



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Jonah Weinstein (10 years old)
Marblehead, Massachusetts

Hi, my name is Jonah. I'm 10 years old and I have Tourette Syndrome. I love to play soccer, lacrosse, football, basketball and snowboarding.

A while ago, I was starting to feel as though I couldn't achieve things because of my tics. Then, I met Tim Howard, who is now the goalkeeper for Manchester

United, from the English Premier Soccer League. He told me that, "Tourette is a speed bump, not a stop sign." He explained that tics may make things harder, but they shouldn't stop you. This experience helped me because I met someone with Tourette Syndrome who has achieved his goals. Now, when I'm in a game, I know that tics won't stop me.



Ryan Rominger
(11 years old)
of
Visalia, California
sent us this drawing



Kelsey Clark (13 years old)
Vernon, Arizona

I was diagnosed with TS in September, 2003. When I was first diagnosed with TS everybody in school used to make fun of me because of my tics.

In May of 2004, my tics got so bad that I could not attend school. I took a trip with my grandparents to Arkansas. One day we went to see the Majestic Caverns.

Even though my grandma told the tour guide that I had TS, everything seemed to go wrong once we started the trip into the caverns. Can you imagine how scared I felt when my tics turned to "bad words" and became very loud? In a cavern, everything echoes! It was the longest trip ever for me and I am sure for everyone else on the tour.

My mom finally found a doctor who was able to help me with some new medications. Now that I am taking medications for TS, no one makes fun of me anymore. I have had a good life since then, but I will always remember my trip to Arkansas.



Denver Stahl (7 years old)
Jeannette, Pennsylvania

I have TS, OCD and ADHD. I play sports. I play baseball. I play football and I wrestle. Baseball is my favorite. I am a catcher. I did not do really good my first year of wrestling. I lost every match. I have gotten a lot better. I have won a lot of trophies since then. I took third place at my Keystone Tournament last year. I am hoping to do better this year.



Emily Cromwell (10 years old)
Warrenton, Virginia

My name is Emily. I have OCD and Tourette. A lot of kids always say things like, "Why do you smell your paper?" or "You're odd." And one time someone even called me a geek. Though it hurt my feelings, I had to learn to get over it because kids will be kids. Though living with OCD and Tourette, I try really hard not to let OCD be the boss of me.



Sean Stigall (14 years old)
Olmsted Township, Ohio

My name is Sean and I have TS. I am not quite sure, but I think I have had it my whole life. It was never as bad as it is now but I try to make the best of it sometimes. I'm not one to lie to you and say it doesn't bother me, because it does, and sometimes it's even painful. I learned to deal with these issues, though. Although I take medicine for my TS, it still doesn't fully help. I also have ADD and ADHD. With those three combined it's very hard for me to work in school. I'm not a straight A student, not a B or even a C student. My grades aren't pretty sometimes, but I try very hard when I see them slip. But sometimes in school I try so hard to stop ticcing that my focus gets thrown off. I'm not blaming bad grades on everything I have, but it does have a lot to do with it.

Sean with his nephew, Nyco

Music is my life. I learned that music often helps me relax which helps me with my tics. When I'm on the computer I listen to music a lot, and chat with my friends online, which also helps. I notice that I have a lot of ticcing while I am typing. I click the caps repeatedly, but I laugh about that one.

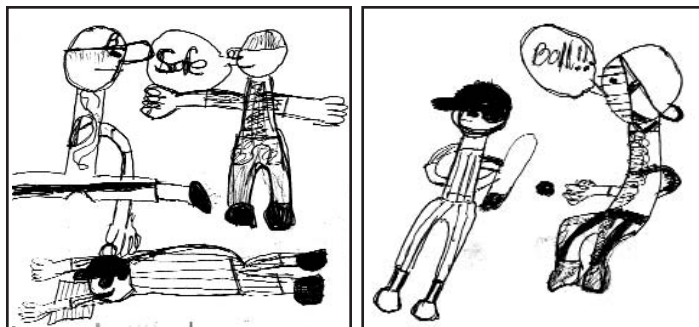
But TS isn't something that you can laugh off. You are going to have friends who are never going to understand it or agree with it, but that's not your problem. If they want to waste their time complaining about it, then tell them to back off.

I'm changing the subject to medicine. Medicine isn't always the right way to go. I am currently on a patch of some sort. But I used to take pills, which were unsteady in the process of working and didn't have good side effects for me. My family and I once tried putting me on Strattera, which is supposed to be an anti-depressant, but it made me very irritable and depressed.

I do a lot of things to help me with my tics. I enjoy baseball, skateboarding, paintballing, and rocking my head to some old Black Sabbath or AC/DC music. Find your way to make yourself feel better.

Anthony Pagonos (9 years old)
Poughkeepsie, New York

I like to play baseball. Last summer I went to Cape Cod for six days. One day my grandpa took me to a baseball game. I really liked the game and I had a lot of fun. When I came home I drew these pictures before I went to bed.



Katherine Burns (9 years old)
Waco, Texas



My name is Katherine and I have TS. I am a straight A student and am involved in a lot of things, like singing, dancing and piano. I sit in the center of my classroom, and it is sometimes hard because people look at me as if I'm making disturbing noises, but I just can't help it. I often can't relax, so my mom lies in bed with me, and we have to count down from 200 just to get me to relax! I have a tic where I sniffle, and people think I have a really bad cold. They always ask me if I need a tissue, and sometimes it bothers me.

My best friends Lauren and Jami understand. They know that I can't help the things I do. They comfort me a lot. One time I was in a school play and I was about to sing a very long song, and I was on the medicine that made me very tired, so I started to tic like crazy! When I got on stage it was like my tics stopped completely. I was very amazed. My music teacher knows sometimes I can't sing or play the piano at the time, so she comforts me and tells me it's alright.

I was diagnosed with tics when I was 7 years old, so it's been two years now. I went to four different doctors before we found the right one. I hope my tics will go away. No one likes them, but one thing I know, is that I am not alone.



Sydney Moskowitz (7 years old)
Potomac, Maryland

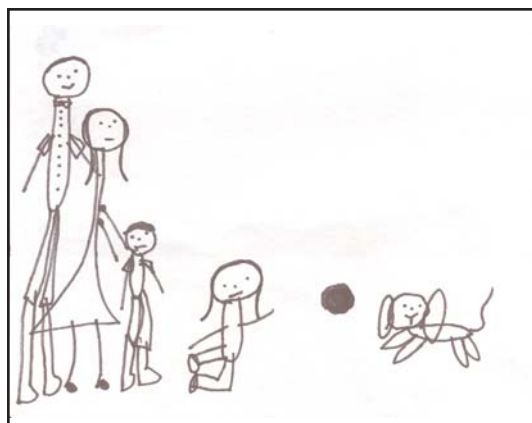
Hi, my name is Sydney and I live in Potomac, Maryland. I have TS. I am raising money for TS by hosting an eBay store with my artwork. All of the money is going to the Greater Washington Chapter of the Tourette Syndrome Association. So far I have raised \$1,054 in my first month. Please come visit my store on eBay—I will be very happy if you do! You can go to: <http://stores.ebay.com/Help-FightTourettesSyndrome> to see my artwork and maybe bid on one!



Jamie Joseph (8 years old)
Berkeley Heights, New Jersey

Hi! My name is Jamie and I have Tourette Syndrome. I like to swim, play tennis, play basketball and play piano. My number one hobby is reading. Tourette Syndrome usually stops me from watching a movie or reading a book...but only for a second or two.

Then I go back to whatever I was doing. My teacher understands. She is really nice to me about it. Most of my friends don't know about it, but some of my very best friends do. They are all really good about keeping it a secret. I have a lot of friends. My mom, my dad, and my brother understand it, too. My mom brings me to doctors and therapists a lot. But Tourette Syndrome is also a good thing. I get to go to sleepaways, people always ask me if I'm OK, and I get to write for papers! I guess Tourette Syndrome isn't all that bad after all.



A drawing by Jamie of her family, including Daisy, their dog



Austin Neece
(11 years old)
of
Mastic, New York
sent us this drawing



Randy Chambers (15 years old)
Hadley, Pennsylvania

Here is my story. One day I was sitting in my home maintenance class and my friend Brandon says politely, "Why is your head shaking so much?" I said I didn't know what he was talking about; I never noticed it, but after he said that I started to notice it. That night I went to my mom and asked her what was wrong and she took me to a specialist. She was a neurologist and she had me take some tests to see what was wrong with me and they finally found out that I had TS. So then I was afraid that something was really wrong with me and was frightened. I started taking different kinds of medications. They were not working for me; they made me very tired, but didn't help my TS. The neurologist decided to try a different medicine called Orap and I started to have back spasms and I started to swell up so we went to the emergency room. Unfortunately, I have to retry this medicine at a lower dose and pray this will not happen again. I don't understand why they haven't found something out there where the side effects don't have to be so bad. Some days I can't stop shaking my head, sometimes it's even hard to eat dinner, my head will not stop. I know I am lucky I don't have cancer or a tumor, but it's hard to understand what's really going on. So that's the end of my story and I hope you enjoyed my story—I certainly enjoy all of yours.



Did You Know...

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



TS Youth Ambassadors Go to



Washington, DC - Special Supplement

The Tourette Syndrome Association held its third annual Congressional Luncheon on Thursday, March 3, 2005 to educate Congressional Members and their staff about Tourette Syndrome and the crucial issues of special education, the importance of an early and accurate diagnosis, and the necessity of continued governmental support and funding for the TS education and research program at the Centers for Disease Control and Prevention.

This year, TS Youth Ambassadors Jackie Baker, Johnny Loder, Andrew Nesbitt, Joriel Sharp and Jennifer Zwilling—all of whom have TS—addressed guests. They all told their own struggles in being diagnosed and the subsequent battles they faced in school.

Here is what some of the Youth Ambassadors had to say about their experience that day.



Jackie Baker (10 years old)
McLean, Virginia

I was an Ambassador for the TSA on March 3rd. I spoke to members of congress about what it is like to have TS and growing up with it. I was the last one to speak and that made it

easier because I got an idea from the other kids about how I was supposed to sound!

The other kids all had TS and their speeches were very good and convincing that TS is hard to live with and that makes me wish they could find a cure. If they don't find a cure at least we can all help to make sure that other people understand what TS is and that maybe will make it easier to live with.

If they don't find a cure I really have to work hard to not be so hyper, to be really good in school and my goal is to do really well in math. When I saw the other kids I thought that they've all done really well and that gives me hope and encouragement. I learned from their speeches and so did Congress.

I felt proud that we had the chance to help other kids with TS all over the world.

Jennifer Zwilling (14 years old)
Brookville, New York

My involvement in the 2005 Congressional Briefing was a truly rewarding experience. Speaking to Senators, Congressmen and their staffs, regarding an issue that is

so important to me and watching how they really listened was wonderful.

The best part about my whole experience was realizing that I was taking matters into my own hands. By telling my story, I realized that I was helping people all over the nation. I know that if TS is included under OHI (Other Health Impaired) in the IDEA (Individuals with Disabilities Education Act), accommodations will be made more easily for students everywhere.

Everyone that I met in Washington D.C. was very supportive and made me feel so comfortable while I was speaking. I also had the opportunity to fly back to New York on the same plane as Senator Hillary Clinton and Congresswoman Nita Lowey.



Jennifer with
Senator Hillary Clinton

They were also very supportive. Congresswoman Lowey was very encouraging and my conversation with her has really stayed with me. She told me not to minimize the importance of what we are doing. She told me that we should keep coming back and to keep on speaking up because the staffers and the Senators and Congressmen really do listen when people come and speak.

I really enjoyed the briefing and I hope that it becomes an even bigger event in the years to come.



Joriel Sharp (15 years old)
Ardley, New York

I was fortunate to have the honor of representing TSA in Washington. I was proud to stand before these people with my Tourette! I felt like I made a difference for all of us! Kids with TS have equal rights too. This was so important as I feel strongly about this relevant cause.



James Overbey

(9 years old) of Fayetteville, Arkansas sent us this drawing of a Power Ranger.

Above is a picture of James with his sister, Brooke



James Ashley Reid (14 years old)
Monticello, Mississippi



My name is James Ashley Reid. I like to be called Ash. I have a twin brother Jamie. We both have Tourette. We started ticcing in second grade. It has been very hard for both of us, from kids making fun of us to doing and saying

mean things. Kids aren't the only ones. There have been some adults, too. We've had to go to schools here and there. Sometimes we feel they don't want to take the time with us. We've had good ones and bad ones. We had a great year last year and some great teachers. I just wanted to let others know when the teachers, students and parents work together, no matter what the problem, you can achieve goals. And one of my goals is to be a surgeon and my brother's is to find a cure for Tourette Syndrome.



Lauren Mazzio (8 years old)
Schwenksville, Pennsylvania



I like me, because I'm me.
It's not the way I look or dress
It's my personality.
Tourette Syndrome doesn't make me different,
It just makes me special.
That's the way I want to be.



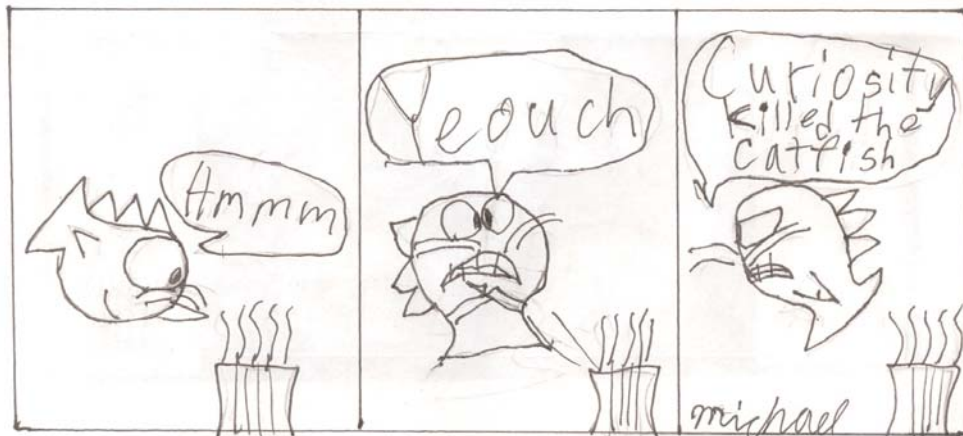
Cayman La Pointe (10 years old)
New York, New York

My name is Cayman. I remember a kid who used to bully me in 3rd and 4th grades. When he saw my tics, he made fun of them. In a mean way, he said, "Why are you always moving your head back and forth?" He made fun of my 'pinky' too. When I was four years old, I had my pinky taken off because it got a bad cut, so I have no pinky on one hand and he made fun of it. He made fun of me when I couldn't stop moving my arms and shoulders. It really bothered me then, but it doesn't bother me now that I have my "Evan's group" with my friends that have TS, too.

My good friends who actually know about my tics never make fun of me. They understand that I can't help it and they still play with me and don't think I'm weird like the mean kids. My real friends think it's cool that I don't have a pinky, and they think I'm brave because I had a lot of operations.

I still have tics but now that I have my group at TSA, I don't let the bullying bother me, I just feel good because of my real friends and the new friends from the group, and Evan, who runs the group, talks to us about cool things.

**Editor's Note: Evan's Group is part of the New York City Counseling Program for families and children with TS funded by the City of New York for the Tourette Syndrome Association.*



Michael Malconian
(11 years old)
of
Los Angeles, California
sent us this funny comic strip

TSA "INSPIRE" WRISTBANDS ARE AVAILABLE NOW!



School-aged children, and children of all ages will want to get hold of and proudly wear the new Tourette Syndrome Association (TSA) Inspire Wristbands!

You have seen these wristbands everywhere across the country! School children and many adults have been wearing the yellow "livestrong" bracelets, with various other colors signifying awareness of different conditions and causes.

Our Inspire wristband is sure to be a conversation starter for anyone who sees it...Now, you can promote awareness of Tourette Syndrome and TSA with these great new items. You can inspire yourself and others to promote understanding and acceptance of TS.

The new TSA Inspire Wristband comes in "TSA teal" the "official" color of TSA. It was designed by the Zwilling Family of Long Island, New York and features the word INSPIRE in bold letters. You can order your TSA Inspire Wristbands (cost of \$1.00 each) from our website (TSA Store) catalog item BX-1, or call 718-224-2999.

That Darn Tic

That Darn Tic is TSA's newsletter by and for children up to 15 years old.

All submissions will be edited for length, grammar and content. Please don't send us your only copy. Drawings, photos and cartoons reproduce best when they are black and white on white paper. We may alter the size to fit the art on our pages. We will publish as many as we can fit—so send us your best and we'll do the rest! Submissions are due by May 22, 2005.

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

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42-40 Bell Boulevard, Suite 205
Bayside, NY 11361

or email: tracy.flynn@tsa-usa.org

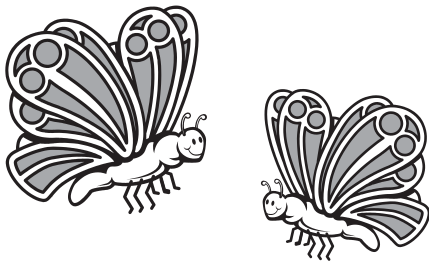
The next *That Darn Tic* issue will be coming your way soon!



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SPRING HAS SPRUNG!

**Tourette Syndrome
Awareness Month is
May 15 through June 15!
Help spread the word!!**