

THAT DARN TIC

A NEWSLETTER BY AND FOR



KIDS WITH TS



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fall 2003

issue no.7



Marcos Diaz, 12-years-old,
made this presentation to his classmates:

Hello everyone, I would like to talk to you about a condition that I have. It is called Tourette Syndrome, or TS. I have involuntary tics and I make some noises that I can't control. It's kind of like having to sneeze; you just have to do it!

This makes it very difficult to concentrate sometimes. TS makes me very sensitive to touch, to sounds and other sensations. So when there is a loud sound or someone is screaming, it really bothers me.

The same thing that causes my TS, the tics and movements, may be responsible for my increased speed (I can be very fast and I have excellent reflexes). This makes me very good in sports and causes me to be more active on the playground.

There are some things that can cause me to make more noises: when I think my noise is bothering someone, especially when we are in a quiet room; when I get nervous; when I am tired; and when I am hungry.

I like reading, playing and being with my friends.

LETTER TO THE EDITORS

Dear Editors:

My name is Jackie and I'm 12-years-old. I live in San Francisco and have a minor case of TS. I was just responding to the article in the "That Darn Tic" newsletter.

Because I only have a minor case, I don't have that much trouble with kids making fun of me but often I have been asked, "why do you keep doing that with your eyebrows?" or "stop blinking."

Sometimes I feel awkward in front of people when I am constantly cracking and moving my neck in odd angles or blinking a lot while having a one-on-one conversation. I am very lucky though because one of my best friends has tics too.

I think that it is really important to have someone to talk to about them, and I don't think that there is anything wrong with tics at all. If anyone makes fun of you, that's their problem.

Thank you for listening, and I think it's at to have this newsletter to read.



Sincerely,
Jackie Lalanne
San Francisco, California

From *Noah Mattson* (10-years-old)
Olympia, Washington

Raging storm of tics,
With no rain or wind or clouds.
Unpredictable.
Terrible, yet true.
Inevitable.
Controllable (sometimes).
Scary.



Because good is being awakened
For all that is sakened.
Please dear Lord,
Let my mind and heart soar to better places
In this wonderful world of yours.

THE MAGIC PENCIL

by *Kevin Josephson*, 8-years-old
of Greenlawn, New York

Once there was a boy named Kevin who was in Third Grade. He was very brave. He lived with his Mom named Barbara, his Dad named Keith and his brother, Timothy. Kevin's mom had a dresser. One drawer was left untouched. At night, weird sounds like tapping and creaking came from the drawer.

One night when Kevin heard the tapping, he crept over to the dresser. He opened the drawer. Kevin couldn't believe his eyes! Can you guess what he saw? A WALKING, TALKING PENCIL! That morning Kevin told his family. They believed him. He went to school with the pencil. All his work was done in about 6 minutes because the pencil helped. He got his homework done in about 2 minutes!

Kevin had found a new best friend!

I AM DIFFERENT

by *Rose Farmer*, 11-years-old
Spanish Fork, Utah

I am different; no one knows why.
They think it's my cheeks, hair and eyes.
Only a few, plus me and you, know it.
It's my condition - TS.

Poem by *Brandon May*, 11-years-old
DeBary, Florida

My heart is full of
And a little bit of



sadness
badness.

But the sun's still shining
So I know there's a silver lining.

ADVICE FROM THE TIC ADVISOR

issue no. 7

Dear Tic Advisor:

The holidays are coming and that means my family is going to get together. On TV and in movies this looks like fun, but for me it's a problem. I'm not the only one in the family with TS. My cousin has it too and none of the aunts, uncles and cousins seem to understand that my TS is not at all like his.

He is a great athlete, a great student and just about the best person you're ever going to meet. His tics don't seem to bother him that much, and even when they do, he never gets upset about it.

Every family party means I'm going to be told over and over again that I should be more like him! I hate it.

Help me figure out how to get them to stop comparing us.

“Other” Cousin

Dear “Other” Cousin:

It sounds like you're missing a great opportunity to talk to a cousin with TS who is coping really well, but it's hard to push through all those negative feelings you're describing. Why not ask him to help you take on the rest of the family? He might really enjoy sharing a few tips with you and instead of suffering from the unfavorable comparison, you two will be a team.

If that's impossible, try to talk to your parents before the big party. Maybe they can help figure out a way to get the other adults to stop saying, “Why can't you be more like...” Most of the grownups probably remember being told to be more like a sibling, neighbor or even a cousin, and nobody liked hearing it.

Tic Advisor

Dillon Goldberg of Boca Raton, Florida,
wrote the following:

Hi! My name is Dillon. I am 12-years-old and I have Tourette Syndrome. I wanted to tell you about my Tourette life!

Some kids make fun of me and of my tics. They trip me and make fun of what I like to do. One boy even copies my eyebrow tic, which really gets me mad. He does it so the teacher can't see! I hope soon I will find kids to accept me as I am. I am a great drummer, good swimmer and basically a kind kid!



**TSA AWARENESS DAY
JUNE 14, 2003
PLAINRIDGE RACE COURSE
PLAINVILLE, MASSACHUSETTS**



A good time was had by all at the TSA Connecticut Pepper Belle Day at the Plainridge Race Course on Saturday, June 14. Awareness raising activities included a TS literature table manned by TSA Connecticut, a DJ spinning music, a clown, a face painter, raffle drawings and the chance to get a picture taken with Pepper Belle.



TS: STRAIGHT FROM THE HORSE'S MOUTH

Retired harness racehorse, Pepper Belle, has the equine (horse) version of Tourette Syndrome. After her successful career racing for Masconette Farm ended due to a bowed tendon, she began her second job as an awareness spokes-horse for TS.

“She is a terrific teaching tool and motivational symbol,” commented Mark Levine of national TSA. “She helps people see past their limitations. Kids immediately fall in love with Pepper and stroke her mane. They cheer her in the videos of her races and listen intently to the message we present about TS and tolerance of people with it and other disabilities. She leaves a tremendous impact.”

She travels to schools in New England demonstrating that anybody – even a horse with TS – can be a winner.



MORE FROM THE TIC ADVISOR

Dear Tic Advisor:

I have to take medicine for my TS and I don't like it. It makes me feel worse and just having to take medicine makes me feel bad about having TS. What can I do?

Medicine Man



Dear Medicine Man:

First of all, you might have to take medicine. A lot of people with TS do and there are many medications that your doctor can give you. If the medicine itself makes you feel sick, it's called a side effect and you should talk to your parents and your doctor. You might need a new medicine, or a different dose. If just the idea of taking medicine is making you feel worse – ashamed of having TS or something like that – get over it! Lots of kids take medicine for all different things (asthma, diabetes, etc). Needing to take medicine is nothing to be ashamed of.

Tic Advisor

**INTERVIEW WITH
COACH MARK WOOTTON**

Coach Mark Wootton has TS but it hasn't stopped him from pursuing his dreams! He teaches high school history and coaches the state champion North Sanpete Football Team of Mt. Pleasant, Utah.

Q When you were a kid, what was the biggest impact of having TS?

A Having TS when you're young can be embarrassing. I had to learn how to roll with it and use humor. It made me quick witted. It also made me more conscious of kids who struggle with different things.

Q Some kids with TS withdraw, some discover a special outlet. What worked for you?

A I've always had good friends and I've always loved sports. I was a good athlete but I didn't have self-confidence. I was a late developer and didn't do really well in sports until I was older. As I got physically developed, I got better; sports kept me involved. I played football in college.

I was kind of the class clown, joked my way out of being embarrassed. The confidence came slowly as I was put in different situations – situations where I'd have leadership opportunities. I met my wife in college. She was a real pretty girl – a cheerleader – and she didn't care about my tics.

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Q What would you like to share with the “That Darn Tic” readers about your experience with TS?

A Having TS has made me stronger. I wouldn't be the person I am today without TS. Believe it or not, it has been a blessing. I view life with so much joy and happiness.

There are a lot of people that suffer with adversity much greater than TS. I consider myself lucky.



Coach Wootton is a great role model for kids with TS. Do you know an adult with TS who has been a role model for you? Tell us about it. Send your thoughts on that special person to “That Darn Tic,” c/o TSA, 42-40 Bell Boulevard, Bayside, New York 11361. If you'd like to read a longer interview with Coach Wootton, see the Fall 2003 issue of the TSA quarterly newsletter.

LETTER FROM THE EDITOR

Micah Smith of Beverly Hills, California

My name is Micah and I live in Los Angeles. In the 6th grade, I had a very bad year. My tics were terrible and my medication did not work. I didn't have any friends and I got bad grades.

My doctor, Dr. Saslow, spent a long time working with my parents to get the right combination. While they were experimenting, I fell asleep in class, stayed awake all night, ate too much, ate too little, or felt very anxious.

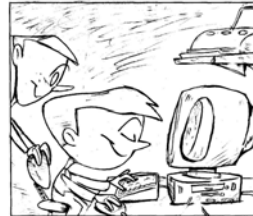
Then they finally got the meds right. I just finished 7th grade and it was the best year of my life. For the first time, I got As, all three trimesters. I made lots of friends. I became "cool."

I got picked by my school to go to Australia for an International Conference. I swam with Dolphins in the ocean, I learned how to drive (on a dirt road when we were on vacation), I learned how to scuba dive and I learned how to play bass.



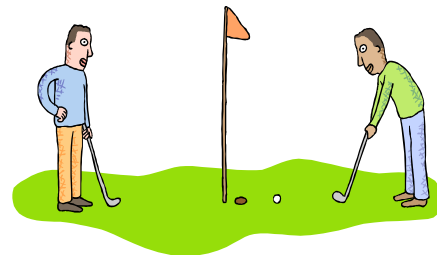
Children's Program
at TSA National Conference
April 23, 24, & 25, 2004
Alexandria, Virginia

**NEW STORIES FOR KIDS
AND TEENS WITH TS!**



A second “Simon” storybook is in production and will be available very soon. Check the TSA web site for news about ordering “Simon the Puppeteer,” story by Candida B. Korman with illustrations by Jake Ospa.

A web novel for kids and teens entitled “Erika’s LITTLE Secret” is TSA’s first all-web fiction. It’s the story of a teen with TS who decides to hide her tics from everyone at her new school. The sometimes comic, sometimes sad, tale takes a good look at the importance of being yourself. “Erika’s LITTLE Secret” will be available in installments for you to download from the TSA web site – starting this Fall!



**TAMPA BAY FLORIDA
GOLF CLASSIC**

by *Josh Ertter*
9-years-old of Cape Coral, Florida

My experience at the golf classic was outstanding. I had so much fun golfing, even though it rained. My favorite part was when my dad and uncle were in the putting contest. They almost made it all the way!

Also, the food was great.

Last, I had a great time at the golf classic and really felt special handing out the prizes with Mr. Preville's son, Joseph.

Pleasantville, New York, wrote the following:

I think of TS as a mountain I must overcome. The problem is, it is as tall as Mt. Everest and I'm not good enough of a climber to climb it. I am gradually getting there. One of my tics is to put my hands at my sides and squeeze my arms as hard as I can while making loud sounds like "EEEEEEEE."

People always ask me, "What are you doing?" I just say I'm cold, or I just laugh if they're laughing and move on.

I have gotten past some of the mountain. I can tell you that I am definitely not at the base. The good thing is there are other climbers with me for the journey.

That's my mom, my family, and a therapist named Marni. She taught me how to control my tics and suppress them and taught me why tics happen. Marni told me that I will have gotten to the top of the mountain when I'm an adult, or maybe when I am only about 17.

Sometimes it never goes away. I think it will because I have hope. My life, I am happy to say, is a very good one. I am thankful for the people helping me climb the mountain that is in my way.

To the Tourette Syndrome Association, I am proud to announce that I am happy with my life and I wish good luck for those who have TS. You guys out there will overcome it, just as I am trying to do.

Thank you!!!

My Three Solutions to TS

by *Michael Arenson*, 11-years-old
El Cajon, California

~~Tourette Syndrome is a disorder with "tics"~~ sometimes verbal, sometimes with body motions. There is no cure for it. People who have it (like me) can control it, but only for a short period of time. I am going to tell you the positives and negatives of the three ways I came up for a cure. Two of my solutions involve a pill. The other one is a test.

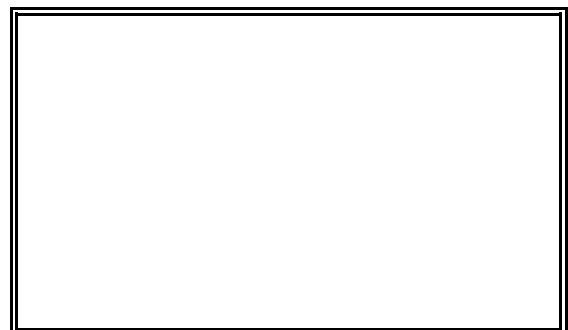
My first solution is in pill form. It is a pill that is 1mm x 2mm. This pill has a little robot inside of it. The robot will find the spot on the brain where it tics and find some way to stop it. Now the negatives: How can they fit a robot in a 1mm x 2mm pill that will go straight to your brain in the correct spot and stop it? And if it does work...think of this...how much do you think a store will sell this for?

camera inside. The camera will take a picture of the part of your brain that makes you tic. Then doctors can operate on it, or simply take it out. The negatives: How can it go straight to the exact spot in your brain? And if it does work, what if they take out the wrong part of your brain?

Now for my last and best solution. I hate this solution, but I think it is the one that will work the best. It's a test that involves two things – you and the things you like to do. First, you record everything you do and see what you're doing when you tic the most. Then, you see what part of the day you tic the most. So now, you know not to do that thing at that part of the day. The negatives are self-explanatory.

These are my three solutions to TS and the negatives too. I hope you learned something.

(note - item removed 10/09/08 at the request of the author)



LETTER FROM THE EDITOR

Zachary Hollis of Albuquerque, New Mexico

I am 12-and-a-half-years-old and summer is over and it's back to school. Nine months of school can become difficult and stressful for me. I have found that I need a simple life for part of the year, my summer break.

The noise, the groups of kids, math gets harder and harder and just the schedule of school gets frustrating. I have a wonderful teacher, Mrs. Hahn. She has learned so much about TS and OCD. I am going to have Mrs. Hahn for two more years. That will be nice; I will not have to educate a new teacher until I go to high school.

While I was out of school, I was able to do research every day on the computer. I like to research exotic and endangered species. Some of the animals I have researched are raccoon dogs, (this was my first animal topic and I spent several weeks on it); then it was prairie chickens, fiddler crabs, degus, tegus, hedgehogs and sugar gliders.

I love all kinds of animals. My family has 3 golden retrievers, (Bob, Sherm and Willie), 3 fiddler crabs, 3 newts, 1 tadpole, 1 bullfrog, goldfish and a hermit crab. My mom says, "no more animals!"

I hope all you kids out there had a great summer and that you have good luck this year in school.

Golden Retriever



That Darn Tic is planning an issue with stories about young athletes with TS. Send us your story – and a photo if you have one. We'll run as many as we can fit in the next issue.

Send your submission to:

That Darn Tic

c/o TSA

42-40 Bell Boulevard, Suite 205

Bayside, New York 11361

Be sure to include your name, address, date of birth and e-mail address.



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The editorial staff and the contributors to this issue of "That Darn Tic" are very pleased that Diane Mallah is the honoree at this year's TSA East Coast Dinner Dance.

A number of the works published in this issue will appear in the 2003 Dinner Dance Journal. Thank you, Ms. Mallah for being a member of the TSA family.

Back in

School