

It's Not Just For Kids Anymore

 An Online Newsletter Written for and by Adults with Tourette Syndrome

Volume I * Number 4



Have Fun With It!

Similar to most individuals with TS, I have heard some interesting questions/comments in my time. "Why are you moving your neck like that, how come you keep looking at your shoulder, are you OK?" This does not bother me in the least. I feel extremely fortunate in life, as I have a wonderful family, great friends and personal traits/characteristics that have brought me great success. All of these factors have helped me to become a positive person, and I never complain about having TS. I recognize that life could be a lot worse, and I can either dwell on the hardships of life, or do my best to be a happy person—I choose the latter. In fact, I can honestly claim that I am grateful for the disorder and I

would not give it up if offered the opportunity to do so.

It may seem strange that I do not abhor having TS in my life, and even stranger to hear that I would not give it up. Let me explain this. I am not, by any means, the kind of person who is always in a good mood, and I do find frustration in certain aspects of life. Thus, do not think that I am proud of TS because I am just unaffected by hardships. However, when I was very young, I realized that we have choices in this world. We can complain incessantly and curse the innate qualities given to us, or we can find humor in the negative and thrive on the positive. I love to make people laugh and comedy is a passion of mine. I have been able to joke about the twitches since I was a kid, once I learned that the idiots who truly have a problem with them are not worth my

time. This has helped me to learn that life is not always perfect, and we have the ability to joke about these imperfections. Every time I twitch and joke about it, I see smiles form on other people's faces. I feel that I am inspiration for them to have fun with their own flaws and not always take themselves so seriously.

Although I only have a mild form of TS, I still feel that it is a major part of my life. I am a successful guidance counselor and tennis coach with a Master of Science in Education, and I have a bilingual/ESL extension on that degree. I have wonderful relationships with my family and friends, and I am never bored in life. I am living proof that a person can take a hardship, embrace it, and use it to his/her advantage.

**Adam Genovese, 26
New York**

Tremors

I have had TS since I was at least seven or eight. I don't remember how old I was, but I think I was in the second or third grade when my tics started. The first tic I remember was eye-blinking, followed quickly by mouth stretching and eye rolling. My tics change every 6 months to a year. I was not actually diagnosed until I was 13, and not treated until I was 16. It was really difficult for me because I did not know what was wrong with me. I just thought they were "habits," even though I had no control over them, or did not know how to stop them.

The worst thing about having TS as I grew up was the embarrassment of it all. People always made fun of me for it, especially as I entered high school. They would count the seconds in between my tics. My nickname was "Tic" or "Tremors" because I would always shake all over.

When I was 16, I was given a medication for my TS that works really

well. I am 25 now and I have been taking it all these years. Sometimes it makes me really lightheaded if I'm over-stimulated, so I take it at night to avoid the side-effects and I get the double-benefit of having a good night's sleep and sometimes some cool dreams. Now no one can even tell I have TS. The bad thing is that it got rid of my tics so well, that I did not tell people in college that I had it, because I was afraid they would think I was weird. Then one day they would find out and stop hanging out with me. So, it's better to be straight forward with people that you have it—it's like clearing the air. You don't have to tell just anyone, but if you're going to be friends with someone, it's good to tell them so there is not a big secret between you.

Actually, most of the time when I tell people that I have TS, they honestly think I'm joking. Then they say something like, "Oh, that would be so cool to have TS so I could have an

excuse for cussing people out." There has been a lot of bad publicity about TS, like

"Deuce Bigalow Male Gigalow," and all those movies that poke fun at it. It's kind of annoying. I wish someone would make a movie about a true story about someone with TS. I mean, it's going to be funny anyway, but someone should show the other, more humiliating side of TS.

In recent years, I have taken pride in the fact that I have TS because it has made me a stronger person. I am also a successful person. I have a Master's degree in social work, and I work in child abuse prevention. I take pride in myself and in my job. I know I would definitely not be a social worker if I did not have the experience of having TS. Thank you TS!

**Lauren MacPherson, LMSW, 25
Kansas**



A Life Hidden Behind a Smile



Growing up I knew I was different, but didn't truly understand why. I knew I had something

that set me apart from everyone else (my family, my peers and the small community I grew up in). The frustrations I concealed and suppressed during my early childhood had a profound effect on the way I lived my life day in and day out. I hid myself from the world.

I never let anyone in. I felt so alone in a world overflowing with love from family and friends (who didn't even know what I was dealing with). I wanted to die. I wanted to belong, but was afraid of not being accepted with this "freakish" problem. I thought nobody would understand me although my poor mom tried with all her might. I took it out on my mom who deserved none of this punishment. It was not her fault that I was a child dealing with the frustrations of Tourette Syndrome. This disorder was not diagnosed by a doctor until I was much older; it was my mom who researched everything under the sun to figure out a way to help me. I was angry that she wanted to understand me; in my eyes, nobody could understand me; I was alone and different and that was that.

Having the urge to blink your eyes continuously makes sense. Having to sniff and clear your throat almost as continuously as blinking your eyes did not. In addition to these abnormalities, I was continuously having to lock my knees, tighten my neck muscles, curl my toes, wrench my wrists, tighten and release my quad muscles, "unpop" my ears (as if I was on an airplane) by moving my jaw and even repeat a tapping sequence with my fingers that made no sense, but I had to do it—*constantly*. This never stopped. I would try to stop

everything when going to sleep and it was a challenge. I couldn't do it. I would try to tell each body part that it was time to go to sleep and see if the urges would disappear in that area of my body, only to find out they wouldn't listen. Eventually my body would get exhausted and I would drift off to sleep only to experience nightmares.

Each morning it was a vicious cycle. I would start to get dressed and nothing would be comfortable. Nothing felt right. Everything felt too tight or too loose or not right at all. I would cry and scream and tell my mom that I hated myself. I would have to lock my knees, tweak my neck and blink my eyes in ways that weren't natural and I would have to repeat it time and time again.

Before leaving the house, my mom would always tell me to "put a smile on your face" and your day will be better, I promise. As soon as we left the house, I was a different person prepared to take on the day with a nice friendly attitude. I had a way of concealing the tics by stretching or saying I had allergies. I knew this was the only way to get by since I couldn't take my frustration out on those who didn't know me and what I was going through. I also figured it would be way too hard to explain to anyone what I was dealing with since in my mind nobody could understand. In public and around my friends I was a different person. Always happy, always smiling and always hiding something I didn't want anyone to know about. I never opened up to let people know the real me. I was afraid of rejection. I wanted to avoid a difficult life. All I wanted was to be normal and happy like everyone else.

Taking the time to re-trace my life and determine what held me back from being myself, I found that it was this disorder. I personally chose not to share fully of myself with others because I had not accepted myself for who I was. I am in search of a way to give back and help young

kids who are facing the challenges of Tourette Syndrome. I want to help them realize that they can be accepted for who they are even if they have tics.

**Lindsey Back, 24
California**

LIVING WITH TS

Adult Challenges

New Webpage on
<http://tsa-usa.org>

On February 6, 2006, TSA introduced its newest website resource: Living With TS. Below is the introduction to this new website feature.

Sharing information and support is at the heart of TSA's mission. This section of our site is the place to access informative articles discussing the everyday challenges of living with adult TS. One of these days, TS will be "irrelevant." Until then, TSA offers these articles to shed light, break down issues into manageable components, stimulate your creative problem solving and support self advocacy.

The writing of original materials, as well as site development, was made possible through TSA's partnership with the National Center on Birth Defects at the U.S. Centers for Disease Control (CDC). TSA has launched extensive medical and professional educator programs, and produced and disseminated resource materials to medical and allied professionals, education professionals and the public to raise awareness of, improve the diagnosis and treatment of, and increase educational resources and supports for persons with Tourette Syndrome.



Taking My Life Back

Growing up, I always wondered what was wrong with me, mostly because I was bombarded with people asking me that very question. My tics started when I was seven years old, which was the same year my parents divorced giving everyone a built in excuse. Doctors told us that I had emotional problems due to my parents divorce. I knew that wasn't true but who is going to listen to a 7-year-old. For the next 24 years I lived with a secret that I didn't even know. 24 years of hearing that I had emotional problems and knowing that diagnosis was wrong. 24 years of something controlling my actions and thoughts. 24 years of no one listening to me.

On June 21, 1999, I was at work when I was approached by a customer who asked me what medication I took for my Tourette Syndrome. I remember my first reaction was anger. I had seen all those TV shows where people with TS swore and barked and I knew I wasn't one of those people. I went home that night and began to tell my wife the story of the stupid customer when I saw a commercial on TV. The commercial showed an outline of a man and his head shook like mine, his arms twitched like mine and he made some of the same noises in his throat I did. The person on that

screen was me. What I saw at the bottom of the screen would change my life forever. The screen read "West Michigan Tourette Syndrome Association." The very day I had someone ask me about TS, I saw this commercial. It was a sign. I know it was. It was the day I took my life back. I was shocked, scared, nervous and excited all at the same time. I went to my new doctor and received my official diagnosis and had a ten-ton weight lifted off of me. I was energized, excited and for the first time I felt alive and in control. My wife, Beth, was 100 percent supportive which gave me the strength to tell others. Unfortunately not everyone was ready to accept this diagnosis. I had family that refused to accept it and my even father told me not to tell anyone at all about it. After the request to keep my diagnosis quiet, I did the most reasonable thing I could think of.

From that day on I dedicated my life to educate anyone I could. I learned everything I could and shared my newfound knowledge with anyone I could get to listen. I began to realize something amazing, there are more people like me in this world than I ever dreamed of. I am a true believer in fate. I believe everything happens for a reason. I have TS so I can help others. I am a better person because of it. I have always wanted to be able to help people and now I found a way to help those who really need it. There are people being diagnosed every day and a lot of these people

need answers and a shoulder to lean on. They need a friend that understands what they are going through and can provide the answers they need without judgment. I could have locked myself in a closet and hid from the world but that wouldn't have helped me. I have had the opportunity to be on TV and radio. I have done interviews, speeches and helped actors portray tics in a movie. Every one of these things I have done has helped me as much as it has helped others. My therapy comes from helping others. My life has finally begun and I plan to live it to the fullest.

Recently, a program aired on HBO called "I Have Tourette's but Tourette's Doesn't Have Me." What a true statement that is. Tourette Syndrome doesn't have me but I do have Tourette Syndrome. As much as TS uses my body, I use TS. I use it to help others deal with it and look at it as another challenge that can be overcome. When a bully hits you and makes you cry, he wins. If you refuse to show the pain then you win. Tourette tries to hit me every day and I laugh in its face. Sometimes it hurts like hell but I laugh in its face and move on. I win.

**Leonard W. Misner, 38
Michigan**

Editor's Note: "I Have Tourette's but Tourette's Doesn't Have Me" is available on DVD from TSA.

TS - It's Not Just For Kids Anymore is a newsletter aimed at addressing issues and concerns relevant to young adults with Tourette Syndrome, ages 18 to 40. Topics such as college life, dating, job searching, marriage and children and features including success stories and profiles of adults with TS will be included. In addition, the project hopes to provide support to those still coping with their diagnosis and help them understand that "the TS they grew up with may not be the TS they wake up with tomorrow."

This newsletter will be available online only, at the TSA website, <http://tsa-usa.org>.

The next issue is planned for September, 2006. The deadline for submissions is August 31, 2006.

All submissions are subject to editing and are included as space allows. There is no guarantee of inclusion.

If you are interested in becoming involved with this newsletter, either by submitting articles or suggesting story ideas, please contact Tracy Colletti-Flynn, Manager, Public Relations and Communications by email tracy.flynn@tsa-usa.org or at (718) 224-2999, ext. 236. Include your name, state, email address and/or phone number so you can be reached if further information is needed.

Was That You?



There are three phrases in the English language that I dislike more than any: "What is that?" "Did you hear that?" and "Was that you?"

Any one of these questions can make my heart drop and my stomach lurch in an instant.

Anyone with TS can relate to the questions and looks (sometimes stares) that are bestowed upon us; often more than once, ten, forty times a day. While I am not yet in a place where I can analyze my feelings, thoughts and anger toward my condition, I can talk for hours about diagnosis, symptoms and the lack of treatment options with anyone that asks. When it comes to actually facing the topic, I back down. This is not to say that I haven't had my moments of rage, pity and embarrassment. I've definitely suffered breakdowns where I can only cry and shake my head yes or no when my boyfriend tries to (very sweetly) guess what's wrong. My breakdowns can be therapeutic, but more often than not, they just push my feelings further toward the back of my head.

So, in my first attempt at discussing TS (I very rarely say "Tourette's;" another issue I need to face) I developed a blog where I write down how severe my symptoms (yes, "symptoms" in place of "tics") are that day or week and what else is going on in my life. I thought that if I could compile my thoughts, activities and symptom severity in one place, I may see a pattern develop. I wanted to find out when my symptoms are at their worst and when they are at their best (best by my standards are when they aren't interfering with my work or when I don't want to cry on the bus because so many people are staring at me).

At any rate, that's where I am today...how I got here is another story. I do not have TS for the typical

reasons (genetics, etc.), but because I developed Kawasaki disease at age one. Kawasaki attacks a child's body with fever, blisters and extreme flu-like symptoms. I spent two weeks in the hospital where doctors tried to diagnose and treat me. During that time my immune system (think little baby immune system) fought so hard against the disease that the dopamine levels in my brain were increased (no exact explanation for why this happens...but it does!).

Around seventh grade is when I began to develop symptoms of TS. At the time, my parents thought that my noises, head jerks and nose twitching were habits that I could control. I too, thought that they were a habit and would pray every night for the strength (with my face down in the pillow and another one over the top of my head to muffle my noises) to break my habits.

During college my symptoms virtually disappeared. It wasn't until my first year out of school that my parents realized that my "habits" were back. At the time I was working at a PR agency and living with a roommate in Chicago. I was at my parent's house for the weekend when my mom woke me up and put a pile of papers on my bed. She said that I had Tourette Syndrome.

Since then, I've been to therapists, internists, pharmacists and psychologists. I've tried three different drugs, nicotine, vitamins, diet, exercise and relaxation techniques.

While there is no cure for TS, I hope to one day find the right combination of vitamins, diet and exercise that relieve me of my symptoms, if only by half.

I strongly believe that more needs to be done by pharmaceutical companies and the media to create an awareness of our condition. Only awareness can relieve us of the questions and stares and only pharmaceutical companies can adequately fund research.

**Leah Farrasso, 26
Illinois**

Interesting Reading...

Getting Personal, Stories of Life with Tourette Syndrome edited by Michael G.DeFilippo. A technical writer and first-time author, Michael DeFilippo was diagnosed with TS in 1998. *Getting Personal* is a compilation of more than 20 stories of real people with TS. Second Chance Publishing, www.secondchancepublishing.com, \$16.95.

Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had by Brad Cohen and Lisa Wysocky (foreword by Jim Eisenreich) is an inspiring true story of incredible challenges and unwavering determination. As a child with TS, Brad was ridiculed, beaten, mocked and shunned. Some people thought he was possessed by the devil. Others, including members of his own family, refused to be seen with him in public. As an adult, Brad overcame all odds to become an award-winning teacher of the year for the state of Georgia. Nothing, not even TS, stops him from pursuing—and achieving—his goals. VanderWyk & Burnham Publishing, www.frontoftheclassbook.com, \$22.95.



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