

It's Not Just For Kids Anymore

 An Online Newsletter Written for and by Adults with Tourette Syndrome

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How I Learned to Accept Myself

My name is Eugenia, I am 36 years old and I (still) have Tourette Syndrome. I am very blessed in several ways. I have a very mild case, I was diagnosed at the age of 5 (in South America no less) and I am married and have two beautiful children.

I've often thought that if I could change something about myself it would be to get rid of my TS. But, TS has shaped me into the person I am today. So, would I change the core of who I am?

I know there are many people who have TS but struggle because they are not diagnosed with it. However, having a name for my tics and OCD was never very helpful to me.

I lost my best friend of 5 years to TS. No, no one died. It's actually worse than that. Throughout elementary school, my TS had been tolerable. But all that changed when I became a teen. My tics got worse and more noticeable and my awareness of people's awareness became my daily battle.

As Junior High School loomed, the decision was made (amongst my family, doctors and teachers) that it would be best to start telling people about my "condition." Up until this point, I had been able to keep it under wraps. I decided to be brave and one day during a play date, I told my best friend what I had (I was 12 years old). I explained to her that it was a chemical imbalance in my

brain and that it didn't impact me in any other way. I told her that I was still the same old me, only now I had a name for the quirks. I'll never forget the blank glaze that came over her face. She never spoke to me after that; not even in high school. After this experience, I completely shut up. I vowed never to tell anyone about TS ever again. I was a pioneer actually, because back then, there weren't a lot of people with allergies like there are now. I told people I had allergies, a bad cold, sinus infection, anything to keep them from the truth. I got through HS that way, and then came college.

In college I met people who were more aware. I actually had a friend who knew all about TS and one day she flat out asked me if I had it. You can imagine my reaction. I had no idea what to say. After 'fessing up to her, I realized that maybe people could deal with it. I told some of my very close friends. They are still my friends now.

My husband (HS sweetheart) is amazing. When I'm stressed out and I start ticcing unknowingly, he gently tells me what I'm doing so I can get a hold of myself. He tells me that I wouldn't be who I am without it and that he loves me just as I am.

Living with TS hasn't been easy. Every August and September my tics automatically get worse (still). I believe this is residual from my school days. Like most kids who are anxious about a new school year, my anxiety was ten-fold. I hated starting

a new year with new teachers, students and tics.

I know I haven't had it as bad as some

other people, but I have always been ashamed of TS. It has been hard for me to share my secret. I am in awe of everyone who speaks up and shares their story.

My daughter is 3 years old and is exhibiting signs of OCD. I worry that she might have TS. I hope that she's just being 3!

I often think about what my kids will have to go through in school and with their peers. There are certain experiences that I've had that I wouldn't wish on anyone. But, TS has not kept me from living life to the fullest and I am a stronger person because of TS. I am gainfully employed, I have great friends (only a couple of them don't know), and I have a wonderful family. I pray daily that my kids won't have TS, but if they do, they will have ultimate support from their parents, they will have a proper diagnosis, and there's always the hope for a cure. Don't let TS rule your life; use it and become empowered!

Jenny, 36
Fairfax, Virginia



Turning Lemons into Lemonade

I was diagnosed with TS when I was in third grade. For the first three years after I was diagnosed, I went on a rollercoaster ride of trials of medications to control my constantly changing and often painful tics. I was teased by older students at school, and it was not an easy time. With the support of very caring parents, a great sister, a counselor and a few teachers who seemed to understand my TS, I survived this difficult time.

From the beginning my parents said to me, "You have TS and you cannot change that, so take it and make the best of it." I was given my first chance to "make the best of it" in seventh grade when I was invited to speak to a children's book club in a local community. They were reading "Quit It," a book about a girl with TS, and they wanted me to come and share my experience in dealing with TS. When I arrived at the library I was surprised to learn that there were reporters from over

half a dozen newspapers, including "The Philadelphia Inquirer," who had also come to hear what I had to say! I found it quite easy to talk to the group about my experience as young person with TS, and I received many great compliments about my ability to speak publicly.

I realized then that I could do something special and use my experience and skills to educate the world about the condition and to help others with TS. To date I have spoken about TS to parents and professionals at two TSA National Conferences and at numerous local and state conferences. I regularly go to schools and help kids educate their peers about TS. I have also received three major awards for my TS work, and this has helped me to be accepted into the very selective college that I fell in love with at first sight. I hope that my message will help other kids with TS realize that having TS does not always have to be a bad thing. As a person with TS, there is plenty that you can do to make a difference.

Jay Geyer, 19
Collegeville, Pennsylvania



Working Out Tourette Syndrome

When I was younger, I always thought Tourette Syndrome would impact my life. I had trouble in school and with my behavior because of TS. My tics

weren't that bad, but they were noticeable. My view of TS changed when I realized that some aspects of TS gave me an advantage over lots of people. My concentration and focus were above average. I would always go over little details in my head, or write down things that I needed to get done. I was good at writing lists, setting six-month goals and achieving them.

When I was 22 years old, my career started to take off because I was so focused on it. I knew it would be hard to sit still at a desk job, and I needed to do something that kept me moving. So in 2007, I started my own personal training company. Every day I create a to-do list for my business and try my best to get it done. I work hard from Monday through Friday (usually from about 6 a.m. to 7 p.m.). I take weekends off to help rest my body and mind. Soon everything just fell into place

for me. I found that I was always meant to be a motivator. I currently have a steady client base of 41 people, and hope to grow BJ's Fitness even more!

I realize I will always have setbacks. Everyone does and they can make a person stronger. My tics get bad when I get nervous or anxious. But, when I focus on relaxing, it helps so much. I don't take medication anymore and have found different ways to channel my TS. I am very active in all sports, and I sometimes listen to music to stay relaxed. When something is bothering me, I might write down how I am feeling, or find different ways to channel it.

I love to teach what I have learned about fitness. Seeing results on my clients makes me even more motivated to do an even better job.

Dealing with my TS has prepared me for the obstacles I'll face in the future. I can channel my stress and anxiety a lot better now that I have gotten older. I also understand TS a lot more and know that I'm not alone in this world. Everyone has problems, it's just a matter of turning them into successes. Finding positive energy from Tourette Syndrome helps you get those positive results!

Hope this helped some of you out there!

Brandon J. Lepp, 24
Cleveland, Ohio

Living with the Monster

When I was about seven years old, I had a hard time concentrating in school. I would never be able to stay focused, and I would always need to be up and on the move. My teacher contacted my parents and they came to the conclusion that I may have ADHD. After some tests, the doctors decided that they would put me on Ritalin for the ADHD. When I was eight years old I started to blink my eyes constantly, it was like I couldn't even walk because I couldn't quit blinking my eyes long enough to see what was in front of me. My parents started to worry about what might be going on with me. They took me to the doctor, and the doctor had told me to stop taking the Ritalin because they thought that was what was causing my eye blinking tic.

Well the tics kept coming, and it went from blinking my eyes, to shrugging my shoulders, to grunting, to making noises, scrunching my face, and it just continued to get worse. My parents decided to take me to see a neurologist. They had done all sorts of tests on me to see what was wrong, but no one could ever seem to figure it out. Finally one day, they said, "I think that she has Tourettes." At the age of 8 when I heard this, I said, "I have what?" It took me by surprise. I used to call it my bad monster inside my body. I tried on all sorts of medicines for my TS, but they all seemed to have side affects to them. One would make me have anxiety attacks, and the other would make me sick. It was just medicine after medicine after medicine.

I was a very smart and successful girl. I just had something different than what other people had. Some people thought that I was just doing it for attention, and other people just thought that it was funny to make fun of me, and tried to imitate the tics that I did. Going through school and being picked on all the time was hard. Many days I would come home and cry and just say, "Why me?" How could kids be so cruel?

I finally decided that this was just something that I had, and I didn't want to take medicine anymore, I was just going to live with it, and people would just have to

accept for me for who I was, and if they couldn't, then that was their loss.

My tics have never been to the point where I have yelled out profanity. I mean my tics are severe, but over the years I have learned how to suppress them, and I really hold them in while I am around people.

When I am by myself, it is like a sigh of relief, and my body is just like, "thank you, for setting me free."

Today I am a successful woman, who has a great job working at a call support center, talking on the phones all day long. I am going back to school to major in Business Administration. I am doing everything that a normal person would do.

Tourette's has not taken over my life, it has made me appreciate life in a whole different way. I am blessed in so many ways. I have great friends who care about me so much, and family and friends who love me to death. And most important, I have my faith in God. He is the most important piece in my life and I know that He has a plan for me and a reason for me having Tourette's.

For all of you out there reading this, don't think of TS as a downfall, think of it as you fighting that monster and telling it that you are not going to let it empower your life.

Thank you for allowing me to share my story with you. I have read some great ones in this newsletter, and some have touched me so much. I hope mine can touch many lives as well.

Britany Beck, 22
Franklin, North Carolina



Circle 'Yes' or 'No'

One of my fondest memories of elementary school—even though I did not think so at the time—was the simplicity and innocence of having a “girlfriend.” I use that term very loosely because I do not know whether being chased around the playground a few times a week or passing “I like you” notes in class constitutes a “girlfriend” relationship. But looking back, it sure was fun to be driven crazy by a little girl and to do the same to her!

Yet somewhere between asking a girl to circle “yes or no” on a “Do you like me?” note and getting diagnosed with Tourette Syndrome, things obviously began to change. I gained considerable weight when I began taking medications. I became lethargic and tired all of the time. And I spent a great deal of time studying because I was afraid (naively I might add) that I would suffer academically. Now, it is no secret that boys and girls develop differently and change at different times in the growth cycle. But when those changes are compounded with the physical, emotional and social aspects of TS, the idea of asking someone on a date becomes a bit overwhelming. Sometimes, the fear becomes so big that many of us just decide to forego the process altogether.

For me, I was fortunate enough to have a supportive family, a small town and school, lots of friends and good grades to keep me going. But I rarely dated and went many years—including most of high school and college—without going on an ‘official’ date. And while some of those reasons were unrelated to my disorder, the tics probably played a role in the beginning. As I think about all the reasons why, I am reminded of a message I received from a girl in the 7th grade when one day I worked up the nerve to write her a note to ask her to attend a dance with me. I spent a great deal of time explaining my condition, my fears and why I would understand her declination of my proposal. She responded with this:

*Jason,
What you need is a KISS: Keep It Simple Stupid! Yes, I will go with you to the dance.*

“Julia” XO

In an effort to “keep it simple,” here’s what I have developed and used over the years to get me through the dating scene. I call it, “Going through a PHASE.”

Patience. Things will happen. They just will. Be yourself and be patient with others’ understanding of your disorder. The right person will accept you...the wrong one does not matter! Even though I have only been in love twice in my life, both were rewarding experiences that took patience...lots of patience!

Humor – Laugh! Laugh at yourself and what is going on around you. My wife tells me all the time that my sense of humor is one of the best things about me. I do not know if I am that funny, but I do know how to laugh at myself and make light of a situation. Someone once told me, “Angels do not fly because they have wings. They fly because they take themselves lightly!” Keep that in mind.

Acceptance. If you have not already accepted your disorder as a part of who you are, then you are probably not ready to successfully enjoy a relationship. If you do not love and accept yourself, it is impossible to love and accept someone else. There is really no other way to say it. Just remember Popeye, “I yam what I yam!” Be proud of who you are and accept that TS makes you unique.

Support. Seek out your family and use your friends for support and guidance. Many times it is our friends and family who see others who fit with our sense of style, sense of humor and sense of self-worth. While their advice is not always “golden,” it is important to take from it what you can. More importantly, use those people to lean on when you struggle. It is a priceless gift!

Experience. Recognize that rejection is not the worst thing in the world. Chalk it up to experience and

move on. Do you hear me? Move on. My dad has always told me that failure “builds character.” I always hated to hear that, but it really is true. It often does not feel good at the time, but bouncing back and trying again always pays off. One of my favorite quotes is from Nietzsche, “That which does not kill us only makes us stronger.” If you are reading this, you are still standing. And if you are still standing, it means that you are better and stronger because your experiences in life—including relationships—have made you that way.

I have gone through the PHASE on more than one occasion. And on the other “side,” I feel that I have come out a stronger person, a more loving husband and a better father because I harnessed the power of patience, humor, acceptance, support and experience.

After being diagnosed at age 12 and living for many years either not dating or dating the wrong person, I found my soul mate. I knew it after one date, and I am not kidding. Ironically, she was a “friend” whom I had met years ago and kept in contact with over the years. She and I are compatible in so many ways that it is amazing we never realized it before, but we were both content in our separate lives. But we are even happier in our lives together. I waited a long time—to the age of 33—to walk down the aisle and say “I do.” But she was the one that brought me to the point where I knew it was what I wanted...and I still do want it every single day. And even though my wife did not chase me around the playground to plant a kiss on me like my little “girlfriend” from grade school, it was just as much fun and even more rewarding than it was way back then.

Hang in there, be yourself, and allow others to love you for who you are...and love will find you for sure!

Jason Miller, MPH, 34
Conway, Arkansas

Calling All Marathoners!

If you are a runner who regularly participates in Marathons, or wishes to, we would like to hear from you. Please contact the TEAM TSA Office at 718-224-2999, ext. 256 or visit <http://tsa-usa.org/teamtsa> to learn more about the TEAM TSA Program!

Save the Dates! TSA National Conference April 2010

Mark your calendars! The next TSA National Conference will be held in April of 2010. General sessions run from April 16 through April 18. More information will be posted on the TSA website as it becomes available. Save the dates and get ready to join us in 2010!



Fighting Back with Prayer and Diet

I was 20 years old when I started noticing the effects of Tourette

Syndrome. I had very mild symptoms up to that point, but it wasn't until the shaking began that I realized that something might be wrong. A negative thought would hit me suddenly and I would shake my head, close my eyes and clench my fists in response. It didn't happen very often and people never noticed. But slowly my symptoms started varying and coming more frequently. My arm or my leg would flinch in response to my thoughts. My family took me to our doctor who mentioned Tourette Syndrome as a possibility, but my symptoms were so mild that he wasn't really sure.

Eventually my tics wouldn't always be related to what I was thinking. Sometimes I would just shake my arm back and forth trying to release some sort of tension. At one point they were so bad that I couldn't stand to be in groups. I would shake constantly as long as I was around people, but it would calm down immediately after getting away. Or sometimes after being out for the day, I would go home and just let it all loose. I would shake my arms and stomp my feet. Sometimes I would jump up and down, spin around in circles and hit my head up against the wall. I would hiss, growl and make all kinds of weird sounds with my mouth. I didn't know what was wrong with me.

My friends and my family didn't know what was wrong with me,

either. My friends, for the most part, didn't ever say anything to me about it. That made it kind of awkward because I knew they noticed it, but I didn't know how to bring up the subject with them. Since neither of us said anything, most of the time we pretty much just ignored it. They were great and just accepted me as I was, shaking and all.

My family was concerned for my health and my safety and prayed about and researched ways to help me. I went to counseling and questioned everybody I knew who I thought might know what it was. Day after day I prayed to the Lord, asking Him to take away my shaking. Sometimes my tics would almost go away and I would have just one or two a day. But they would always come back, a little worse than before.

One day, right as my tics were increasing once again after a few low tic months, I met a man who was teaching a relationship class I was going to. He seemed to know so much and have a lot of experience with people and the problems they faced. The way he taught the class impressed me and I remember thinking that if anybody would know what my problems were, he would! He agreed to meet with me. Not long after I explained to him what my problems were, he told me that he thought that I had Tourette Syndrome. I remembered what our doctor had mentioned to me about it earlier and I immediately began researching the disorder. The more research I did, the more confident I became that that was what I had. I later went to a neurologist that agreed that it was probably Tourette Syndrome. I was very relieved to finally know what was wrong with me, but I still didn't know what to do about it.

Then, one day I was visiting with a

friend and we started talking about how the food we eat affects our health. She suggested that I look at what I was eating and consider changing my diet. After thinking about it and doing some research on it, I made some dramatic changes in my diet. After a couple of weeks I started noticing some differences and today I live practically tic free. All of my major tics are gone and only a very mild form of Tourette's remains. As long as I continue to eat healthy I do pretty well. What a relief!

I don't claim to have a miracle cure that works for everybody with any form of Tourette Syndrome. I do know that the foods we eat have a whole lot more to do with our body than we give them credit for. My advice to anybody with TS is, not give up searching for answers. Although there is no cure for Tourette Syndrome, there are many ways tics can be controlled. Pray and ask God to help you find a solution and He will. It may not be the way or the timing you thought it would be, but He cares about us and wants us to live healthy and Godly lives. When I started praying about my TS, I expected him to sort of just snap His fingers and take them away. There were times when it seemed like He did that, but the shaking would always come back. It wasn't until He placed people in my life to help me did He fully answer my prayers. Now He can use me to help others with similar problems. One of the biggest lessons I learned from my struggles with TS, is that God answers prayer and that we can trust Him every day of our lives regardless of what problems and difficulties we have.

May God bless you wherever you are in your life-journey.

Rebecca Baehr, 24
Sterling, Nebraska

Keep on Ticcin'

Well, spring is here people, and with that comes everybody heading outside to enjoy the warm weather. If you have Tourette's, some of you may see that as a curse, others as a blessing. Myself, being diagnosed about 15 years ago or so, have learned how to deal with this time of year as self-assessment. Is this the year I tackle my TS head-on and face it, or do I just put it away and hide it from people? I use to do the latter more often than the former. However, I've found by being upfront with people about it, they will either accept it or not. In fact, in many ways, having TS may be a plus. People pay attention to you, that's

for sure. You will not be ignored if you're over in the corner twitching. You can say to yourself, 'Hey, that's who I am!' OK, so we're all basically young adults here. We all know about that. But I will admit there's a lot of you who were not diagnosed until your late teens, twenties, some even older, but that's OK. We all have learned how to deal with problems small and large. TS is just another thing on the list. Let's all make a pact not only to acknowledge our Tourette's, but to bring it out in the open. Let 'em think we're all freaks. 'Cause if you're looking for more attention to help your current career, help with you're child's problems at school (they may have

Tourette's as well, and in that case, make sure the teachers and other school officials know they have it as well), they will remember you. There's no better way to be recognized or remembered. Once they know who you are, you're already a step ahead of the game. Thanks again, and keep on ticcin'!



Kevin "The Ticcin' Trucker", 35
Doran, Minnesota