



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Samantha (9 years old)
Anaheim Hills, California

I have had TS since I was 5 years old. I want to tell you how I handle my tics. First, I take a deep breath and I say to myself, "I can handle it, I can handle it."

Sometimes I feel like someone else is controlling me. I pray every night to the Lord that he will help me with my tics. When kids pick on me I tell them how I feel and what I have. Usually they understand and sometimes they become my friends. Some of my friends (Alex and Jordan) stick up for me and help me out. Right now I have a couple of tics. One that makes me scream and another that makes me hold my breath. Sometimes I also jump up in the air.

My favorite things to do are: clog dance, swim and exercise. Math is my favorite subject in school. When I grow up I want to help kids with TS and become a mom. I would also like to be a singer. I hope that God will help all the kids and adults that have TS



Alyssa (8 years old)
Turlock, California

Hi, my name is Alyssa. I have had TS and ADHD since I was 7 years old. My tics are blinking and jerking my neck. I used to do Tae Kwon Do. I started when I was 4 years old. I have a first degree black belt. I currently am taking piano lessons and am in third grade. I am at the top of my reading level in school. I like my tics because they are a part of me. They make me who I am and who I will be when I grow up. When I grow up I want to be a model, or a nurse or a teacher. I wish I never had TS and ADHD because they make it hard to be good for my parents. I try really hard to be the best that I can be.



Nathan (13 years old)
Yatesville, Georgia

Hi! I was diagnosed with TS when I was 5 years old. I also have Asperger's Disorder. I get picked on a lot at school, but I do not let it get to me. I also have friends who stick up for me.

I love to play with my dog, Dixie, everyday after school. She is a great pal. Whenever I am sad, she cheers me up by licking me on the face. Dixie is my best friend.

Some of my tics are grunting, blinking, stuttering and twitching my face. I might have tics but tics do not have me. All you have to do is believe in yourself and sooner or later other people will, too.



Tomas (10 years old)
Buenos Aires, Argentina

Hi! I like to receive this newsletter! I have Tourette Syndrome and tics. I live in Argentina, Buenos Aires. I have many tics with my eyes and with my hands.

I don't know any children with tics in my country. I would like to write letters with children who have tics in the U.S. My mother has tics, too. In school, children see me as strange, but I am happy anyway. Did you know Mozart had tics, too? Wow!





Katie (14 years old)
St. Louis, Missouri

Hi! My name is Katie and I was diagnosed with TS when I was only 4 years old. I am now just around the corner of my 15th birthday and my tics are getting a little bit better over time.

When I first really understood what TS was, I was scared. I didn't know what was going to happen to me. I wasn't sure if I would be treated as a regular kid and if other kids would accept me. But that all changed when I got to 5th grade.

You see, my classmates had been wondering about what my movements and noises were since I had started going to that school in first grade. I finally got enough courage to go talk in front of my entire grade! I wasn't nervous because I knew enough about it to answer most of their questions. When the day came for me to make my speech, I was excited to let my class know what had been going on with me for all those years. The speech went better than I had ever expected! When I was done my classmates were on their feet clapping for me!! I was on top of the world.

Now in high school, most of the people know about my disorder, because when I tell someone, they tell someone else to make sure everyone knows the real deal. Before my speech, I had felt like a weirdo, like kids didn't understand me. But after I got the courage, I knew that they didn't care if I was different, because my personality was the same. I hope that all the younger children with TS will learn from my experience and learn to face their fear if they don't know what kids think. It worked for me! And I hope that in the future the young kids with TS will come to see that they are exactly like everybody else, they just have a small difference that makes them who they are. Everyone is unique in their own special way, and TS is something that makes us ourselves! Live your life proudly, and if someone asks you about your TS, say "I have Tourette Syndrome, and I'm proud of it!"



Boston (9 years old)
Elizabethtown, Pennsylvania

Hi! My name is Boston. I really like to skateboard and really like to do the Ollie! The Ollie is when you make the board go up without using your hands. (I am doing an Ollie in this photo!)

My tics are shaking my head and wiggling my ears. Four kids in my class asked me, "Why do you shake your head?" and "Why do you wiggle your ears?" I do not know what to say.



Jennifer (16 years old)
Troy, Illinois



My name is Jennifer and I've had Tourette Syndrome, ADHD and OCD since I was 7 years old, although I wasn't diagnosed until the age of 14. Through the years TS has taught me some of the hardest-learned, yet most rewarding lessons of my life. Here are the top five.

1. Be Forgiving

Like many with TS I've had many obsessions including doing something horribly wrong. This led me to perform a tic-like compulsion of saying "sorry" over and over, but also showed me how easy it is to make mistakes in life and that life is too short for long-lived anger and guilt.

2. Be Accepting

In elementary school before I had ever heard of TS I had two tics in which I would begin laughing and barking like a dog. Peers I once called friends began to ridicule me and finally my last friend asked me why I would do those things. She said "Jennifer! Why can't you take anything seriously? Everything is a joke to you," and all I replied with was laughter. The loneliness hurt, but also taught me that everyone has differences and seeing past those differences can make a world of difference to a different person.

3. Always Keep Hope

Towards the end of middle school I had finally been taken into the mental health community. I received excellent help for my OCD, however, soon after, I began repetitively saying the words die, kill and murder. My psychiatrist at the time was a wonderful person, however, he believed my tics were related a psychotic disorder. Although I had never had any sort of hallucinations or delusions he claimed that I most likely heard voices telling me to say those words but was too afraid to admit it. I was hospitalized three times for these "voices." I remember at that time feeling the lowest I had ever felt. No one would listen to me and I believed there was no hope left in the world for me. Today, however, my life has taken a 180 degree turn for the better and I know that there is always hope.

4. When You Need Help, Help Others

Around the time of hopelessness I had given up on just about everything. Then I met someone who was really, really depressed and I talked to her and helped her find treatment. Seeing her recover was one of the most beautiful things I had ever experienced, so I began talking to other people who were having hard times and doing whatever I could to help them. Soon my situation seemed to look up as well.

5. Have a Positive Attitude

There have been three major things that have helped me to overcome the challenges of TS: a school for children with similar difficulties; a brilliant therapist; and friends. However it took me months to trust any of these things and people. This has taught me to enter each situation with a positive attitude.



Daniele (10 years old)
Mount Vernon, New York

Hi, my name is Daniele and I have TS. I am in 4th grade. I was diagnosed with TS in the summer of 2005. My TS symptoms are twitching my neck and head. When people ask me about my twitching, I feel uncomfortable sometimes and I tell them that I don't want to talk

about it. I get annoyed when too many people ask about it.

When I twitch, sometimes it hurts and other times it feels good when I release myself. It also annoys me at other times. One time it was out of control for at least two days. It gave me muscle spasms in my neck and head. The doctor told my parents to give me Motrin and use a heating pad. My twitch usually goes to the rhythm of a song in my mind. This is kind of strange and I don't know why it happens that way.

I go to a great Catholic school in the Bronx. My principal talked with my mom about my TS and she is concerned and supportive. She gave my mom ideas on how to help me with handling stress. My second grade teacher told my mom that she and her family are praying for me. And my third grade teacher wrote me a very encouraging letter when she found out. My fourth grade teachers also support me. They check on me to make sure I am okay. One of my teachers told my mom that she has started researching TS so she can learn more about how to help me. I am happy that God gave me this school to help me deal with my TS.

I don't let TS stop me from doing the things that I like. I play basketball and softball, but my passion is basketball. I am also in girl scouts. I have a very active social life and I like to read books about TS.

With the help of my church, family and school I have gotten closer to God. My church family prays for me all the time and that makes me feel loved. Whenever I need help with my TS and no one else can help me I go straight to God. I believe that God will find a way to help me feel better. He has given me strength and courage to deal with TS. God made me in His own image and He made me perfectly, so I see myself as a child of God made in his perfect image. I believe that God has a plan for my life, which includes TS. I believe that he will use my TS to help someone else. I am happy that God has given me a great school with supportive teachers and friends, and a supportive family and church community.

TS will never stop me from doing anything and I hope that it won't stop anyone else. TS does not define who I am. I have TS but TS does not have me! My favorite scripture that has helped me during this time is Isaiah 49:15, "Can a mother forget her nursing child? Can she feel no love for the child she has borne? But even if that were possible, I will not forget you! See I have written your name on my hand."

Jessica (13 years old)
Needham, Massachusetts



My Life with Tourette's in a Nutshell

It all started April 16, 1993 on a mild sunny day, 2:30 in the afternoon. I was born. I arrived into the world like any other baby, crying, small and a little wrinkly. I guess I must have seemed normal because my parents decided to keep me.

By the time I turned five, I had started kindergarten and was significantly losing weight. Around the same time my younger brother, David, was born, which added more stress to my life. I was seeing every doctor in the Greater Boston area with no answers. During kindergarten I started doing these little "habits," like blinking my eyes real fast, for example. My mom said it will soon pass.

By the time I was 7-years-old, I was classified as malnourished. In third grade I had started sniffing; a constant feeling that I needed to blow my nose. When fourth grade approached I was to figure this mystery out.

My mom and I went to a special doctor for some tests. On the way home I was hungry (there is a first time for everything). So we stopped at Bertucci's. As I lifted my pizza off my plate my mom started to say, "The doctor told me something today."

"What?" I replied.

"You have Tourette Syndrome. It's a disorder that makes you do tics," mom said slowly.

"I have what?" I practically screamed, not even knowing how to say the word.

Mom calmly told me what it was. That explained the little habits. I sat there watching the tear drops fall into the cheese of my pizza. I was feeling confused, excited for answers and overwhelmed all at the same time.

Years passed with lots of different tics and finally I was 10 years old. My weight was going up and my ribs were no longer visible. In fifth grade my mom had to offer me a prize for turning 60 pounds, while every other kid was well over 80. When I was 12, I will never forget going on an airplane with the worst tics of my life. The lady in front of me asked loudly to be moved away from me because I was disturbing her so-called peace.

I am presently 13-years-old, on very good medicine and I seem tic free. I have just reached a milestone of 100 pounds. A day to cherish!

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, www.tsa-usa.org and look under Publications.



Hannah (13 years old)
Pleasant Garden, North Carolina

I was just diagnosed with TS on January 5, 2007. It is very hard for me knowing that I am even more different than everyone else. Not that I ever tried to fit in, in the first place. I mean not that I am calling myself weird or anything, but I do a lot of

things that the people at my school don't much like. I am very different from all the other kids. Now I am terrified to go to school. Today I went to church and I felt so bad when all the other kids laughed at me. The only person who didn't laugh at me was the Pastor's son, Andrew, because he himself "suffers" from TS. I use the word suffers because I think that we are specially chosen to carry this burden, so that we can hopefully be the strong ones just as any one is chosen to carry any disorder or disease.

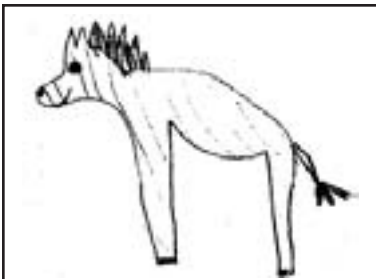


Danielle (9 years old)
Burbank, California

Hi! My name is Danielle and I have TS, ADHD and OCD. They do not bother me all the time, but sometimes they do. I jump, sniff fingers, do a humming sound, a touching compulsion and make a kissing sound with my lips.

At school, nobody teases me, except one person, and I told her about my tics. I can be a friend. I can do what you can do. I'm not different.

I can do gymnastics and ballet. I love to ride horses and maybe one day I will get a horse.



Here is a picture I drew
of a zebra.

I love SpongeBob Squarepants, and Patrick is my favorite character. My best friends are Alyssa, Scottie and my cousin, Alex. You can be my friend, too. I had a dog, Sevshoon, a pit bull, who died. Sevshoon means "black dog" in Armenian.

I have another pit bull now, whose name is Pepper.

I am half Armenian and half Texan. I had a hamster names Choo Choo who died. She was sweet. My mom had breast cancer three years ago and is fine now. My dad is very strong and is a mechanic.

My tics began in kindergarten and come and go. They were very intense last year. I tried a lot of medicine, but none of them did that great for me. I am not taking any medicine now.

People love me as I am. My jumping is less now. School makes me nervous.

Kevin (16 years old)
Castle Rock, Washington



My name is Kevin and I have had severe TS for six years and have had many ups and downs with my TS. I am very comfortable sharing my story with anyone who takes the time to listen. I look at my TS as a gift instead of a disability. Since I was 10 years old I have shared my story with my classmates at the beginning of each school year. I also educate anyone in public who asks me what is wrong with me, or for that matter anyone that looks at me funny.

I have dealt with people who refuse to acknowledge my tics as a part of who I am, instead they just look at me like I am some punk kid. It takes awhile but I usually get them to understand.

School can be difficult for me at times, but I do not give up. I always find ways to complete what I have started and enjoy good challenges. I have to spend more time than other kids doing homework, but it is worth it to see the good grades. Now that I am in high school some of the kids try to be mean to me, so I educate them again and again. If they still choose to not understand me, then I just choose to ignore them.

Things that help to reduce my tics are drawing (I love to draw and am pretty good at it), weight training class, chopping wood and bike riding. Anything physical helps to bring my tics down. I spent last summer bucking hay and working as an apprentice diesel mechanic. I have very good work ethics. Once people see that I can handle machinery without getting hurt, they are more willing to let me try things.

Last summer I also got my driver's license. Even with my tics I passed the driving part on the first try with a 98%.

In my free time I like to hang out with my friends and my twin brother. I also do a lot of drawing and when the weather allows, I spend a lot of time outside playing with my dog, riding my quad and swimming in my pool. Of course there is always work to be done, so I help out with that also.



Corinne (8 years old)
Sarasota, Florida



Hi! My name is Corinne and I have TS. My tics are whistling, coughing, cracking my neck and kicking my legs. I don't like my tics, they embarrass me. My friends don't understand TS. I don't like it when they ask me why I'm doing my tics.

When I am doing things that I enjoy, my tics don't bother me. People wouldn't even know I have TS. Some of the things I enjoy are gymnastics, playing video games and riding go-carts.

After reading *That Damn Tic*, my mom and dad wanted me to write and tell you about my TS. My dad made a copy of *That Damn Tic* for my teacher to help her to understand more about TS. My teacher said that if I could bring in a copy of "I Have Tourette's but Tourette's Doesn't Have Me" to help my class understand more about TS.

Rachel (14 years old)
New York, New York

He jumps. He squeaks. He shouts things he shouldn't. This is Tourette Syndrome. TS made its way into my life through my younger brother, who lives with it. This neurological disorder is something he lives with everyday, and it has definitely had an impact on me.

I always knew that there was something a little different about my now 12 year old brother. CJ would have a hard time sitting still while my mother read to us when we were younger. He would have many visits to doctors, and take medicines whose names I couldn't pronounce. He would also get away with doing things I couldn't get away with, like writing on the walls.

In the fifth grade, there was a shelf of books called "Great Reads" in my classroom. It was supposedly full of, well, great books. I picked up a book called *Quit It*. It was about a girl in the seventh grade who had a rare disorder called Tourette Syndrome. I didn't know what that was, so I put the book down, feeling a little unsettled. The symptoms



Chloe, CJ and Me

described were much like those of my brother's. I discarded the thought. A few nights later, while observing CJ, I once again asked my mother what was wrong with him. The thought I had discarded earlier that week had resurfaced. She explained to me that he had a disorder called Tourette Syndrome. She explained that it caused him to move and make noises. The word "syndrome" struck home with me, though.

Thinking that night, I just couldn't accept that my baby brother had an incurable disorder. I didn't understand why his twin sister, Chloe, didn't have it too. I mean, they were in the womb together. Pondering this, I asked the next day why she didn't have it. It turns out that this disease has a 75 percent chance of affecting boys rather than girls. It is also hereditary, which means someone along the line of my family probably had it before him.

As we grew up, CJ's symptoms have become worse. What started out as mild TS, progressed into a more severe case. OCD, ADHD and learning disabilities were all part of the package that is TS. He was also ticing more and more.

It is sometimes very difficult living with him. He is an amazing boy, and on top of having all his problems, he still ran for student council (and won), still has great friends and still participates in all social activities. However, all his energy is very tiring to the rest of the family. He is the human equivalent of the Energizer Bunny, always talking, always moving, always fidgeting.

Having a brother with a disorder has made me more accepting and more aware. It has made me less

superficial and less judgmental. I can see somebody with a disability and not have the urge to disrespect or to make fun of them. I understand more, and know that most people with disabilities don't let it run their life. I honestly don't know if I could deal with having TS myself. It takes a very strong-willed person to even begin to think of tackling it. Though there is no cure, there are psychological ways to sometimes rise above it.

This disorder has made me more informed. Most people are ignorant of TS. I believe that if one is close with somebody like my brother, they will be better people. They will accept and be better informed. This is why I am glad CJ has Tourette, even though I would give so much to free my brother from it. Being a little selfish, all and all, it has made me a better person. This is Tourette, and it is life changing. All because he jumps, and squeaks, and shouts.



Cason (12 years old)
El Dorado, Kansas



Tourette's takes time to trail away.
Tourette's is always in your way.
Tourette's is what bugs you night and day.
It stinks it won't just go away.
Instead it just wants to stay.
Tourette's is a ghost,
And you are it's host.
Tourette's is a ghost that scares your friends,
Tourette's is a ghost that never ends.
Tourette's is like a storm.
It doesn't keep you warm.
It goes against your thoughts.
It makes you skip and hop.
It's like a storm in many ways,
the rain, it makes you sop.



Laine (14 years old)
Fort Plain, New York

I love science. I study global warming, evolution, geology and most of all, paleontology! I go up to the park from where I live and collect fossils.

I also have ADHD, OCD and tics. Mostly I have tics like squinting and expanding my hands. I have a tendency to be loud in quiet places, and sometimes I have to yell when I'm walking home from the youth center.

Times are hard, but you can do anything you set your mind to.





Rosario (15 years old)
Metepac, México

Dear That Darn Tic,

I have just received the Winter 2007 issue of the *That Darn Tic* newsletter, and I have to tell you the expression on my my mom's face when she read my story. The look in her eyes, and the words, "I am proud of you" will be a lifetime memory, and this couldn't have been realized without you and amazing team that works with you at the national Tourette Syndrome Association.

Again, thank you so much for giving me this great opportunity to express my ideas and feelings.

Sincerely, Rosario

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, ran or biked on behalf of TSA in our TEAM TSA Marathon Program. Send us your stories and photos today!

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 June 1, 2007.

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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Contact your local Chapter
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