



# 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 ♦ web site: http://tsa-usa.org

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**Matthew** (13 years old)  
*Santa Monica, California*

I have Tourette Syndrome. I am a straight A student, I have lots of friends and I play soccer on the Santa Monica All Star team.

Soccer is the one thing I love and I am very good at it. Me and my team go and play at tournaments around California. We have won three tournaments and I have been playing great.

My friends are really nice to me and once I told them, they had no problems with it. I know it is sometimes hard to tell people. I think we all have that same problem, including me at times.

TS has never stopped me from achieving my goals. It might get me down, but I always seem to overcome. I believe that whatever you want to do, you can do it. No matter who you are, what you have, and how bad it is, you will always be able to do what you want to do. All you have to do is set your mind to it and do it.



**Cassie** (14 years old)  
*Whitney, Texas*

My name is Cassie and I have had tics for 7 years. I am going to tell you about a contest that I was in for 4-H. It may not sound like much, but as you know, when you have tics everything seems harder. I have been in 4-H for one year and one of my projects was a thing called Consumer Decision, which teaches you to become a better consumer. You learn about different products and how to choose them for a certain situation that you may need them for. Then you go to a contest and judge six different products based on a scenario. You have to stand before a judge and tell why you rated the product the way you did. It sounds a lot easier than it really is.

I studied hard and passed the county level contest, but after that came District! Our district consisted of 21 counties, so there were a lot of people there. I was REALLY nervous. When I get nervous I TIC! I also was on no medicine at the time so my tics were pretty bad.



Well, after all was said and done...our team came in 1st place! There are also places given to the 10 highest individuals. One of my teammates got 3rd place, and out of at least 50 kids, I took 1st place.

I could not have done it if my teammates, our coach, and some other ladies in our group had not stood by me. I owe it all to Jesus, my friends and my parents.

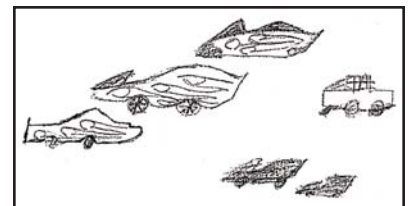


**Austin** (9 years old)  
*Sarasota, Florida*

Just because people have Tourette Syndrome, does not mean they are stupid, weird, dumb or retarded. It means that some people are different. Sometimes I make silly noises and my friends laugh. My teachers don't think it's funny; but I can't help it.

Sometimes it gets me in trouble and makes me sad because they don't understand tics.

If people are mean and not nice to you about it, just ignore them. You might even be better than them at stuff, but don't make



them sad too! Just ignore them. My friends at my school have TS too but I won't make the person sad about it.

I love cars. My favorite Nascar driver is Dale Earnhardt, Jr. - Number 8. We love driving cars in our aftercare class.



**Gavin** (11 years old)  
*Tunkhannock, Pennsylvania*

My name is Gavin and I have TS. I got my diagnosis last year at age 10, but my mom knew I had it for years before that since she has it and my 14 year old brother does too. It is difficult having TS at times and some of my tics cause me pain, but what I hate most of all is when kids at school tease me about my tics.

This past year in 5th grade when I was 10, I was in an after school activity called The After School Players which was an acting and theater program. On the first day of class, I told both my acting teachers about my TS, but it didn't bother them at all. At the end of the program, we put on a play. I got a leading role and had to memorize LOTS of lines. I love acting so this was a great activity for me, and when I'm wrapped up doing something that I like, my tics are not as bad.

My mother was worried that the day of the play I was going to tic like crazy on the stage because my tics were starting to get worse again, but I didn't. A few months after the play, we got a call from an advertising agency a few towns away. A lady there saw me in the play and was impressed with my performance. They needed a boy my age to do a TV commercial for a local newspaper and they asked if I wanted to do it. I said yes.

This would be a great experience for me. When we were driving to the shooting site, I was ticcing like mad and I wasn't sure if I would be able to do it. But when the director said "action," it was like my tics turned off. In between takes, I let out all the tics, then I held them in while they were taping. I had to concentrate really hard but I was able to pull it off. I love acting and I wasn't going to let TS get in the way of what I like to do! And I can't wait for next year's acting class!



**Christina** (9 ½ years old)  
*Staten Island, New York*

I have TS. When kids make fun of me I cry. And when I smell my sandwich, I told my friend what it was. But some people don't understand so I tell them over and over about TS. But my best friend, Nicole, sticks up for me because she understands and she knows that I have TS, that's why she is my best friend.

## IT'S CALLED TOURETTE SYNDROME

By **Julian** (11 years old) and mom, Diane  
*St. Louis, Missouri*

Do any of you know anyone with asthma? Do you think they're weird when they use an inhaler? Do you know anyone with diabetes? Would you make fun of them for having it?

I want you to know, but I'm not comfortable telling you in person, it's called Tourette Syndrome (TS). That is the name of the hiccup-like, muscle movements I make. The movements are actually called 'tics' and they are completely involuntary like a hiccup or sneeze or needing to itch.

I can't help it and there's nothing I can do to stop my muscles from doing them. It is not a habit. It's like having bad eyesight and needing glasses, you can't die from it but it's a nuisance. The tics come and go as you have probably noticed. Usually they go away when you're an adult.

You know when you have the hiccups and don't want them and can't stop them, or when you have to sneeze and you try to stop it but you sneeze anyways...or when the doctor hits your knee to test your reflexes and your leg jumps? Well, it's the same with Tourette Syndrome.

The only difference is having your muscles moving all the time can make your muscles sore. Sometimes I have these hiccup-like tics in my face so I make faces, (I'm NOT making faces at you); sometimes I have them in my neck or shoulders or knees ...and that's all. They can be a real pain in the neck (or jaw), literally, seeing as it's my muscles moving- like when your eye twitches! I really don't like it when people stare and imitate me and whisper behind my back.

It's embarrassing. Sorry if my movements bother you, but trust me, they bother me more.

There are many professional athletes with Tourette Syndrome who play basketball, football and professional baseball. Tim Howard, goalkeeper for Manchester United in England—the largest soccer team in the world—also has Tourette Syndrome.

I'm the same person I always have been. I'm not sick and Tourette is not contagious. My having TS has nothing to do with the brain tumor I had removed in third grade. I feel fine. I love playing football and baseball and basketball and soccer and kickball and everything else we have all played together for the last six years—just like you. Tourette does not affect my abilities. Now can we just forget about it and move on?

Thank you in advance for being my friends and supporting me.



# 2004 TSA National Conference



## Special Supplement

**Jay** (14 years old)  
*Trappe, Pennsylvania*

In April, I made the trip to Alexandria, Virginia, along with my mom and others from our local support group. The conference was a great experience for me and everyone else. I attended the Advocacy and Leadership Training before the conference began and I took a trip to Capitol Hill to speak to my senators and congressman about TS. These were amazing experiences!

There were hundreds of classes to attend to learn more about TS. There were also many tables set up with pamphlets and information about TS and the related disorders. At night, there were get togethers and socials. It was an amazing experience for me to talk to others with TS and to learn how they deal with their symptoms. It was cool to see and hear different kinds of tics, medicines and things people do to help manage their tics.



### The Big Trip

By **Zak** (14 years old)  
*Albuquerque, New Mexico*



Congresswoman Heather Wilson was our first visit on Capitol Hill. I spoke with Congresswoman Wilson about the IDEA (Individuals with Disabilities Education Act) and Mental Health Parity. After we spoke with

her, we spent time with her Health Staff Person, Joe Moser. Mr. Moser did not have any knowledge of Tourette Syndrome.

The we went to Congressman Udall's office and spoke with his Head Staff Person on Health, Mr. Collins. Mr. Collins only knew about TS as the "swearing disease."

Next, we went to Senator Bingaman's office and spoke again about Mental Health Parity and IDEA. His staffer's name was Mr. Bruce Lesley. On our last trip to lobby on Capitol Hill in 2002, we spoke with Mr. Lesley and he remembered us and what Tourette Syndrome is all about.

Our last visit was with Senator Pete Domenici's Head of Health Staff, another Mr. Collins. The important thing about Senator Domenici is that he is the main sponsor of Mental Health Parity.

The reason Mental Health Parity is important to me is

that I have TS. I believe TS should be classified just like any other disease or syndrome, such as diabetes, cancer or Crohn's Disease. People with TS are not given as much medical insurance coverage because people see brain disorders as being different from disorders of other organs.

The part of the IDEA we worry about people changing is the discipline section. TS is a disorder of the inhibition part of the brain. This means that people with TS can be impulsive in the things they say and do. This can get you into trouble.

The Congressmen and the staff took ' had to say very seriously. I learned that these bills are important to different people different ways. The people we visited were very busy and hard working. On April 22, there were only forty legislative days left. This means that we need to push fast or wait a long time before it has another chance.

While lobbying on Capitol Hill, we walked around the Capitol. Our meetings were held in the Hart Building and the Canon Building.

Through my mom and her friend, I met Matt. Matt is 21 and has TS. Matt and I took a shuttle to the Pentagon City Metro station in Arlington. We rode the Metro to the National Mall area and got off and saw the Smithsonian Museums. The museums we went to were the Air and Space Museum, the Sculpture Garden Museum and the National History Museum. I definitely liked the Natural History Museum the most. I really enjoyed the Mummy exhibit. We saw a real mummy, fossilized dinosaur bones and model ones. The fossilized trees were really cool. We also saw fossilized Trilobites. They looked like miniature horseshoe crabs.

National TSA had a children's' conference. We went to the National Zoo. We had a special guide that took us around. This guide showed us the pandas, the Komodo dragon, marmosets and many others. We went swimming and had discussion groups. We discussed living with TS. My friend, Matt led a drumming circle. It was fun.

On the last night, there was an awards ceremony. My mom got a plaque. There was a really great entertainment show. All the entertainers had TS.

This was my second National TSA Conference. Meeting other people with TS encourages me to keep on going. I saw Michael Wolff again this year. He is a world famous jazz pianist. I met Brad Cohen, a really good teacher, and Peter Hollenbeck, a molecular biologist. All of these people have TS.



*Diane* of Horsham, Pennsylvania,  
wrote the following:

My son and I both had a great time at the conference. Randy enjoyed meeting all the other children with TS and he even made one special friend named Ryne from Texas. The Kids' Program was great. Randy enjoyed the trip to the Zoo but wished he had more time to see the animals.

He loved swimming and other activities offered like the puppet show, earning the ribbons with medals and the play-a-thon. Randy obtained sponsors for the play-a-thon and was able to donate \$300 to TSA at the conference. My company, GMAC Residential Mortgage, matched his contribution with an additional \$300 making his total gift to TSA \$600.

Randy felt good about that and he was allowed to select an additional toy from the play-a-thon for his contribution. It was nice to contribute to an organization that is very personal to us.

One thing Randy particularly enjoyed was meeting Judit Ungar. He really liked her. She gave him her badge at the end of the conference with the "president" ribbon on it and he still has it hanging on his bulletin board.

Here is a picture of Randy with his friend at the conference. Randy and Ryne are both 9 years old. Randy lives outside of Philadelphia.



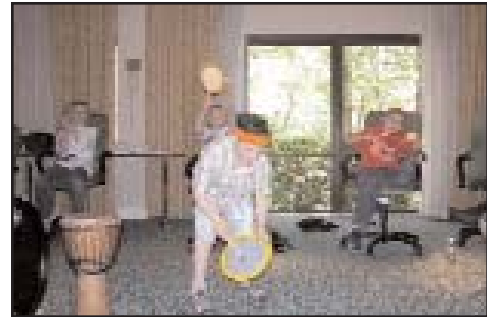
**Randy and Ryne**



**Ryne** (9 years old)  
*Wildwood, Missouri*

I've been to two conferences and I loved it. At my first we went to the Kids' Museum. There were so many interesting things. My favorite was when you stood on a platform and a hoop would make a bubble around you. It was so totally awesome.

At the second conference we went to the National Zoo. There we saw pandas, hippos, camels, tigers, and much more! So that's my story and I hope to see you at the next conference.



**Here is a picture from the drum circle**



**Alyssa** (11 years old)  
*Henderson, Nevada*

My name is Alyssa and I was diagnosed with Tourette Syndrome when I was 8 years old. Ever since then, I thought I was the only kid with TS since I never met another kid who had tics like me. In April, my Mom and Dad surprised me with a trip to the 2004 National Conference for Tourette Syndrome in Washington, D.C. That's when I discovered I wasn't alone

I met lots of nice kids and their parents too. I saw many ways that TS can affect kids' lives. It made me feel so much better because I knew, for sure, that I wasn't the only kid in the world with TS. I really wasn't alone.

The kids' camp was awesome! We swam, went to the National Zoo, and had a Mini-Olympics where everyone won a gold medal. They had a great ventriloquist at the banquet, and I got to dance all night long with a nice boy named Ryne. I think that going to the National Conference was a great way to meet other kids with TS, become friends, and have lots of fun. It was also a great way for my parents to meet other parents who have kids with TS and become friends, too. You can never have too many friends.



**Ryne and Alyssa with ventriloquist, Kellie Haines and entertainer, Jeff Brown**

## Ask the Tic Advisor

Dear Tic Advisor:

The holidays are coming up and I know I'm supposed to be happy, but I'm not feeling all that happy. Everyone keeps talking about how much fun we'll have. My brother is all excited about getting presents. My parents are planning fancy dinners. My grandmother is visiting. And everybody at school is talking about their winter break plans.

I'm not happy about it because last year I got so stressed out that I had a holiday tic-a-thon—non-stop tics of all kinds. My mother said that it was because I was too excited and nervous. When I get nervous before a math test I get a lot of tics. It doesn't make sense to get nervous before a family party but I'm sure I'll start ticcing again this year.

Am I weird? What should I do? I want to have fun like everybody else.

*Like Everyone Else*

Dear Like Everybody Else:

You are like everybody else. Good things, like parties and holidays, cause stress. Maybe it's not exactly the same kind of stress as a math test, but stress is stress and if stress makes you tic—you'll tic.

Holiday time can be very stressful for everyone in the family. It's not just you and your TS symptoms. People eat too many sugar cookies and too much rich food. They don't get enough sleep and run around shopping in a frenzy. A lot of adults gain weight because they skip exercise. And a lot of kids get upset stomachs because they eat too much candy.

It all comes down to changes in routines. If you are used to eating oatmeal for breakfast and for a week you eat leftover Halloween candy or candy canes—you are not going to feel like yourself.

Routines can be very helpful in regulating anxiety and keeping you healthy. Routines are the way we make sure to take our medicine, eat our vegetables, get enough sleep and remember to walk the dog—before he gets really stressed out too!

Because last year's holiday-related changes in your routine made you tic a lot, you might want to think about ways to keep the changes to a minimum. Enjoy the big turkey dinner, but remember that getting to bed at a reasonable time helps you feel better—and less ticcy. Enjoy the family gathering but if it gets too noisy and frenetic—take a break and relax for a few minutes. If you think about how you can make your holidays less ticcy—you just might enjoy them more.

It might also help you to remember that you are not alone. Everybody might be having fun, but they are also experiencing stress. You are not weird at all.

*The Tic Advisor*

## Dear That Darn Tic Readers

The Publishers of *That Darn Tic* have asked me to talk about our Fun & Fiction issue. A folder with some of the stories, poems and drawings was lost. Everyone feels terrible about it, but a new Fun & Fiction issue will come out soon. Please send your stories, poems, riddles, cartoons and drawings so we can put out the best issue yet!

I want to remind you that you don't have to write about TS. TS is only part of who you are. Last time we had Science Fiction and Fantasy stories, poems about friendship and more. See the back of this issue for information about where, when and how to send your submissions.



This is "Flying Fighter"  
by J.C. (12 years old)  
of Hillsborough, New Jersey

## Life with Tourette Syndrome

Ben (12 years old)  
Ladysmith, Wisconsin

Living with Tourette is not easy. I have problems controlling myself, especially in front of people. When people touch me, I have to touch them back. My behavior is weird to others. It hurts my feelings when people mimic my tics and when people stare at me. They also call me dumb and retarded. My mom treats me good and understands my problems and helped me write this letter. My dad and my brother, Johnny, try to understand me, but they don't always. I hate taking medicine everyday, but I do, because it helps me. I have problems with reading, writing and comprehension. Typing is also very hard.

I once went into the hospital for a long time. It was hard being away from my family and it made me cry. Being in the hospital helped me take control better. I also used to be scared of bugs. I do have some pets.

I have two dogs and two guinea pigs that I take care of everyday. I also like arts and crafts. I like to make things out of pipecleaners. I also love video games and swimming. I hope God heals me or they come out with a cure for Tourette Syndrome.

## That Darn Tic: Fun & Fiction Issue

*That Darn Tic* is TSA's newsletter by and for children up to 14 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 December 10, 2004.

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

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

or email: [tracy.flynn@tsa-usa.org](mailto:tracy.flynn@tsa-usa.org)

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



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FALLING LEAVES!!**