



THAT DARN TIC



A NEWSLETTER BY AND FOR KIDS WITH TS

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Joshua Skaug (12 years old)
Tucson, Arizona

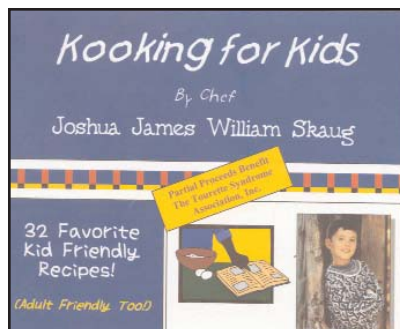
My name is Joshua and I have Tourette Syndrome Plus; the "plus" stands for OCD. I am now home schooled since three different schools that I went to did not work out. They did not understand why I was doing the things Tourette made me do; such as tics and aggression. My aggression was mostly caused by frustration from my teachers; since they did not understand and figured TS was an excuse for bad parenting and bad children.

Some of my hobbies are cooking, reading and writing. I especially like to read Harry Potter and action/adventure books. But my main hobby right now is cooking. To remember my recipes, I write them down. One day, I just decided to make a cookbook. I decided to "sell" my cookbook too. Since I have TS, I decided to send a portion of each book sold to the Tourette Syndrome Association to help find a cure for Tourette Syndrome Plus. This is not only to help me, but to help everyone else that has Tourette.

My cookbook is called "Kooking for Kids." It is not only for kids, it is for everyone. It even has recipes for Pet Treats. These are my favorite recipes; but I also have favorite recipes for the holidays and favorite Mexican food recipes too.

Other than school, having TS-Plus has made barely any effect on my life.

Tourette Syndrome hasn't slowed me down from doing anything!



*Emily with her horse,
Walker*

Emily Burford (11 years old)
Maysville, Kentucky

My name is Emily and I have Tourette Syndrome. I am home schooled with two sisters. A few of my favorite hobbies are jumping my horse, playing the guitar, playing baseball, training horses and training dogs. I have lots of friends who really understand my

problems. My mom really understands me even when my two sisters and my dad do not. I really get tired of taking three medications twice a day. But I am very thankful that I have medicines that I can take. And I haven't had people ask me for a few months now "why are you twitching like that" or "what are you doing?" It is really hard to tell them, and a lot of times they say "what's that?" and then I have to explain my TS to them.

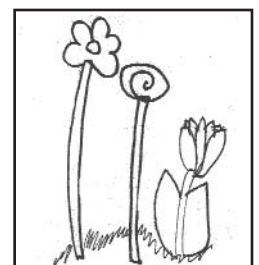
I pray every day that they will soon come out with a cure for Tourette Syndrome.



Emily Bash (8 years old)
Stevensville, Michigan

My Tourette makes me do things without thinking and that makes me feel bad. But in a way I like my TS.

I like that little flower in my drawing... It's different from the others.





I HAVE WHAT?

by **Dylan Stein-Corman** (12 years old)
Piedmont, California

"Dylan, I think I know what's wrong with you," Blake said to me as I was on the playground trading baseball cards.

"You have Tourette Syndrome, just like me." Now this was the most meaningful thing that anyone had ever said to me, though I did not know it. In fact, at the time, I thought that Blake was crazy, so I just played along.

"So what exactly is Tourette Syndrome, Blake?" I said trying to sound serious.

"Well, Dylan, Tourette is..." Blake stammered, and then he paused. "It's very hard to explain, why don't you ask your parents if they know what it is."

Later that day, going to baseball practice, I asked my dad if he knew what Blake had diagnosed me with, though I forgot exactly what it was called. I could only tell my dad that it started with a "T."

"Yeah, about that," he said, "There is something your mother and I have been meaning to tell you," he paused, "but we didn't want to scare you," he paused again, "and we didn't want to tell you unless we were sure..."

"Yes?" I prompted.

"Well, we think you have Tourette Syndrome," he said quickly.

"That's what it was called!" I said rather excitedly.

"Yeah," my dad said in an undertone.

"Why didn't you tell?" I screamed.

"We didn't want to scare you."

"Wait a minute, what is Tourette Syndrome?" I questioned.

"Well, to put it simply, it's a neurological disorder that causes your brain to tell your body to do things that you don't necessarily want it to do."

"Like what?" I asked.

"Like your tapping the ground and spitting," he explained.

"How did I get it?"

"It's hereditary...and we think your great aunt had something like it," he told me.

Now that you heard this much, you probably want to hear the whole story. Well, I'll give it to you. I'd always been a curious child--asking a lot of questions, making small noises, very talkative. Nothing much out of the ordinary. I was always a bright kid and as I got older I was a good student but I had trouble writing. And I sometimes seemed to be in my own little world. I also started spitting uncontrollably for a period of time and was going out of my way to bend down to tap the ground. Because of this, I got made fun of a fair amount at school. I always seemed to be a major bullying target, at least for some people.

As you might have guessed, at the time, this did a lot to my dignity and self esteem. I am now a quiet person around people I don't know and get very easily

overpowered. Then during the summer before third grade, my family moved from San Francisco to Piedmont. The strange behavior continued. In fact, it seemed to be getting worse. The librarian always told me to stop "clearing my throat" so she called it.

I would get into trouble for spitting on the playground. I would tell the teachers that I couldn't control it. But as long as I had no other explanation, they wouldn't let it go. I had never been a troublemaker before so this felt terrible. I had wanted to know what was wrong with me for quite a while, until one day when I was on the Wildwood playground trading baseball cards and my friend Blake enlightened me.

Which brings us right back to where we started. I have Tourette Syndrome. It is something that I must live with. It has greatly affected me and I have had to build my life around it. Fourth and fifth grades might have been the two worst years of my life in terms of the symptoms, which are called tics. In sixth and seventh grade it has gotten much better. I have learned to deal with it over the years. And even with this disorder, I have led a completely normal social life throughout the years. I play organized sports and do well in school, for the most part (nobody's perfect!). I look forward to the years ahead in which the tics are supposed to lessen even more. And I'm grateful that I don't have something worse and that my family and friends are supportive. Tourette Syndrome is not the end of the world...but this is the end of my story!



"Dr. Incredible"

by **Wright Walters** (10 years old)
Auburn, Alabama





Opening Night

Jackie Baker (10 years old)
Norfolk, Virginia

When I was first diagnosed with TS I was making lots of weird noises in my throat and squinting and blinking my eyes a lot. My teachers gave me water bottles in class because they thought I had a cold or something. They didn't understand. Then a doctor told me I had Tourette Syndrome, a neurological condition. I didn't understand at first and worried that something was wrong with my brain. When I learned more about it and we started seeing a really good doctor who has helped me find medicines and ways to deal with it, I started doing really well -but it took a long time. School was still a little bit hard for me but now I am doing very well there, too.

My favorite thing to do in the world is act. I first started out doing school drama class. Then this summer my big sister got me an audition for "A Christmas Carol" at Ford's Theatre in Washington, DC. I was cast in the show! At first it was hard for me, the rehearsals were so so long and very hard. I wasn't used to being up late and I'd never had a real job like this. The directors were very strict because

they want the show to be great. It is really important to listen to all that they tell you and sometimes I had a hard time concentrating, especially when I was tired.

Tonight is opening night! The theatre will be filled with lots of people. I can't wait for tonight. I am very excited and very nervous. But I have practiced and gotten very good at doing my part. This proves that I have tried so hard, done my best and gotten much better.

I would tell a child with Tourette to work very hard and to never stop looking for your strengths. I think I have found mine. I love to act!!



Mark Ciulla (11 years old)
North Arlington, New Jersey

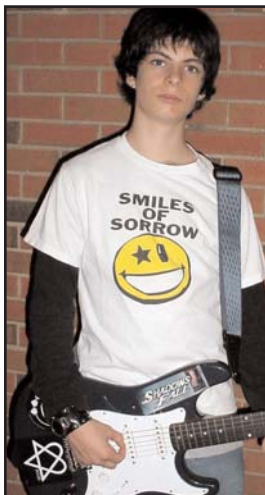
My name is Mark
I'm like a lark.

I like to sing
about anything.

Sometimes I'm loud
But my family's always proud.
Because I'm me, that's who
I want to be.



Alexander Larson (11 years old) from Midlothian, Virginia sent us this drawing showing how sometimes playing video games can be frustrating when you have tics



Randy Clark (13 years old)
Hopemills, North Carolina

I have just finished reading the Genius Factor article in the Fall 2004 TSA quarterly newsletter and I just had to write to you. In the Genius Factor, you talk about musicians with TS.

I was diagnosed with severe TS when I was eight, but over the years it has gotten better. But I am a guitarist! I play guitar in a rock band called Smiles of Sorrow. But I like to play the blues in my spare time. In our band, we have a drummer (Cris), a bassist (Philip), first guitar (me), second guitar (Cris) and a vocalist (Roy).

I love music and when I have my guitar I totally forget about my tics. It's like they're not even there. I read and write tablature and I'm pretty much self-taught. I can write several songs a day, both lyrics and music, and I can pick-up a song by someone else and master it in about 15 minutes.

I've been getting the newsletter for a long time now and I've attended one organized TSA conference. I also enjoy skate boarding. I'm pretty good. But when I'm skating my tics go away and I get focused on something else. Guitar and skateboarding are my escape from the rest of the world. I guess it's because they are independent activities. Thank you for reading this.



Brandon Freeman (11 years old)
Concord, California

Hi! My name is Brandon. I have Tourette Syndrome and it is a neurological brain disorder. I'd like to tell you about a very special friend. His name is Jonathon and

he would stick with me until the end. He once said to a group of kids who were teasing me, "Tease me instead of Brandon!" Now that's a true friend.

Dreams

Every night I dream about
Going out and walking about
Going around and saying "hi"
Instead of hearing laughter
And walking away and start to cry
But I have support of a friend
and to me his strength he will lend

"If I Were A Superhero"

by **Lucas Short** (14 years old)
Hustonville, Kentucky

If I could be a Superhero, I would name myself "Super-Ted." I would make it my goal to help others understand what is like to live with Tourette Syndrome. I did not choose to have Tourette, but since that is how God made me, I would like to play the role of Super-Ted long enough to make a big change in what others think of me. This would be Super-Ted's greatest wish.

Super-Ted's most famous powers are learning to cope and learning to accept that he is at times a little different from most of his friends and classmates. He is not always able to control his actions, but being the Superhero that he is, he would very much like to fit in and be a part of things.

Once you get to know him, and understand why he is different from everyone else, you might find that Super-Ted is really a cool guy! Whenever Super-Ted is blinking his eyes, he tries not to mind that someone thinks that it is a funny thing to do. He would rather they laugh at him, than get upset with him. After all, it could be just a different way of telling someone across the room that he thinks they are really cool too!

Super-Ted might touch people a lot when he is trying to communicate with them. Do not worry, touching someone will not give them Tourette. Super-Ted may get into trouble at school from time to time, because he often asks too many questions and becomes frustrated with himself for not having been able to pay enough attention to the teacher as she was trying to explain something.

Super-Ted has lots of energy. He is kind of like that Energizer Bunny that you see on TV. He just keeps going and going. Sitting still is hard for him. You can usually tell when Super-Ted is getting restless. His face might start to twitch a little, and he may become too loud, but he is not casting an evil spell on anyone, or trying to get all the attention, it just happens!

Super-Ted realizes that his problem is difficult to understand, and that is the reason he tries not to be too hurt when someone makes fun of him. He would like them to learn more about Tourette, and would like for them to know the daily medicine he takes does not always work as well as it should. Just as Superman has a bad reaction to Kryptonite, there are times that Super-Ted can have a bad reaction too.

Sometimes Super-Ted feels left out, and he could become very sad about that, but he is also a very strong Superhero, so he tries to be positive and remind himself that he has a big job to do. That job is to hope that he can use his own experience and develop a power to help others who live with Tourette to become Superheros too!



Brennen Forster (13 years old)
Dix Hills, New York

In October I had my Bar Mitzvah, which is when a 13 year old boy is considered an adult and becomes responsible for his moral and religious duties. During my Hebrew studies, they taught all the students wonderful things about life, One of those things is to share and contribute back to society. If you have a lot of something and no one to share it with, then what good is it?

During the celebration after the service, I received a great deal of money for my Bar Mitzvah. I decided I wanted to donate a portion of the money to the TSA. My first cousin Alex and my good friend Eric both have TS. They met for the first time during my Bar Mitzvah.

Eric is a cool guy who wants to be a chef one day. The first time I met him, he made me the best ice cream sundae that I ever had. I didn't even realize he had TS until years later.

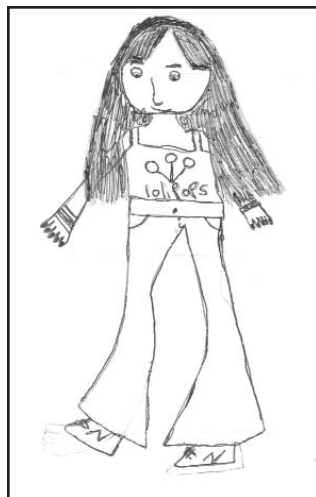
My cousin Alex is like a brother to me. He was always there for me and he will always be there for me. When we were younger we used to live around the block from each other, but now he lives in Florida. Our relationship only grew closer. As we get older, we understand each other more. When people first meet Alex, they only see what appears to their eyes. They see he has tics and assume things about his character. People made fun of him and it got to the point where he wanted to be home schooled because he was so ashamed of his TS. People think he's a bully because he's so tall and strong, but he wouldn't hurt a fly. When you really get to know him you don't notice his tics. You only see the inside of him. He's sensitive, loving and caring. These tics changed his life but won't change the way he treats others.

So this is why I chose to contribute to the TSA. I sincerely hope that my donation will go towards research so that people such as my cousin and my friend will never have to face the troubles they have seen. I hope they will find a cure for all the future Alexes and Erics in the world.



Amanda Bernard
(13 years old)

of
Westmore, Vermont
sent us this drawing



"DIFFERENT"

By **Joshua Cage** (15 years old)
San Diego, California

Born and raised like anyone
How was I to know I'd be the one
Unlike most and yet like most.

Unique Yes

A freak No

Tourette's

Tourette's is hard to have
They effect me and they effect others.

I cannot control the urges to cry out.

I don't know why it chose me,

They say its in the genes.

But why are people so mean?

It bothers me when people stare,
wonder if they really care.

No one's perfect, no not one.

How would they feel if they were the one.

But when it is all said and done

I won't be one to fall,
for, I will rise above it all.



Gina Melissa Velez (13 years old)
Whittier, California

I was diagnosed with TS when I was nine. I'm 13 now and love to act. I take advanced drama at my school and I'm also a very good artist. I've been in over 10 plays. Ever since I could walk and talk I was dancing and singing, so my mom got me into dance. At my dance studio, their recitals were musicals. So I would sing and dance at the same time.

When I was nine I got into theater. I've performed in "The Sound of Music," "The Wizard of Oz" and "Annie." I received a Gypsy Coat Award which is presented to eight people a year. It means you have "what it takes" to be an actress. (It's an honor to get it.)

After "Annie" I played a dancer in "The Music Man" then I was in "Joseph & the Amazing Technicolor Dreamcoat" and after that I played Wendy in "Peter Pan," which was a blast! I did another "Peter Pan" at a different theatre, where I was a main dancer/Indian. I am now doing "The Wiz" which I got a main lead called a Yellow Brick Road. It's not just a person dressed up as a brick, it's a main lead with major dancing, acting, and singing roles. Next I am auditioning for "Alice in Wonderland" and for "Tom Sawyer and his Adventures."

I also love to draw. I draw cartoons, realistic, abstract, basically anything. I've gone to art schools and camps and have gotten better each time.

When I'm drawing or acting, my TS escapes me and I'm transformed into a different world. It's so neat to have that feeling. I love being on stage the most, though!



Jenny Whitaker (13 years old)
Lawton, Oklahoma

I went to a camp in Lees Summit, Missouri last summer. It was a camp especially for kids with Tourette Syndrome. I think other kids with TS might want to know about it. When I found out about this camp from the

Joshua Center located in Kansas City, I was so excited.

I thought I was like the only one who had the burden of Tourette. But then I got to see other kids that are dealing with it, too.

When I got there, two counselors met me at the front. They were so cool. I knew I was going to like this camp. Little did I know I was going to end up *loving* this camp.

The first day we chose our cabin names. My cabin was the "Ticcercs." Then we designed flags to represent our cabins. Our mascot was a clock.

Some other activities we did were fishing, boating, swimming, arts and crafts, building a campfire, hiking and so much more. Now, I'm a picky person, but the meals were great. This camp was the best thing that ever happened to me.

We Need Your Help!

That Darn Tic is TSA's newsletter by and for children up to 15 years old—but we can't do it without you!

Please send us your short stories, poems, essays, drawings, riddles, cartoons and jokes. Try to include a photo of yourself as well! Make sure you include your age, address and phone number. All submissions may 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 will publish as many photos and stories as we can fit. Submissions for the next Spring issue are due by April 22, 2005.

TSA

That Darn Tic

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



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