



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Ben (6 years old)
Guilderland, New York

My name is Ben and I am 6 years old. When I went to kindergarten, my teacher and my classmates and I didn't realize I had Tourette Syndrome. When I went to first grade, I had it. It felt weird. It was a little embarrassing. Now my teachers and my classmates know what it is like for me to have it. This is

because I asked my teacher if I could tell my classmates about it. She said yes. I stood up and told my whole class how it feels to have TS. They thought it was really good to learn about it. It made me feel proud to tell them.

My tics are squinting and blinking. When I am really tired, my tics get bad. But most of the time they don't really bother me. I am a fan of the Naked Brothers Band. I am really good at playing the piano. I also like to make and read comics. I love to write stories.



Amanda (16 years old)
Indianapolis, Indiana

Hi! My name is Amanda. I have had TS for almost three years now, but I'm a late bloomer. I was diagnosed at the age of 13 and I'll be 16 at Christmas. I've been a soccer player since I was four. While I'm still playing soccer in HS, the medicines are impacting my performance and making it harder to run up and down the field. The soccer headline for this past soccer season was "Amanda Scores the Winning Goal of Final Game." Yeah for me!



I've had slight TS symptoms since I was five, but my parents and doctors never figured it out. My parents were the first to notice something serious was wrong. That happened one evening when my Dad caught me biting my

tongue, and I couldn't stop! It was a classic case of TS and OCD. Well, I've tried lots of doctors and medicines since then, but my tics are still around. What's weird and unfortunate about my tics is that they are all facial. I bend my ears, scratch my face, bang my nose, pull my hair...you get it. My verbal tics are pretty boring, just a few squeaks here and there. The toughest part of having TS is the cruelty of the HS kids around me. They prefer to mock the TS instead of trying to understand it. I make it a habit to speak out about TS whenever possible. Once you tell strangers at school, they are usually sympathetic.

I visit the Tourette's Center at the Cincinnati Children's Hospital for check-ups, but the coolest TS doctor I have is Dr. Doug. He is a soccer dad on my HS soccer team, so I get to see him all the time. I wish everybody could be as understanding as his family!



Jacob (11 years old)
Goldsboro, North Carolina

I Will Live With Tourette's

My TS started when I was two. It has given me a lot of problems. The first problem is that I have tics. I have all kinds of tics. One of my tics is what I call my neck tic. When I was younger I blinked a lot and my arm would jerk. This still happens sometimes. I also have what my family call, "my little bunny nose." I have had different kinds of tics, but they don't come all the time.



Having TS is not the worst thing in the world, but sometimes it feels like it. But it has never stopped me from doing anything, like playing ball, soccer, riding my bike and doing my very best in school. A lot of people don't even know I have it, and we don't try to keep it a secret. I have a loving and understanding family, teachers and a very good doctor who help me through whatever comes up. So, if you have TS, do not feel like you are different, as my family says, you're just very special. Don't ever give up.



Alyssa (16 years old)
Elk Grove Village, Illinois

During my sophomore year of high school I was given the task of completing a semester long research project as part of a two-year "gifted" program. Most of my peers developed their research projects based on what they love – their passions. I chose to work with a subject – a passion – that I detested with

every particle in my 16-year-old body. It was something that had taken up countless hours and days of my life as a child, shaped who I was, and taught me how ignorant people can be – even people I am close to. It was Tourette Syndrome.

As a child, I was clueless about TS. I didn't know why we drove all the way downtown to have me placed alone in a room with electrodes attached to my head for what seemed like forever. This was, I learned later, part of the process of being diagnosed with TS. Since TS is a neurological disorder, doctors sometimes perform brain scans on TS patients. As a 4-year-old, I didn't know why my parents looked at each other with frantic eyes when I threw my head back time after time (to the point of risking permanent damage to my neck, I was later told.) The doctors told me I had Tourette's, it was fine, and I went on with life. The only point in my childhood that I remember when anyone was cruel to me about my TS symptoms was in kindergarten. I was waiting in line at the door when I was faced with the toughest looking 6-year-old I'd ever encountered. He had been standing in front of me, when suddenly he reeled around and shouted, "Stop making that noise!" Apparently, I had been making a loud grunting/throat clearing sound, a behavior that I had been completely oblivious to at the time. Like most kids with TS, I had absolutely no idea how to deal with this scenario.

Another instance that formed the real-life basis for my high school TS project was during junior high in 7th period health class. My teacher happened to mention Tourette Syndrome in passing, and a few people snickered. I immediately began tearing up, and I vividly remember the utter horror at seeing my classmates react this way to a condition that while at times was unnoticeable, could also ruin lives. I became very sensitive to the fact that I had been diagnosed when I was age four. Instead of bragging about TS as I used to, believing it was something special and unique about me, I went on automatic shutdown. I refused to speak about my TS, and if someone mentioned it, I would tear up again. It was the first time in my life I thought of Tourette's as something to be ashamed of.

Things became worse when I entered high school, especially as I became aware of teenagers who had the more serious form of the disorder. Those teens with

noticeable tics became what my peers believed was the norm for Tourette's, and TS seemed even more looked down upon by other teens. As freshman year progressed and I found my overall opinions and beliefs changing, I found my attitude toward Tourette's changing as well, but not for the better. I would stay in a maddened rage for hours after someone made an unsolicited comment about it. In fact, I nearly left my long-term boyfriend after he had been describing some kid's ridiculous antics by stating, "He looked like he had Tourette...uh, a crazy disease." What infuriated me even more was the fact that he replaced the word "Tourette's" with "crazy." I was not crazy.

However, my sophomore year research project was the turning point in my life with Tourette's. I decided to write a children's book about TS. As I spent my days researching, analyzing and writing about TS, I became more in tune with my condition. I noticed that if I heard a remark made about TS, I would now stand up and defend people with TS and not become angry or hurt. I also was able to put parts of my life down onto paper as my research project evolved into a fictional book about a young girl with TS, entitled "Emmy." Writing my book was a way to get out a lot that I had been holding in for most of my life, and it was a sort of release for me.

Plenty of people were unaware that I had TS, and by sharing my story with my classmates and other individuals in the community with this project, I felt like I was no longer hiding some horrible secret. In fact, I was proud. I was proud of how TS had shaped my character and taught me to be a stronger person. I was no longer a shy, meek girl when it came to discussing a disorder that I had no control over. As a result of my experience writing a book about TS, now when I am confronted about my condition can I say, "TS? Oh, it's no big deal," and mean it.



John (9 years old)
Carmichael, California

Hi, My name is John and I am 9 years old. I was diagnosed with TS when I was 8 years old. I have vocal tics and some motor tics. I make a lot of noises and sometimes I have a hard time concentrating at school. I tell my classmates that it is allergies because I feel like they will make



fun of me. My mom tells me that it's okay to tell people about my TS. My favorite subject in school is math. I play soccer at school and I belong to a baseball league. At home my favorite thing to do is play video games. I love to go camping and hang out with my family. I hope someday that they come up with a cure for TS.



Ben (14 years old)
Morristown, New Jersey

Hi, my name is Ben and, like everybody else who writes in this newsletter, I have TS. I play the bass guitar and I run for the track team. I am the fastest 400-meter (quarter-mile) runner on the whole team. I also have ADHD and PDD.

I was diagnosed when I was in fourth grade and I remember being really excited going into school and showing off to all my friends that I had Tourette's. My parents were a little bit unsure of how to react to me having TS, but I seemed to deal with it just fine at first. I had my downfalls throughout the years up to seventh grade because I was on lots of medication that helped a little, but they needed to be increased almost every six months and it got quite annoying. I saw a neurologist now and then to check up on me and see how I was doing. I wasn't doing so well with my behavior in fifth and sixth grades but I wasn't being bad, I was just really hyper and I couldn't help it. Sometimes I thought that TS would make my life completely suck, but I have good friends who stick up for me and don't care that I have TS.

The summer going into seventh grade, my mom got a reference from a friend to see a special doctor called a chiropractic neurologist. I've been going to him for almost two years now and it's amazing what he has done for me. There are only about 1,000 doctors in the world who do the same types of things as he does, because this "practice" is very new. When I first went to my doctor and he said that he could get rid of my TS, I gave him a hard time because I didn't believe him. This therapy nows works for me, but it's not long term and it won't completely get rid of my Tourette's forever. [Editor: This treatment is not for everyone.]

My doctor is a cool guy and he gives me these special exercises that help my TS. I have to follow through and do these exercises every day because I see my doctor once a week. This may seem like a lot, but I usually end up getting out of school, which is a plus. Now as you guys read my article, you may think I'm the biggest liar on the face of the earth and I don't really blame you. In this situation it's more of a seeing is believing thing than trusting my word. Well, what I've learned about having TS is that everything is really not as bad as it seems because it helps me to learn to deal with other things better.

Well, I hope everyone else reading this can try to find out more about the kind of doctor I go to and for those of you who have bad lives with TS, just learn to ignore it. My friends like me for who I am. They honestly couldn't care less about my Tourette's and trust me, it takes a bit to realize that, but people really don't care!

I wish all of you people with TS the best of luck and that's my story with TS.

Deja (10 years old)
Northshore, Massachusetts



Hi! My name is Deja and I'm 10 years old. I have one sister (Monique) and one brother (Timmy). I have two cats (Otis and Lily) and two dogs, Bella (a mini dachshund) and Siren (a Rottweiler from Yugoslavia). I live with my parents, Rene and Tim. I have the best family ever and they are very supportive.

I was diagnosed with Tourette Syndrome in 2004. It all started with a sound of a little cough, but it wasn't. Then I began to squint my right eye. I make a lot of sounds as well. I make a sound that sounds like I'm clearing my nasal passage. This is a very loud and annoying tic and it sometimes hurts me. This is the big mama jama of my tics. I crack my knuckles now, too.



I know my tics bother people, but my family makes sure that I don't let it bother me, but deep down inside it really does. I know it often hurts my family when people make rude comments about me. I can see my parents get really sad. But I let them know it doesn't bother me even though it really does.

My mom, at the beginning of the school year, had a meeting with my teachers to let them know about me. My teacher makes sure my school days go by smoothly for me. If I begin to tic a lot she will let me excuse myself until I can get myself together again.

I have the best doctor in the world, Dr. Oppenheimer. He lets me know that it's OK to tic and that not everyone is the same, because the world would be so boring.

My mom has a Tourette Syndrome Awareness page for me on MySpace. Please feel free to read more about me on this page: www.myspace.com/ihavetourettessyndrome.

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



Allison (17 years old)
Woodstock, Georgia

Overcome

It was in my fourth grade class when it was noticed by someone other than my parents. My teacher asked curiously, "Are you cold?" I answered back in a scared state, "Umm, no, why?" She replied, "Then why are you shaking your head?" I did not

know what to say as I felt the whole class staring at my beet red face. Mrs. Houston realized she had completely embarrassed me and quickly changed the subject to draw the attention to something else. As I walked back to my desk from hers, I couldn't help but wonder, had others noticed my tics also?

That was the time my parents decided to take me to a psychiatrist because the regular M.D. could not help. I remember walking into the cold room with my family behind me, feeling as if I was being pushed into a crowd of lions. My family sat on the leather couch, and I "got" to sit in the chair closest to the doctor's desk. He asked me a series of random questions, and I gained this worried feeling in my stomach not knowing what the outcome of our visit would be. I sucked on the yellow butterscotch candy as I left the room with my sister while my parents stayed behind. I later came to find out via my parents that I had been diagnosed with Tourette Syndrome. The only good thing that came out of that day was knowing I didn't have the vocal component, only the motor tics of Tourette's.

They put me on medicine for the tics and my worrying. It seemed to help a bit, but the tics would never be completely suppressed. The quick movement of my head or the shrug of the shoulder could only be controlled by me they told me. Of course, Tourette's usually gets better as you get older, but at that time I felt that it never would. After a full day of tensing my neck, it felt like two people were pushing on either side of my head with an extreme force. The bones on my thumb would ache continuously from the sharp movements I had the urge to do and could not stop. It isn't like you can't stop the tics if you really try, but trying to stop drains your body energy and you simply want to do certain movements. Keeping a positive outlook was hard, but my parents were always there for me. I tried to see the light shining through on the other side every time I woke up.

Children and even adults would stare and wonder and I had to act like nothing was different about me than any other person. There were hurtful encounters all through my childhood, but the one that stays with me the most was one that took place my freshman year of high school. It was a normal day of lunch, laughing and eating with my closest friends, but I could feel the stare of one boy at the end of the table. I heard my name called by this boy knowing that something bad was going to come out of it so I started to get jittery. He said to me, "Just look at me for

a minute." Looking at him and trying to hold back from moving my nose upward or downward or any movement at all was a stress no one should have to endure. Looking back at his buddies he said, "Look, she did it, haha!" Laughter arose and I felt like the whole world was watching my every move. At this point, I was in shock that anyone could be so cruel, but I grabbed my things and left. As I left, I could faintly hear my friends yelling at the boys at the end of the table but that truly did not help. Tears came down my face as I sat on the toilet seat dialing my mom's number. My tears formed into anger and I finally realized I should not let this stupid boy undermine me or hurt me in any way. I remember thinking that I had so much more going for me than him. My Tourette's and these situations would make me stronger. I heard her voicemail and put the phone away realizing I could handle this myself.

From that point on, I learned not to care what others thought of my problem. If people are going to judge me by movements that are practically uncontrollable, then they are low themselves and I didn't need them as friends. Tim Howard, a professional soccer player who formerly played for the famous Manchester United, helped me through this. Tim also has Tourette's and went public with it to try and help kids like me. Being a soccer player myself, I thought it was awesome to have someone with Tourette's to look up to not only as an inspiration to get through my syndrome but for his soccer skills, also. Reading his articles just gave me hope, and he spoke about how he suppressed his tics and I tried his methods. As I got older, my tics did get better and I learned how to make them as least obvious as possible.

The last pill I swallowed for Tourette's was about a year ago. I made the decision to go off of the medicine and fight this by myself. Teaching myself to not do the tics so often was extremely hard and still is not completed. I will have to deal with having tics for the rest of my life, but not nearly as bad as when I was younger. Looking back, it's quite comical remembering that I used to kick my leg out while casually walking or shrug my shoulder while sitting in class. I can imagine what people thought and can't blame them for being a bit scared. When I show people how I used to walk, it never fails to get a laugh. All in all, I am truly glad I have Tourette's because it has made me so much stronger and taught me to be myself without worrying if I would be accepted by others. I believe overcoming this battle and continuing to fight has been my greatest accomplishment.

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)



Amanda (16 years old)
Southaven, Mississippi

Hi! My name is Amanda. You might remember me from the TSA-HBO documentary, "I Have Tourette's but Tourette's Doesn't Have Me." This year I am in Accelerated English and am a sophomore in high school with a B average. Today I got my driver's license! (On my first try!) I am a cheerleader on the varsity ballgame squad. I enjoy going to youth choir, youth group and cheering. Oh, and I

am crazy about my one-year-old niece!

In the summer of 2008, my youth choir will be touring the New England states and stopping in New York for at least one night to see a Broadway play. The tour starts June 6 and will go on through the next weekend.

Here is my poem called, "My Disorder" which I wrote in my freshman year for my Honors English class.

My Disorder

I hate my disorder
Yet I still live with it
I hate the medicine
Yet I still have to take it
I hate the rough times
Yet I'm still strong



Chase (14 years old)
Richardson, Texas

Hi, my name is Chase and I'm 14 years old. I've had TS for a long time. I don't recall the exact date I was diagnosed, I just remember having my one tic: constantly stretching my mouth which, in most cases, is very hurtful. This caused my lips to be constantly chapped. I do believe that last year in the seventh grade I had developed the nickname chap-stick boy. Many tics come and go, but this one has always stayed with me. I cannot control it, and I can never have something tight around my chin restraining me from this awful tic.

One thing I do find amusing is the fact that people are always thinking I am tired because the tic looks like a yawn.

Other tics I have are spitting, cracking my neck, toes, knuckles, blinking multiple times, mashing my eyelids shut and an elbow popping motion that doesn't really pop my elbow because I've already popped it. I have tons more inconsistent ones, but those are the main ones.

What people who don't have TS seem to not understand is that it is impossible to control my tics.

People take it lightly, as a joke, and will start doing things like shrugging their eyebrows, knowing that if I see them do it I will start doing it and I won't be able to stop.

I'm not on any medications for my TS right now because they don't seem to help me; they just make me eat more.



Marques (11 years old)
Flushing, New York

A Day In The Life

I will never forget it as long as I live
The day I threw out the first pitch for the Mets
I had, A Day In The Life.

The nervousness running through my body,
as I raced to the mound with the team ahead of me
I knew at that very moment I was having,

A Day In The Life.

The frustration of the tic
The motor tic increasing

I threw the ball

I threw a strike!

Yes! A Day In The Life.

Nothing can stop me now
Nothing can stop you, too

We may have tics in our lives,
but we all have that moment,
you know, A Day In The Life.

Dedicated to all those with Tourette Syndrome who have had or will have, A Day In The Life.



Marques throwing out the first pitch at a New York Mets game on September 25, 2007



Emmet (11 years old)
Dundalk, Ireland

Hi, I'm Emmet and I have Tourette Syndrome. I live in Dundalk, a town in Ireland. My tics are stammering, shouting, jerking my head and a few more.

I like sports and my favorite sports are soccer and swimming. I love reading and some of my favorite writers are Kenneth Opel and Robert Muchamore.

My teachers are very understanding about my tics and I even get to come out of class if my tics are bad. I have a little room of my own where I can go when I need a break.

Sometimes people stare, but I've gotten used to it. There used to be a boy in my school who always called me a freak, but he does not call me that anymore.

My sister is helpful, but we fight a lot! I take medication, but the pills make me tired. I used to be depressed and stressed a lot, too, but I try not to let it get me down. My tics are just one part of me!

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 March 1, 2008.

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

TSA

That Darn Tic

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



tourette syndrome association, inc.

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Make new friends and have fun-filled days at the National TSA Conference from April 4-6, 2008 in Alexandria, Virginia!

While your parents are attending workshops and seminars, you can spend the day with other kids just like you and attend a non-TSA off-site youth camp program for ages 7 to 14 on Friday and Saturday through the Tourette Syndrome Camp Organization. Scholarships covering part of the camp expenses are available. There will also be tracks for teens with TS and their siblings ages 14 to 18.

For more information on the National TSA Conference, visit www.tsa-usa.org.