

THAT DARN TIC

A NEWSLETTER BY AND FOR



KIDS WITH TS



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Interesting Facts About Tourette Syndrome by Zachary Ashinoff

1. Famous people with Tourette: Samuel Johnson = wrote the first English Dictionary, Mozart = music composer, Jim Eisenreich = baseball player.
2. Who was the first person diagnosed with TS? The Marquise de Dampierre and several other people were seen by the French neurologist, Georges Gilles de la Tourette.
3. Do people 'outgrow' TS? Many adults have fewer tics than kids but everyone is different. Often, the last few years of grade school are the worst and tics start getting better during high school.
4. What are the last symptoms of TS [when it's getting better]? Usually, the tics just get milder and less frequent, and some people are just left with a few facial grimaces or an occasional sniff or throat clearing.
5. How well do people with TS do? What becomes of them? Mostly it depends on what sort of person they are, how bright or hard working they are, what their personality is and how well they get along with people. There are people with TS who are top-notch lawyers, surgeons, airplane pilots, violin players, rabbis, soldiers, professors ... People with TS can be just as good at anything as anyone else.
6. How do you know when you have TS? A lot of kids, maybe even as many as 15 percent, have a tic that lasts for a few days or weeks. But a smaller number of kids have tics that last or that come and go, get stronger or weaker, but have more than one tic - several motor tics (movements) and vocal tics (sounds) over time.
7. How many people have TS? Since many people with TS have yet to be diagnosed, there are no absolute figures. The official estimate by the National Institutes of Health is that 100,000 Americans have full-blown TS. Some genetic studies suggest that this figure may be as high as one in two hundred if those with chronic multiple tics and/or transient childhood tics are included in the count.

What Tics Look Like by Kerry Temon, 8-3/4 years old

CHILDREN'S TICS

Eye Tic



Shoulder



Tic

King Tic





Brittany Rogers turned 10 on March 2, 1999. She has TS and has participated in Minnesota family camp.

OCD

by Daniel Kendes

OCD is sometimes positive
 But other times it's bad.
 People tease you many times
 And that makes you very sad.

OCD is a certain disorder
 That many people hate.
 It's a very bad disorder
 That people just can't shake.

But look on the bright side
 You can be sure you're not alone;
 You can still do many things
 Like listen to music and talk on the phone.

So never give up
 Because you won't always be this way.
 Because it will get better
 So take it step by step
 And take it day by day.

My School

by Zachary S. Ashinoff

After having spent a year being frustrated by my Tourette Syndrome (TS), I came back to my senses and went back to school. During the Summer, I had forgotten the many emotions I experience when I am in school with teachers, the nurse, the principal and many other very special people.

I remember the times when I visited the school nurse with fake sicknesses. She always understood the truth and the fact that the reason I was there was because I had a tough time dealing with my tics. I guess that I just needed someone by my side – and she was ALWAYS there.

Then I remember the times when the school psychologist came to seek me out when I was having a bad time with my tics. She gave me the courage to get through the “hassle.”

In third grade, she spoke to the class about my symptoms and how I feel when other kids tease me. Sooner or later, every child in the school stopped invading my space. I really appreciate what she did for me. We have accomplished a lot together.

I also appreciate the administrators and the teachers for letting me take tests in different rooms so that I could have space to tic and concentrate. They have proven to be compassionate and understanding in giving me space in school when I need it and knowing that my behaviors are not ill-intended.

I feel lucky to be in this school and to be surrounded by people who care about me.

We would like to hear from you and get your feedback and articles for the next newsletter.

LETTERS TO THE EDITOR

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Story Idea by Nathan Larson

I am a 12-year old boy that has Tourette Syndrome. I have a special friend that plays basketball at North Dakota State University (NDSU) in Fargo, North Dakota, that also has TS. His name is Brian Silk and he is a 6-foot, nine-inch Sophomore Forward.

My grandparents live in North Dakota and saw a sports interview on TV approximately one year ago about Brian Silk and his TS. My grandparents told my mom about it because they know that I really like basketball. My mom thought that Brian would be a good mentor for me, so she helped me write him a letter. That first letter was a year ago and we have become great friends. We write letters, send e-mails and call each other. NDSU is about 250 miles from where I live in Plymouth, Minnesota which is a suburb of Minneapolis so I don't get to see him very often.

Last Winter was the first time that I ever got to see Brian play a basketball game. We saw a couple of his games in Minnesota and a couple of games in North Dakota. His last game of the season was at the University of Omaha in Nebraska so my dad and I flew to Nebraska to surprise Brian. It was a blast.

Brian understands the problems that I have because he has TS too. He has helped me to understand my TS better and has given me the inspiration to know that I can do anything in spite of my having TS.

Hi! My name is Andy Lee. I'm 11 years old, and I have TS. I have trouble with handwriting but not with drawing. I love to draw. It helps me relax. Sometimes kids pick on me because I'm not real good at sports. They do seem to like my drawings though. A lot of times

they ask me to draw things for them. I like that because then I feel like they respect me and fit in better.



A Letter from Zak by Zachary Hollis

Hi, my name is Zak Hollis and I live in Albuquerque, New Mexico. I am eight years old. I live with my mom and dad and I have a sister and two brothers. I am in the second grade at Albuquerque Christian School. I love to play soccer and I want to play baseball. I collect rocks and Volkswagen Models.

I have Tourette Syndrome. We found out that was the situation last Fall after school started. I was very scared and we did not know what was wrong. I had an eye tic, a head tic, a hand tic and a throat tic. My tics got really, really bad very fast. It seemed like we went to a hundred doctors. One doctor thought I had allergies, one thought I needed to have my tonsils out and one told my mom I was just trying to irritate her. We finally found out it was Tourette Syndrome.

My parents talked to the school and we told them all about TS. I talked to my classmates in school, Sunday School and Cub Scouts. I told them about it. Some thought I had a disease and thought that they might get it. I told them it was a syndrome not a disease and they could not catch it. My mom got on an airplane and flew to Houston to a conference on TS. The national association put this on. My mom learned a lot and came home and told me all about it. Then we flew to Baltimore, Maryland, to see a doctor who knows a lot about TS. In the morning, my tics are not as bad as at night. When I get tired, they can get very bad. Sometimes at night, my whole body hurts and my mom gives me massages. I also have different hot packs that feel good on my muscles.

The kids at my school are really nice about my TS. No one teases me. My teacher, Mrs. Pippert, is the greatest teacher in the world. She learned all about it and lets me do different things that help my TS. She lets me run errands, so I am not always sitting. Sometimes she lets me run in the gym. If I feel I need to be in a quiet spot, I am allowed to ask a friend to eat lunch in the classroom where it is quiet. I told Mrs. Pippert my back hurt because of a tic in my back and she even gave me a back massage! I have a nice doctor. We visit with him for my rage. It got bad when my TS got bad. He is helping with my medication.

Our family is helping to start a chapter for the Tourette Association here in New Mexico.

SYNDROME

by Nick Silver

Medicine in hand
Water wash it down
Normal once again.

She wakes to a world of hate, disrespect, teasing,
mocking, laughing.

Boys who don't understand the normalness
of imperfectness.

Doctor's office, pharmacies, documentaries.
Reason to seek protection, perhaps a shield of armor,
strong and sturdy enough to repel the stares,
snickers, and jokes,
like a bug spray that repels the mosquitos.

Medicine in hand
Water wash it down
Normal once again.

I see her pain in every tic conquering her body like the
Egyptians did to the Jews in the time of Moses.

Inside something is lost, misplaced by God
in home-ec class.

Reward if found:

All the money in the world.

I hear it in the hoots and hiccups that shoot from her
mouth like cannon balls out of a cannon.

I smell the fear she hides in the country apple spray,
always overused and lingering after when it is gone
like a bad memory.

Medicine in hand
Water wash it down
Normal once again.

Their laughs tear at me, wear down on me, don't care for
me, louder with every tick of the clock.

Gazes anger me; the mother who forgot to teach her child
not to stare, as waterless tears run down my face.

Resist raising the white flag.

Medicine in hand
Water wash it down
Normal ever again?

Amazed by her strength, determination, success;
jealous of the will to live; angry at her forgiveness.

Hiding her face like a shameful puppy.

Right to live her life, her self, not protected in the
land of the free.

Yet it is she, the epitome of the home of the brave.
But to find purpose in illness is the treasure she already
has a map for.

Medicine in hand
Water wash it down
Normal once again.

HAVING TOURETTE SYNDROME

by Leo Jackel

I have Tourette Syndrome. Tourette Syndrome is a neurological condition that makes my body do certain things. Due to the disability, I have a difficult time controlling impulses I have, such as playing with my fingers, lashing out, tapping and grimacing. These impulses listed are called tics. Even though I have made friends in this school, it is hard for me to add more friends. Some girls run away from me because they are afraid of me which makes me very sad. I'm not even trying to scare them, I don't even want to. It is probably because I grimace a lot. I'm afraid if I tell any of my classmates, they might take me for retarded. I am not retarded. I am very intelligent and have good social skills. I am able to look at things from different aspects than everybody else.

I need somebody to help me overcome all of this. I want to be able to stop it. Are people going to look at me funny for the rest of my life? I don't know. If I didn't tic, I would feel all squirmy. I really want to fight this off.

In order to fight this off, I'm taking medication. The side effects I've noticed are drowsiness, not being able to think straight and being giddy. I take medicines to prevent the tics and to help me concentrate. I go into Manhattan for my chiropractic adjustments which helps me relax. I go to the Tourette Syndrome Association in Bayside to talk to the social worker and other people with Tourette Syndrome. I talk to friends. These things mentioned help me. Love, understanding and being accepted for who I am also helps me. Being able to express myself without being afraid of people laughing at me or ridiculing me is very important to me.

Maybe if people understood me, they just might be more comfortable around me. They might forget that I do some weird things, but inside I'm just like any other kid with feelings, a sense of humor and friendship to share.



'That Darn Tic' was written by and for children with TS. The opinions expressed are those of the writers and do not necessarily reflect the policies of the national Tourette Syndrome Association, Inc.

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