



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

tourette syndrome association, inc.
42-40 bell boulevard
bayside, new york 11361
(718) 224-2999 ♦ fax: (718) 279-9596
e-mail: ts@tsa-usa.org ♦ website: <http://tsa-usa.org>

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Sydney (9 years old)
Seymour, Indiana

My name is Sydney and I am 9 years old and I just entered the 4th grade at Immanuel Lutheran School in my hometown of Seymour, Indiana (home of Miss America, Katie Stam). I have a big family with five sisters and a baby brother.

I enjoy playing softball and I am in gymnastics. I love cheerleading, also.

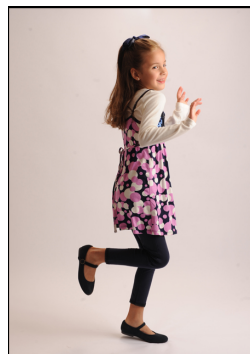
I was recently diagnosed with having Tourette Syndrome. I have about 12 different kinds of tics, but I do not let my tics bother me anymore. I have adjusted to my tics. I was worried starting the 4th grade with having these tics, but my family and I have gotten more educated on having Tourette's. I like going to the kid websites and reading other kids' stories like mine. My teacher wants me and my mom to teach my whole class about Tourette's and I am looking forward to sharing my story with my class and my friends. My doctor at Riley Hospital has told me how I should answer when I have kids ask me why I shake my head all the time, and now I am confident in telling the world that I have Tourette's, and yes, I am normal like you.



Hannah (7 1/2 years old)
Houston, Texas

My name is Hannah and I have been diagnosed with Tourette Syndrome.

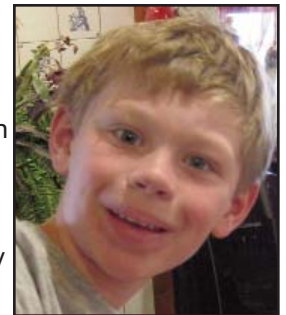
I like to dance. I put my heart into it. Sometimes my tics make me do things I don't like to do. When I dance, I get to move the way I like to move.



Max (9 years old)
Allentown, Pennsylvania

My name is Max, and I am 9 years old. I am going to 4th grade. I live in Pennsylvania and I have TS. I was diagnosed with TS when I was 7 years old. I also have ADHD. My brother, Ben, is 7 and my sister, Lily is 6. I have a very playful dog named Maddy.

My tics make me talk out of one side of my mouth, pick my scabs, make my leg turn in circles, want to make my eyes blurry (I do not wear glasses) and make it harder to breath sometimes. My best friends are Caden, Warren and Justin. I love origami, swimming and doing art. I like meeting people who treat me as an ordinary person and making friends.



Patrick (11 years old)

Hi! My name is Patrick and I am 11 years old. I was diagnosed with TS when I was 9. I don't let TS stop me from doing things that I like, but my tics do get in my way sometimes.

I like to play lacrosse and basketball and I ski every other weekend in the winter.



My tics are eye blinking, skipping, humming at night, and sometimes I have to look around a certain way.

I like playing video games. My favorite games are Rock Band and Madden 09. I have lots of friends and they are all very understanding of my tics. All of my teachers are too, which helps a lot!

I went to Washington, D.C. to meet with my Congressman. I told him about having TS.

I look forward to becoming a TSA Youth Ambassador when I am old enough.



Jake (12 years old)
Gaithersburg, Maryland

TS + Tennis = Success

When I was 7 years old, I was diagnosed with Tourette Syndrome and began playing tennis around the same age. This has offered many challenges in my life and I have learned to deal with them.

The main problem with TS having started simultaneously with tennis, is that it gets in the way of my serve. The serve is when eyes are all cast on me. My opponents tend to rush me when I have tics during my serve and this adds stress and pressure to my game which then takes longer until I can actually serve. Once the ball is in play, my tics are reduced because I'm focused on the game and trying to win the point.

On the positive, TS has given me a "tourettic nervous system" (a term from my doctor) which gives me tons of energy. The effect of the "tourettic nervous system" is that I can really run around the court fast, I chase after every ball, and I have a passion and commitment to become a professional tennis player.

I play tennis today with Tourette Syndrome and have learned to deal with the disorder and play successfully. I now play in Mid-Atlantic L5 tournaments, play on Quince Orchard junior team, continue private lessons with Doctor Tim and group lessons at Georgetown Prep.

Sometimes losses are hard to take because tics can get in the way but the wins feel great!



Jim (9 years old)
Cambridge, Massachusetts

Hi! I'm Jim. I have had TS since I was 7 years old. Sometimes I feel like something stole my body, but not my mind. I can still tell myself to stop doing a tic, but my body won't listen. But I kind of like my tics because they keep me from being bored. Whenever I'm bored, that's when I have my tics. I barely ever have them when I'm in the middle of a big exciting game. If I'm waiting for something to happen, that's when I have more tics.

Some of my tics are facial expressions, nose twitching, clicking sounds and clenching my hands and feet. Also, when I'm thinking about tics, like right now, I get a lot of them. But it doesn't stop me from doing anything and it doesn't really make anything harder for me - unless someone throws a ball to me and I do a really quick tic,



like clenching my hands, before I catch it. I get a lot of tics in big transitions. Every time I have a big transition, I get a new tic.

I do all kinds of sports like baseball, soccer, gymnastics and ice hockey. I like every sport I've tried so far. I like doing active stuff. In school I do not like writing or reading, but I do like math and science. Those are my two favorite things at school besides recess.

Most of my friends don't notice my tics, but a few times I had some close calls. One day I was talking to my friend and I froze for about 10 seconds in the middle of my sentence, which is one of my tics. He thought I was done with my sentence so he started talking and asked, "Why did you stop talking in the middle of your sentence? Did you not want to say it?" I said, "No, it's a tic." He said, "Where are they?" I said, "Not that kind of tic." And then he just said, "Oh," and walked away. But I bet people do notice my tics a lot, but they just think it is something I do because it's fun for me or it's a habit and they don't say anything about it.

In school I make a lot of the noise tics and those are the ones my teacher gets annoyed about. And sometimes she takes me into the hallway and tells me not to make those noises because it distracts other people. But it actually doesn't. One time when she took me into the hallway and said, "I'm tired of telling you not to make those noises. Why are you making those noises?" And I said, "It's because I have tics." And she said, "What are tics?" And I said, they're something that makes you do something that you can't control. Like making those noises. Even if I try not to, my body just does them." She said, "Really?" and I said, "Yes." And she said, "Oh, I'm sorry for all of those times I took you into the hallway for making those noises. If I hear you make those noises, I won't take you into the hallway again, OK?" And I said, "OK." Then I went back into the classroom and had a couple more noise tics but I didn't get taken into the hallway. And for the rest of the year I didn't have to go into the hallway (which had been very annoying).

Tics kind of make me feel like I'm special.
The End.

You Can Become a Tourette Syndrome Youth Ambassador!

TSA's Youth Ambassador Program trains kids and teens (ages 14 and up) to talk about TS. The program gives young people with TS, their siblings, friends and classmates the preparation they need to speak about TS before their peers.

Learn more at:

<http://www.tsa-usa.org/People/kids/YouthAm.htm>



Maggie (18 years old)
Naperville, Illinois

I was diagnosed with Tourette Syndrome when I was 8 years old. I learned that a lot of good can come from TS, not only bad. I just graduated from High School and along the way to earning my diploma, my TS inspired me to do a lot in my life; writing was the biggest. This piece below, that I wrote, was inspired by my TS.

Time passes with a sense of eagerness and I hold my breath in hopes that everything will be

okay again, but I know it won't. Is it time that makes us unsteady and unstill, or is it knowing that as every second passes you lose it forever? Time is nothing but a mere illusion of the present and future within it that it holds. The fear of knowledge strikes again, knowing I am next to experience my destiny, but I am not afraid for fear is nothing more than an excuse for being weak ... so I suppose everyone in this world in which we live is weak to a point ... becoming part of something great, something inevitable, but planned for us. But just know that I do not fear the unknown, for I am not weak. One at a time people begin to crumble under the unbearable pressure in which the universe hold us under, tighter and tighter until we all remain breathless, lifeless. The problem we all share is living life to standards which are unattainable.

Life consists of mechanical errors, we were all built with flaws, and the flaws are made into lessons, which we all at some point must learn. Without knowledge we would crumble even faster into the dark of the universe. I'm shocked into reality; the arms on the clock are ticking harder and harder as every second passes, moving swiftly and pounding just as my heart does. Unsteady and unsmooth because the tension in the room leaves me short of breath, but still I am fearless, I am completely unafraid.

Zach (18 years old)
San Ramon, California

Lots of kids I know can relate to this. I hope this helps someone realize that someone cares.



We all have times
When we think
There's no way up
All that's left; to sink
You think that if
You slipped away
No one would notice
With nothing to say
If you just
Disappeared
You think that
No one would care
Through all this grief
You've got to know
Someone cares
They love you so.
You may think
No one cares for you.
But just ask them
I'm sure they do
Don't give in
Don't give up hope
There's light ahead
Just a few more strokes
Don't die if
You think you should
Someone would notice
I know I would
So if you want,
Life to just end
Don't give in
I'm your true friend.

Did You Know?

That you can read this issue, and all 32 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)



Spencer (10 years old)
Ottawa, Canada

My name is Spencer and I have Tourette Syndrome. Living with Tourette's isn't always easy but there are certain things I don't mind. For instance, when I tic (which is jumping up and down and flapping my arms), I like to imagine things like playing a soccer game or

playing hockey! And at other times, there are things I don't like about having TS. I don't want anyone knowing that I have TS because I feel like they're going to laugh at me and look at me and think, "Is he human?" I prefer to tic in private at home and at school so that no one sees me.

I have a few other conditions that come with my TS. I have Obsessive Compulsive Disorder. I don't find there is anything good about having OCD, but my mom keeps saying, "It's a gift. You should be proud of it." I listen to her, but I still don't like having OCD. I don't really like OCD because of my compulsions. Before I go to bed, I always go to the washroom. After I go, I run to my bed quickly. If the lights are on or there are sounds disturbing me, I know I'll have to go to the washroom again. I become pretty frustrated and then I have a hard time falling asleep. I almost forgot - I also have ADHD, which is when you have plenty of energy. There's nothing bad about it because I like running around, having fun, doing activities and playing. But sometimes I can be pretty distracted and the consequences are not always fun.

I also have anxiety and depression, as well as a sleeping disorder. Anxiety is when I get worried about stuff or what I eat. Sometimes I think I'll choke on certain foods. Depression is when I get so depressed that I bang my head against the wall or I feel really bad. I'm learning how not to hurt myself when I'm sad. Finally, my sleeping disorder is no fun because I really need my sleep. Even though I have all these conditions, I still love who I am.

One of the good things that has come out of my TS is my Mom's books. My mom's name is Jill Bobula and she's an author. She's a wonderful person! Because my mom has learned a lot about me and what I have, she has chosen to write books about kids who have special needs, syndromes, disabilities and disorders. She's written books on Attention Deficit Hyperactivity Disorder (ADHD), Attention Deficit Disorder (ADD), Asperger Syndrome (Autism), Tourette Syndrome (TS), Fetal Alcohol Spectrum Disorder (FASD), Obsessive Compulsive Disorder and Anxiety (OCD), Dyslexia and Depression. Her books help other children understand the conditions and know they're not alone. She's also president of the Ottawa Chapter for the Tourette Syndrome Foundation of Canada. She organizes these pool parties, activities and all sorts of fun stuff for kids with Tourette Syndrome. She writes her books

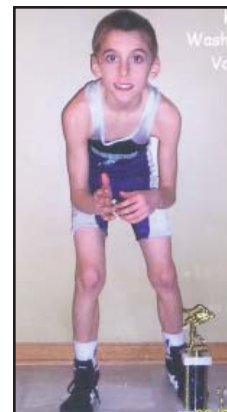
with her sister (my aunt) Kathy. They work together to bring the books to as many kids as possible. I'm proud of my Mom.

Even though I'm not always happy living with my Tourette's, I know some good has come out of it and that's really important for me.



Kyle (9 years old)
Washington, New Jersey

Hi! My name is Kyle, and I'm 9 years old and I have TS. Even though I have TS, it does not stop me from doing sports I love. I play baseball, football and my favorite is wrestling. I made the varsity wrestling team. I also worked hard and made the states and came in ninth. Even with my TS it does not hold me back.



Jason (17 years old)
Schaumburg, Illinois

Hello! My name is Jason and when I was 7 years old I was diagnosed with Tourette Syndrome. I am now 17 and have been wanting to send this in for years. Ever since I was diagnosed I have been writing poems about TS. Here is one I hope you enjoy. It really

demonstrates the true fear most people with Tourette's have when confronted with social issues. The title of this poem is "Mask."

Everyone wears a mask at some point in life. It is the people with real courage who take that mask off and show their face. This phrase has been told to confused individuals for ages, but in order to do this it takes more than courage; it takes the understanding of your peers. What if, when you take that mask off another mask is underneath it? And when that last mask finally comes off everyone is afraid. I know, I know, don't listen, but come on, it's way harder to let this in one ear and out the other. Kids are cruel; they point, they stare, they laugh and they joke. They make fun of mere imperfections. I always thought that the only way to make them stop is to make fun of yourself. But people go too far sometimes and mimic. Everyone has heard it. If you stutter, it's the whole "Hey G-G-Guys" you know the elongated stutter, or if you are dyslexic the "hurry up already" when asked to read for the class. Oh no, for me my favorite has to be the swear for no reason or the random seizure in front of me. So I plead to everyone who reads this, the next time you see someone down, pick them up!



Alexis (18 years old)
Moreno Valley, California

I was in the fall issue of 2007. I was diagnosed with Tourette Syndrome on February 5th 2007. So I am almost at 3 years! My tics consist of my head jerking to the right side, a loud "EEEE" sound, a laugh, my arms and legs kicking and head nodding. I blink, clear my throat and roll my eyes a lot also. My tics came when I was in

my sophomore year of high school.

When I first got diagnosed I was shy about telling others and I would fight to hide my tics, but I finally became really open about it. I started telling people about it and everyone I ran into thought it was cute. I eventually got the nickname "Twitchy" from my friends because of the motocrosser Jeremy "Twitch" Stenberg who has TS and now that's what everyone calls me.

These past couple years have been life changing to the fullest. I've tried meds twice and I refuse to do it again.

The first time I tried meds was October 29, 2007. I felt like I was holding up a globe and if I leaned over it would just pop off. I had knots all over my back and it was getting hard for me to move because of the pain. Once I took the meds, I knocked out almost immediately. I was weak, would cry all the time, hardly ate, never smiled or talked, and I was starting to fall behind in school. I joined the theatre (like I wrote in my last article) and the day after I started meds everyone found me asleep on the back couch. Everyone knew it wasn't my normal behavior. They let me sleep and when I woke up I was not allowed to use the power tools for my safety. I didn't mind it at all. This lasted for two months and I finally stopped taking them because I felt like a coward hiding something that was a huge part of me.

By February 2008, I was on top of the world. My tics began to get worse once again and I could hardly hold my big globe up. I ticced the longest I ever had before and it scared me. I broke down 3 times in 10 minutes. My mom had enough and scheduled me for an appointment on February 26, 2008. I put my foot down and said I wouldn't do it. Well, we got to the doctor and I had no choice. I cried so hard that day. So I started and a week later I stopped without my parents knowing. I finally told them after 2 weeks and they were upset, but understood why I stopped.

I am now on top of the world embracing my TS with everything I have because I gotta live with it, so I might as well be happy, right? It's the other half of my personality. It had it's own voice, too. I actually find my TS quite funny and entertaining. I get a good laugh every time I have an outburst. I may be on top of the world, but I have my moments just like everyone else. I just deal with it and smile; sometimes cry, but not too often.

I am currently taking 15 units in community college (which is 5 classes). It makes me a super full-time student. I plan to tell my classes about my TS soon because I don't like people asking a million times throughout the semester. I know it will act up eventually, so why not get it out of the way now? I love talking about my condition and I am so proud of how far I have come.

I know one other person with TS and she was diagnosed after me. I want to meet more people with the condition because I am the first on both sides of my family to ever have it. I made family history LOL! I want someone who I can talk to and relate to. I get a lot of friend requests sent on MySpace, so if anyone ever wants to talk you can reach me at www.myspace.com/lexsi_luvs_grumpy_bear.



Joseph (12 years old)
Tumwater, Washington

My name is Joseph. I live in a house with my dad, step mother, Dawn, Dawn's pug Dorsey, and last but not least, Jennifer Lopez! Weird, isn't it? You're probably wondering why in the name of God Jennifer Lopez would be living with me! Well here's your answer. One or two summers ago I went to a Pet Smart and got my third hamster. I named her J-Lo a.k.a. Jennifer Lopez.



Some of my hobbies are beading, cooking and karate. When I get out of high school I want to take culinary classes at the Art Institute of Seattle, so I can become a celebrated five-star chef.

I personally love the outdoors. I like hiking, fishing, camping, kayaking, exploring, etc. – the list goes on and on and on and on ... you get the picture. The one outdoor activity that I find the most fun is bike riding. In fact I'm biking all the way to Yelm and back tomorrow.

Some of the things I like to do when it's rainy are read a book, work on homework, play the Sims 3 and listen to my iPod. I also love to sleep, especially when it's rainy.

Sometimes I have lucid dreams, where I can do anything I want because I know I'm dreaming. If there was only one dream I could dream and it would actually come true, I would create world peace. I would love for everyone in the world to, at the very least, treat each other as equals. I wish also that the poor and hungry would have clothes, food, money and a roof over their heads. I would return prosperity to this world and stop global warming. Finally I would bring all the species of plant and animal back to life and put them in their proper biome.



Brandon (13 years old)
Merrick, New York

Hey, I have TS, and I consider myself lucky. I feel as though I am a part of a special club, that only certain people with the special "abilities" are allowed to join. I was diagnosed with TS at age 4. Some of my twitches are neck, finger, eye, head and nose movements. I flick my fingers, like I'm picking my nose. I give the finger (just kidding I wish!) and scrunch my nose. I'm lucky I'm a big kid who is on first string football, because people don't usually physically pick on me for it, but there has been some verbal abuse in my life. Here's a poem dedicated to having confidence, and not thinking you are any less than others. People won't care, if you don't care. Don't let your TS bother you like it use to bother me.

The young boy,
solely sat alone on the playground bench,
drowning in sorrow,
weeping in pity,
"will they accept me,"
"I'm different?"

The young boy pondered,
deep in thought another boy came aside him,
along with a tough group of boys,
"Would you like to play," the young boy asked,
"sure," said the boy,
walking towards the courts,
with that group of boys,
not so tough, after all.

That Darn Tic

That Darn Tic is TSA's newsletter by and for children up to 18 years old.

All submissions will be edited for length, grammar and content.

Drawings and cartoons reproduce best when they are black and white on white paper. We may alter the size to fit the art on our pages. Submissions for the next issue are due by December 1, 2009.

Send your short stories, poems, essays, drawings and photos to:

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

or e-mail: tracy.flynn@tsa-usa.org

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



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Make new friends and have fun-filled days at the National TSA Conference from April 15-17, 2010 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.