



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Benjamin (9 years old)
Vineland, New Jersey

Hi! My name is Ben and I am 9 years old. I have a lot of annoying tics. TS is not a bad thing and thousands of people have it. I get very angry and then feel bad and don't like myself. My mom prayed for understanding and got an article in the mail about rage. We found out my fits of anger are part of TS and that I am not a bad

person. It makes me feel very relieved and good. My mom thought it was time to tell my classmates about my TS, but I am not ready yet. I try not to tic until I get home. She said it was up to me to tell them now or not. We are going to wait until I am ready. I get good grades but hate doing homework. I like my dog, riding my dirt bike, fixing old bicycles, baseball, basketball and walking.



Jarod (9 years old)
Warsaw, Indiana

I was diagnosed with TS when I was small. I shake my head a lot and kick because of it. I hum sometimes, too, and blinking is often hard for me. Some of my classmates make me feel good by not teasing me. But some other classmates make me feel bad by making fun and teasing me. I am lucky, though, because my tics do not hurt me.



I like to play video games like Lego Star Wars, Big Red One and SpongeBob SquarePants. They help me to stop ticing. I am good at climbing and like to swing. Sometimes when I swing too high I get scared and my TS makes me feel like I will be electrocuted. School is

fun for me. I like doing homework and participating in fun events. My favorite subject is Science. At home, I have two pets. Jack, my German Shepherd and Baby, my bunny, are lots of fun to play with.



Khristopher (9 years old)
Virginia Beach, Virginia

Hi! My name is Khristopher. I wanted to write an article about me and TS. You know how sometimes people say that people with Tourette's don't have a successful life? When they say that I want to tell them to look at me. I am an athletic person. I play football, baseball and basketball for my City. The



guy beside me in the picture is my mentor, Steve. He is a pilot and very successful. He also has TS.

In the beginning when I was first diagnosed, everyone was joking me and calling me names. I thought no one would understand. After I got diagnosed I was scared to tell my friends and classmates I had TS. Then my mom talked to my class about TS. That made it a little better. My mom has done a lot for me to try and help me through this. After that, Steve talked to my whole school about TS and it has made it a lot easier for me at school. Now when people ask me why I am making those noises I don't say it is just my allergies or lie. I tell them the truth; I have Tourette's and that makes me feel better. Since Steve has come and talked to my school it is easier for me to work in school and I am not embarrassed or scared anymore. I want to thank Steve for everything he has done for me and my family. I want to dedicate this article to Steve, my mom and my dad. Thank you Steve, Mom and Dad!



Dylan (10 years old)
Olathe, Kansas

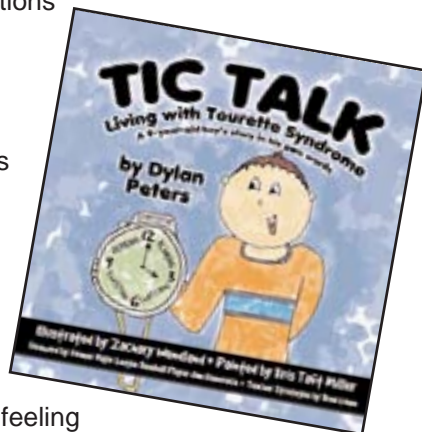
Hi! My name is Dylan and I have had Tourette Syndrome since I was 4 years old. I was worried about how my friends would react when they found out I had TS, so I asked my family to keep it a secret from everyone but our closest family members. I was able to keep it a secret until the summer before third grade when people started asking me why I was blinking my eyes so much or

opening my mouth so wide all the time. I decided that it was time to tell my friends about my TS. I was terrified because no one else in my school had TS. I did finally tell my class, the entire third grade, and eventually my entire school about my Tourette Syndrome. Everyone was extremely understanding and compassionate.

Several months later, my third grade teacher told me I should write a book about my experience keeping TS a secret and then sharing my secret with others. I thought about it for a little while and then decided that it would be great to help others with TS know that they are not alone and to challenge kids to be accepting and tolerant of anyone with a challenge.

I wrote *Tic Talk – Living with Tourette Syndrome – A 9 Year-Old Boy's Story in His Own Words*. The book was released in January 2007. I have also been touring my state to give presentations

to schools, events, organizations, etc., to spread my message. I have been e-mailed, called, received letters and talked with after my presentations by kids, parents and teachers. They have told me their story of living with TS or other challenges, keeping it a secret or feeling alone. Many kids have just said, "Thank you for having the courage to tell people you are different." Maybe they will accept others now.



My mission is to "Create Awareness and Tolerance One Tic at a Time." You can visit my website if you want more information about my book at www.tictalkbook.com or www.tourettesyndromebook.com. The most important lesson I have learned through writing and publishing my book and speaking about having Tourette Syndrome is that people really do care and that I can make a difference by helping others to understand TS.

Jamie-Grace (15 years old)
Atlanta, Georgia



Alone.
Secluded.
Separated.
Distant.

That's how I felt when I was diagnosed with Tourette Syndrome.

Shh. It's a secret. Don't tell anyone!

Hold it back.

That's how I reacted.

I was 11 years old when I found out I had a disorder that would change my life negatively, but more so, positively. Through the medicines and hospital visits I have found a way to hold my head up and not let my TS get me down.

How?

Well, after years of holding tics back and keeping my Tourette Syndrome a secret, I realized that I was making it harder for myself. I was the one making myself feel alone. Was I ever going to feel "normal" if I acted like my life was over? No, I had to speak up and speak out.

In the summer of 2006 I made a friend named Sarah. We had things in common, but the most obvious was TS. It was pretty cool meeting someone "like me," someone who I could share my TS experiences with and, in return hear someone else's. We were able to encourage each other and relate to each other's stories.

I soon realized how fortunate I was to have met someone with TS, but couldn't stop wondering what it was like for the other teens who knew no one else with TS. I couldn't wonder what it was like, because I already knew, and so I figured it was my duty to help them.

I started a website called "teensWts" a Tourette Syndrome support and awareness site targeted to teens, though open to anyone. I never imagined that the videos I uploaded to a website called YouTube would consume over 40,000 hits, or the petition I have to stop the negative portrayal of TS in our media would have over 400 signatures, or that the positive response from parents of kids with TS would be weekly. I never thought that a website I started for my own comfort would reach so many people and become sort of like a community for teens who have TS.

I encourage kids and teens with any type of struggle to speak out about it, and not try to be someone they're not. Don't think you are different or abnormal; there is no standard for normal. Just be yourself. Unfortunately I learned the hard way, but I still learned. Now I am no longer alone, secluded, separated or distant; but an advocate for Tourette Syndrome awareness, and an encourager to those who need it.



Jake (15 years old)
Mokena, Illinois

Late in elementary school, my parents started saying that they noticed I had been twitching and making some noises over the last couple of years. I was never bothered by it. My dad would tell me that he thought I had Tourette's. I thought nothing of it, but it just annoyed me when he said stuff like that because I thought he was kidding. None of my friends ever said anything. Nobody ever made fun of me, so why should I care?

My parents told me that we were going to see a doctor and find out what was causing me to do these things, even though I could tell they knew what it was. I refused to go to the doctor. I didn't want to go, I didn't need to go, and I didn't want to know. But, I was forced to go see a neurologist who my parents found out about through the TSA. It was a long 45-minute drive to this place, which did not cheer me up! Why was I taking this long drive to be told something I did not want to know? We walked in the office and my parents were telling the doctor why they brought me there. It took only a few minutes after we walked in the door for the doctor to tell me that I had Tourette Syndrome. When he told me this, I was not happy. It completely changed my thoughts of myself. My mother was trying to show me famous sports stars who have TS, knowing that was the only thing that might cheer me up. But, I could not stand the fact that something so serious could be wrong with me. Then, once everyone started noticing and asking me about it, I could not have been more embarrassed and self conscious with myself.

I am now in high school and play on the freshman basketball team. Today I realize how lucky I am that I don't have a serious mental or physical disability. I am much more comfortable talking about my TS and even find myself making fun of the tics that I have when I am with my friends. Tourette's is not the worst thing on earth. It is only a minor setback for me in achieving my goals.

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

Tara (12 years old)
Beverly Hills, California



I first was diagnosed with TS when I was 7 years old. I was petrified because I didn't know what it was. Then, my mom told me it was a hereditary disorder that is not curable and that it's what makes me move uncontrollably and sometimes make loud and repetitive noises. It was upsetting to me at first because everyone would stare at me like I was crazy or that I said something wrong.

I want to be a model or an actress when I grow up. I have two amazing parents, but I don't treat them how I would like to because I am so frustrated about my tics. I also have an amazing brother named Austin. He's been the most loving and understanding brother. He sticks up for me at school when someone laughs at me or talks bad about me. That is why I love him so much. I also have a cousin, Jordyn. She's practically my sister. She's always there to help me calm down either by distracting me from my tics or by just being the amazing person she is. My best friend, Megan, helps, too. She deals with my anger and my tics the way she should. When I've had a stressful and bad day, she's always there to cheer me up and to calm me down. If it wasn't for her I wouldn't be who I am today.

Living with TS is a challenge but sooner or later I need to accept that it's not going away and that TS is a part of me. If I didn't have it I wouldn't be the strong girl I am today. My tics are at a high peak right now but I don't let it slow me down. I thank the TSA for helping me not feel alone by sending me newsletters of people who experience what I have to deal with everyday.

I am still acting and modeling. Even though people may think it's hard to act on stage with TS, it's never been a problem for me. I've been acting since I was 4 years old. It's my passion and dream and nothing is going to change that.



Jacob (10 years old)
Haddonfield, New Jersey

Arrow Necklace

Inside an arrow necklace, a forest.
Inside a forest, a blooming tree.
Inside a blooming tree, a beacon of hope.
Inside a beacon of hope, nature's survival.
Inside nature's survival, a power within, usually.
Inside a power within, usually a new life.
Inside a new life, a twinkling star.
Inside a twinkling star, an arrow necklace.



Harrison (10 years old)
Lincolnshire, England

I wanted to let you know how much "That Darn Tic" has inspired me. I have saved them on my computer and read them regularly when I need some support.

I was diagnosed with Tourette Syndrome in January of this year. We went to see a really nice neurologist who examined me and

told my mum and dad that I had Tourette's.

I felt a little bit sad but then a little bit happy because now I know that it wasn't just me and that I cannot help it when I have lots of jerky, noisy moments.

Speaking to the neurologist really helped my mum and dad because they were very worried about me.

Today, my mum phoned my school to ask if my teacher could speak to my class about my tics. After that I felt much better and my class was very nice to me. Most of my classmates are very nice anyway and helpful. I am really looking forward to reading the next newsletter.



David (14 years old)
Jersey City, New Jersey

My name is David and I was diagnosed with TS when I was 4 years old. I also have OCD and ADHD.

I love reading these stories because it makes me realize that I'm not the only one out there with TS. I used to feel alone, but now I feel free to share my life. Sure, tics get a hold

of me and it's not easy to control. I've unfortunately found out the hard way by making loud noises, touching objects, twitching and even spitting. But if you look deep inside yourself and find whatever is stressful to you at the moment, you can free yourself from it and from your TS.

Kids at my school understand me and they don't care what I have. They are just like me. So to everyone out there with TS, don't keep yourself hidden from the outside world. If people make fun of you, just ignore them. Find true friends and don't let your tics control you, you can control them!



Logan (10 years old).
San Antonio, Texas

Hi! I have Tourette Syndrome. I do not like it, but I have to deal with it. TS is when you have something called a tic. It is not like the tick that's on an animal. It is an involuntary movement that is caused by a neurological problem that is in my brain.

In a day of life it is fun but hard at the same time, because when I play, I shake my head and a lot of other stuff. Sometimes people have a tic where they say curse words. I hated it when I had that tic, because you should never say curse words; they are bad. There is another kind of tic that is called OCD. OCD makes you wash your hands a lot. I do wash my hands a few times. Or like me, I'm obsessed with lots of things. I like my bed and stuffed animals a certain way. I hate the dark and going to sleep at nighttime. Also, this may seem gross to you, but some people have a tic where they lick walls, bricks, fences and rocks. I do not have that, but I do have a tic where I pinch people. I feel bad because my little brother has bruises when I pinch him too hard, but I just have to do it.

TS is not contagious, so I wish people would not think if they play with me they can get it. I'm normal just like other kids. I was in a play in the Missoula children's theater. It was hard backstage because I was ticcing away, and it was so embarrassing and hard to remember my lines. I love to play the piano and write songs. My mom loves my music and says one day I will be a star. I think she will be a great fan. I am also learning to play the violin.

Every once in a while we go to a TSA meeting. The parents go in a room and listen to someone talk about TS, and the kids get to go in a room and play games and other fun stuff. Then I go home and go to bed.

My worst times are in school because people make fun of me and make me cry. People call me "Login," and I really do not like it. I wish people could understand about Tourette Syndrome.



Jordan (12 years old)
Galva, Illinois



My tics really bother me. My favorite thing to do is skateboard. My best trick is an "impossible." It seems that when I'm skating, I just relax and don't even notice my tics. Some of my friends used to ask me why I am doing these tics, so I decided to go in front of my class and talk about my TS.

I recommend people do the same because my friends understood. I would love to hear from other skaters!

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,

<http://tsa-usa.org> under Publications.



Keith (10 years old)
Chadwicks, New York

I have had TS and OCD since I was 4 years old, but I was diagnosed at the age of 9. My tics are stretching my mouth and making grunting noises. I bowl on a league on Saturday mornings, which ended last month. I am going to be on a league that's a one-on-one with someone who has

an average of over 200. My current average is a 98. I started this year with a 65. I got "most improved" in my league. Although it is my third year bowling, I have made it to the New York State Finals in Staten Island. I came in 7th out of 12 in my division. My uncle from Rhode Island came up and surprised me.

I am in fifth grade. My favorite subjects are math and science. In math we are working on algebraic patterns. In science we are working on chemical relationships. I am also in a band and I play the trumpet. We had our spring concert and went to Darien Lake for a band competition in May. I did a duet in the solo fest. I am a scout in Boy Scouts and I went to Camp Sitrin in May.



Cameron (14 years old)
Suffield, Connecticut

Worry for a Brother

I can't help but stand back and worry
about the things you say, see, want, and feel.

I want to cure you in a hurry
but I see you repeat like an old movie theater reel.

At night you'd be poised like a viper.
We notice you stop crying, we check and you're sleeping.

And our love for you is a panda
taking care of its week-old cub.

When you panic, you act like a rat cornered by a cat
and it pains me to see you like that.

But usually you look alright
because it happens before the blanket of night.

I can't help but stand back and worry
about the things you say, see, want, and feel.

I want to cure you in a big hurry
But I see you repeat like an old movie reel.



Me (on the left) with my brother Patrick

Jordan (8 years old)
Mayerthorpe, Alberta Canada

My name is Jordan and I have TS and ADHD. Sometimes it is hard to sit still in school.

I have one really good friend named Selena. I told her that I have TS, but she doesn't really understand. Writing is hard for me and I get frustrated easy. In school I have many vocal tics like barking. At home I shake my head a lot, and I have always had a blinking tic.

I have a baby brother and I hope he doesn't get TS. I was sad when my Mom told me I had TS. Sometimes at home I get yelled at because my ADHD makes me forgetful and my Mom has to remind me to do everything, especially brush my teeth.



Zachary (11 years old)
Newfoundland, Pennsylvania



I was diagnosed with TS when I was 8 years old. I also have ADHD and Oppositional Defiant Disorder. This is a picture of me and my sister, Ally. She is really understanding and always tries to explain to her friends about my disorder. Sometimes my tics get

on her nerves, but she never teases me about them. Sometimes we laugh just to make it easier on me.

School is hard for me but most of my friends know that I have TS and they don't tease me because of it. I showed "I Have Tourette's but Tourette's Doesn't Have Me" to the whole school and it seemed to help them understand. My doctors try as hard as they can to help me but they have a hard time because of my other disorders.

My first tics were small ones like eye blinking and grunting sounds, but now they are getting worse. Now I make funny faces, have arm and leg jerks, scream and even say bad words. I get embarrassed from them, but my mom says not to let them bother me and that I was chosen by God to be special. Sometimes I go into rage attacks and can't control my anger, but my mom is really good about helping me calm down. She tells me to do something I enjoy to help me settle down. I love to ride my dirt bike and 4-wheeler and I spend a lot of time with my dog, Izzy. I also like to swim and go to the park with my sister.

My mom is the best person in the world because she is always there when I need her. She gets me all the help she can and she tries her best to help me through my rough days.

I hope that someday a special doctor will come up with a medicine to cure TS so no one else will have to go through what I do each day.





Denver (9 years old)
Jeannette, Pennsylvania

Hi, my name is Denver. I will be 10 years old soon and on my way to fifth grade. I have Tourette Syndrome, ADHD and OCD. I was diagnosed when I was 7 years old. If it were not for a friend of the family, I may not have known for a long time. I have found that a great support system with friends and family has helped in learning to accept my TS. I want to thank my whole family, the Theys' family, Jay Geyer, Mrs. Geyer, LA LA, Mike Weir and

Nate Long. My friends at school have been awesome. The past two years my teachers and I have talked to the class about my TS. They have been very understanding, and very good to me. It has made school easier with the kids knowing why I do the things I do. I am a gifted student. I only mention that because there is no limit to what I can do, unless I stop trying. I do get frustrated with the medicines and the side effects from them. I wish there was something better for all of us. The picture is of me (#23) and my brother Cody from football season last year.

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 September 1, 2007.

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!



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Summer's Here!