So even though it's hard each day  
I know that God made me this way.  
It's who he wanted me to be.  
It's just what it's like being me.

**Vincent Veach** (10 years old)  
Lakeland, Florida



My name is Vincent. I have TS and ADHD. I like writing, playing on the computer, reading, and watching TV. I have a throat-clearing tic that I do every time I am thinking about it. I try to hide it by making a coughing noise every time I do it so that my friends won't make fun of me or think I'm strange. I just found out about it today. My parents used to tell me off because of it.



**Travis Carson** (13 years old)  
Yadkinville, North Carolina

My name is Travis and I have TS. It bothers me so much. Even when I take my Orap it still bothers me.

So the reason I am writing is so that people will pray for me. I sometimes look at the sun.



**Jamie Joseph** (9 years old)  
Berkeley Heights, New Jersey

Hi! My Name is Jamie and my friend's name is Danielle Walters. We both have TS and this is how we met.

We met in Camp Bernie (it was a camp for kids who have TS). I was walking home from Arts and Crafts and Danielle and her sister were on the porch. It was raining. I had brought a deck of cards to the camp. Me and Danielle were both bored, so I brought out my deck of cards and we played. We went to dinner together and we decided to sleep in the same bunk. That is how we became friends. We e-mail each other a lot.

Right now she is at my house helping me write this letter. We are having a sleepover. We live about an hour and 45 minutes apart. That is our story.



**Danielle and Jamie**





**Matthew McGeehan** (14 years old)  
Valencia, California

### A Never-Ending Battle

I lay in my bed. The crisp breeze shoots in through my open window. The air is cold; my room is dark, as it is outside. It's late. For most people it is a time for rest, to regain energy, and to lay deep in thought. Though for me, it is a constant struggle.

As I lay in my warm bed, the air touches my face. It feels good. I am peaceful under my blanket. My dog is sleeping soundly at my feet. I hear the crickets outside my window; their songs fill my ears as they make their night sounds. I close my eyes and begin to think about my day.

Suddenly, without warning, without control, my mind takes over. I become a prisoner of my own body. I scream loudly, no words, just sound. My jaw twitches over and over. My muscles are sore. They rip against my braces, as they tighten up. Again, without warning I release another loud scream, like the first, but this one louder and followed by three more. All is quiet. Stop, I protest back to myself. Stop, I command. I am fighting with my brain, trying to regain control of my body.

At night this happens constantly to me. It is very hard to sleep, for I have Tourette Syndrome. This causes me to have uncontrollable tics. Nighttime is a never-ending battle. I go through more than most people do. Yet, I never give up, and this I feel is a very strong quality that I possess. Perseverance has gotten me through many times like this. I cannot think of one time when I have had a good night's sleep and did not tic.

It is now 12:30 in the morning. My muscles hurt. I begin to tic again, and this time thoughts race through my mind, thousands of them in a second. Thoughts about myself, school, my dog, my parents, homework, and friends. Suddenly, I feel my throat close up, I can't swallow. Water, I think to myself, I need water. I reach over and take a sip of water from a glass by my bedside. It is necessary for me to place water by my bed at night, because this happens very often. Soon I can swallow again. I close my eyes and try to take a deep breath, attempting to relax myself.

"You'll be ok," I repeat out loud. Then I finally go to sleep. It is late.

I can't imagine most people having what I have, and still persevering through it. Acting the same way they do, as I know them now. I think the burden would crush them physically and mentally.

I have had this all my life, and still, I wake up every morning and give the day my best.

**Jay Geyer** (15 years old)  
Collegetown, Pennsylvania



In May of 2005 I joined my mom at the Annual American Occupational Therapy Association Conference in Long Beach, California. I was there for about five days.

At the conference my mom and I gave a presentation on "Occupational Therapy for Children with TS."

Approximately 75 Occupational Therapists attended our 2-hour presentation. It was a very rewarding experience. We used Power Point, and I learned new techniques to use in my future presentations. After I spoke, many of the therapists came up to me and said that it was a great presentation and that they learned a lot about TS that they had never known. They really enjoyed asking me questions about my personal experience with TS. Two people even said ours was the best session they attended at the entire conference!

At the next Tourette Syndrome Association national conference in April 2006, my mom and I will be doing a similar presentation. We hope to see some of you there!



Following is a story by Veronica, one of the stars of the TSA-HBO documentary, "I Have Tourette's but Tourette's Doesn't Have Me," to supplement the special Fall 2005 edition of That Darn Tic.



**Veronica Bartram** (14 years old)  
Shirley, New York

The memories that I have are full of scariness and hurt and love and are great all at the same time. I made my mark just last year in an HBO special about my disorder called Tourette Syndrome. This was a big thing for me to tell the world my secret of having Tourette.

Tourette is a mental disorder of the brain and how it functions. I am a normal kid with a normal life. I make honor roll in school and have chores at home. The only thing different about me is that I have Tourette. I shake and sometime squeak and my life has had many ups and downs over the years.

But this is an important time in my life. There are a lot of decisions to make and enough still to learn in life. Being in middle school is hard. Life is hard and easy at the same time. There are days when I come home and I still just cry because I'm hurting and tired from the long days.

But for me life is reasonable. I like the way I live and how I am. I will not change for anyone except for myself because I am proud of who I am. I like the HBO special because it taught me to speak out about my disorder and who I am. This was a great chance for me to show the world my true colors.

**Aidan Keeble** (9 years old)  
Dyer, Indiana

My name is Aidan and I am 10, in fourth grade, and I have Tourette Syndrome and OCD. Most of the time it's like the dark side of the moon, but there are also times that are good. I'm really 9, I just don't like odd numbers, clothing tags or socks. Occasionally I'll wear socks.

I like to play with my animals. I have a farm and 2 horses, 1 pony, 2 sheep, a fish, 3 cats, 3 dogs, 2 chickens, 2 goats, 1 guinea pig, and 1 rabbit. That's 18 animals, plus a bunch of ducks. I like horses, and I'm in the Just Horsin' Around 4-H club. I ride my horses a lot.

In third grade class we grew green beans and I got to take care of them this summer. There are 26 of them. In my family it's kind of hard to be normal. During dinner my mom teaches my 7 year old brother how to burp. Actually he teaches her how to burp. My friend Elizabeth and I have belching (burping) contests as well as my mom, brothers, sister and dad.

I love ballet. I have been in the *Peter Pan* ballet and *The Wizard of Oz* ballet. I'm also taking lessons this summer. I go to Broad Street Dance Co.

I like to invent things. Once I built an unelectrical tape rewinder. I build rides like roller coasters and I'm working on a hovercraft. I built a giant paper tepee that I sleep in. I like to play on the computer sometimes, but I love Legos. I made a Lego country 6 foot by 3 foot. Now I'm working on a *Star Wars* galaxy. I'm in Cub Scouts, too. I'm in the bear den. I love to go to Camp Betz for Cub Scouts. Once I got first place for the pinewood derby car racing at a Cub Scout meeting.

Sometimes it's hard to get along with people who do not understand me. That's okay because there are enough other people in the world.

P.S. My hovercraft works great. You can find hovercraft instructions on the internet.



**Me and my dad making the hovercraft**



**Jackie Staffier** (10 years old)  
Mansfield, Massachusetts

Hi, my name is Jackie and I have TS. I hate it. It makes me sad and I cry a lot. I used to cry every night, but I don't cry that often any more.

I love animals. I am a vegetarian. I have a guinea pig named Cocoa. She helps me a lot with my TS. I love her so much.

It is very hard for me to concentrate in school. Sometimes I don't finish my work.

Math is a difficult subject for me. My favorite subject is reading. I love to read Goosebump books by R.L. Stine.

This year I am going to Camp Connect in Maryland. I can't wait. I want to meet kids that are more like me. I am so thankful for my mom, dad, and sister, Marissa, because I know they love me very much no matter what!



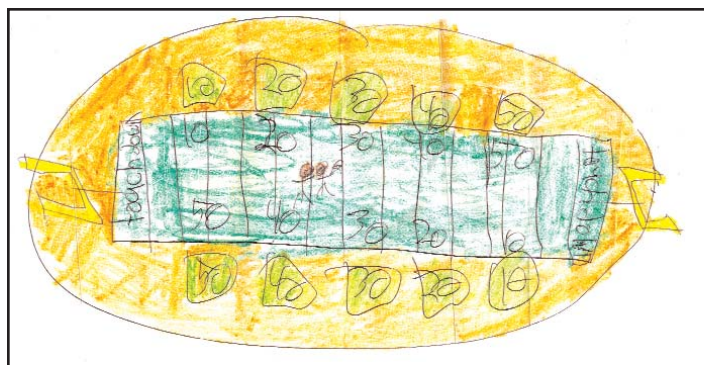
**Nathen Mee** (11 years old)  
Acton, Maine

Hi! I'm Nathen. I have tics and speaking problems. I never write because I think people would tease me. People at school and on the bus tease me because I am off the wall all the time and mad all the time. But then I read the "Why Me" story in an issue of "That Darn Tic" and I say I don't care if you tease me because sticks and stones might break my bones but words will never hurt me. Call me stupid - I don't care. By the way, when I am off the wall and I can't handle it, it's like Plankton on *SpongeBob Squarepants* takes my body over.

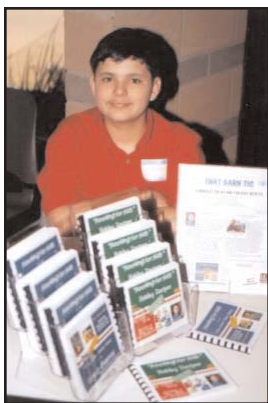


**Nafi Meles** (11 years old)  
Philadelphia, Pennsylvania

I have TS but I can still play football good and I am happy too.



**Nafi's drawing of a football field**



**Joshua Skaug** (13 years old)  
Tuscon, Arizona

**Having Tourette's Is Easy...  
It's Getting People To Accept It  
That's Hard!**

In school I read about the witch hunts hundreds of years ago. I can't help but think that maybe some of those people had Tourette Syndrome. I mean, any kind of behavior that seemed different

back then, people were frightened of. Today, in the 21st century, it isn't too much different when it comes to TS. I find that people are still very afraid of what they don't understand!

I have Tourette Syndrome Plus. From what I viewed from other Tourette kids when I was at Tourette camp in Texas, I have a pretty mild case. I don't use profanities or bark or anything, I just tic. Sometimes it is in my shoulder, sometimes it is in my lips, sometimes in my eyes and a couple of years ago, I would tic really bad in my hands and wrists which made learning to handwrite hard.

TS caused problems at school, because I couldn't sit still when the teachers told me to. And, I would get angry when teased by other kids. What really made it hard was my principal didn't believe my Tourette was real. She told me and my parents that "Tourette was just a convenient excuse by bad parents for their children's poor behavior." My dad ordered pamphlets from TSA for the school and gave an in-service day for the teachers, as he is a teacher at a different school. Some people were afraid of my anger busts and the parents of some neighbor kids at school with me were afraid of me or that they might catch TS from me. Mom and dad had to take me out of school and I am homeschooled now.

I like to cook and I also like to write. I wrote a cookbook called "Kooking for Kids" and joined a big, local writers group even though I was the only kid there.

I was invited to sell and autograph books at the Sierra Vista Book Fair in Arizona. Some people there were afraid of being embarrassed by me because of my TS. These were grownups! I was surprised that people would be so mean because of my disorder. If I was in a wheelchair due to a disorder, I bet they wouldn't have been so mean.

People believe things they can see like wheelchairs. They don't want to believe things they can't see or notice; which can be the case with TS. Out of the 25 authors at the book fair, a total of 99 books were sold and 9 of those were mine!

I would like everyone to help me and TSA spread the word that TS isn't something that you can catch! And, it isn't something that is so embarrassing that we kids with it shouldn't be able to go places because of it. And that people with TS are not awful people; we are just as good as anyone else! It shouldn't make any difference if I have Tourette or not!

Tourette Syndrome Plus is a very real disorder – but not one that should trouble anyone else. I have always said, "There isn't anything I can't do;" but apparently, there is one thing... I can't make believers out of people who don't want to believe or make people not be frightened of me because they don't understand what Tourette is all about!



**Tonya Ingram** (14 years old)  
Bronx, New York



My name is Tonya Ingram and I'm 14 years old. I have just recently seen the HBO special, "*I Have Tourette's but Tourette's Doesn't Have Me*" and I was so moved by it. I have never heard of Tourette Syndrome before I saw the show. I really think by releasing that special many people will know of Tourette Syndrome better.

I was also moved how the kids in the documentary were treated different because they did things irregular from "regular people." It opened me to a world which I didn't know existed. I was so moved, I want to work with such children when I get older to cope with what they have and for them to take it as they have something special, whether it is they twitch or yell words out of nowhere.

In my school there is a teacher who has TS. His students make fun of him because he can be talking, then all of a sudden he'll twitch and they would be like, "What the heck is wrong with him?" I think if everyone was aware of TS people would be more understanding and everyone won't jump to conclusions so fast.

I just want to say thank you for educating me with something new, something I never heard of. I think it would be really cool if I get to know a child who has TS to see what they go through everyday and to know they are normal like anyone else. The most down-to-earth person who really didn't care what people said was Colin in the documentary. He gave me a laugh.

I root for you guys! Keep going and don't let anyone say you don't fit in. You are you and no one can change that. You guys have inspired me and I say thank you for that!

## Did You Know...

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

**Zack Patton** (13 years old)  
LaVerne, California



**Tourette's**

I am Tourette's  
I am fed by stress  
I give pain when I get the chance  
People fidget by the thought of me  
I use my most repetitive friends  
They feed off the smallest of stresses  
When I'm done, I'll move on  
I will not die  
I'll just take the express  
To the next generation  
Then I'll do it again  
I am Tourette's

**TSA National Conference**  
**April 6 through 9, 2006**  
**Alexandria, Virginia**

**That Darn Tic**

*That Darn Tic* is TSA's newsletter by and for children up to 15 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 March 1, 2006.

Please 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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