

# It's Not Just For Kids Anymore



An Online Newsletter Written for and by Adults with Tourette Syndrome

Volume 1 \* Number 3

## My Monster Within



**A**s I sit back in my chair, closing my eyes, at peace with myself, I look back on

that day which feels like lifetimes ago. I was lost. And there was a hidden secret that was becoming unbearable to hide. I had no answers. The monster had awoken and began to chase me again, haunting my days and leaving me cherishing my lonely unfulfilling nights. I thought I had outrun him—or it—but I now realize there was no escaping it. Whenever I looked over my shoulder, it was there, whenever I closed my eyes and reopened them, it was there.

It was one of those invitations you get a week in advance with no way of

avoiding it. I had to go to my aunt's house for dinner a few years back. She wasn't really my aunt just one of those people that your parents are so close to that they become family, in many different ways.

Considered my mother's best friend, I assumed she now felt a need to look out for me with the passing of my mom only a short time ago.

Arriving at her house 30 minutes late, due to a holdup at my seemingly dead end job, I jumped the three cracked steps leading to her front door. Knocking lightly, as to not awaken the old house from its slumber. I ventured through the unlocked screen door with a hesitant pace.

Upon my calculated entrance I noticed my Aunt sitting at the dining room table talking to a stranger. "Now who is this and what is he up to," I quickly muttered although it was not

uncommon for my aunt to have numerous visitors at any given time.

After being introduced to this guy, my aunt's 40-something year old nephew named Frank, I sat down and readied myself for the barrage of questions that were destined to be thrown in my direction. However, while sitting there biding my time, I noticed something unusual about this guy, almost as soon as I placed myself in a chair. Something that I had equated in myself, something that I revered, that I hated.

And instead of my aunt striking up the conversation, it was Frank who broke the silence and engaged me. When talking to him, he stared at me intently seemingly consumed by my story. Yet when it was his turn to speak, what I witnessed was something that I had never before seen

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## A Bright Future

**I** don't have a success story...yet. You see, I have a severe case of TS which has disabled me from living a full life.

School was a pain in the rump, starting in fourth grade when my symptoms first appeared. I did all but maybe one year of middle school on homebound and over a full school year, total, of high school on it.

A couple of months before senior year started, my tics got exponentially worse and I was back on homebound again; I finished high school on it. I talked about dropping out and taking the GED, because I was having such difficulty with my class load, but I had a wonderful teacher who wouldn't give up on me and who saw me all the way to "walking the plank."

College has been difficult, to say the least. I've dropped as many, or more, classes as I've signed up for.

But the classes I've completed have been all As and Bs. I know that I'm plenty smart to be a college graduate; my tics, it seems, have something else in mind, but I will continue to nudge my way through school.

Even though the aforementioned doesn't have a very positive ring to it, I remain positive with the not-yet-discovered parts of my life. I am hopeful that my doctor will find a medication regimen that will get my tics under control. And because of my experiences I am wise in the ways of education problems and may be able to help others with TS. All in all, I know that things are likely to get better, but could be a lot worse.

I believe that I will have a bright future in writing. Although I would really like a career in music (being a guitar player), I know it's not a very realistic goal. So I am going to pursue writing; I

have a book in the works right now. Hopefully, it will touch many people's lives.

My closing thought is to other adults who have a severe case of TS. I know the tics are unbearable and cause extreme physical and emotional pain. But, come heaven or high water, you need to find an outlet that makes your tics go away—or decrease to the point where you are semi-comfortable. Pick up an instrument, write poems about anything under the sun, do anything.

It may not bring you monetary riches, but having your body tic-free is one of the best rewards you can have. Peace be with you.

**Mark Cady, 21  
Florida**



# My Monster Within

(continued from cover)

first hand. His body began to convulse in an attempt to forcefully spit out what his mind was thinking. I quickly thought to myself, "Wow, he's got it pretty bad."

It turned out that these sudden movements occurred not only when he spoke but at numerous other times. At the sight of this I realized why he was here, furthermore, why I was here. He suffered from the same, sometimes debilitating disorder that I did, albeit in a much more extreme and visible manner. It was an embarrassing one that ate away at your self-confidence like a hungry dog being thrown a bone.

"Well at least I only turned my head occasionally and blink my eyes," I thought as my eyes became fixated on the object in front of me. He then proceeded to discuss with me his story, sensing that it had gotten the best of me at this point in my life. He talked about his battle fighting an uncontrollable disease throughout his life.

"You can't let this thing win, I know, trust me I know, it gets hard but you gotta think about what means something to you," he said, while soup ran down his chin due to the sudden yet awkward head movements that continually interrupted his attempts at eating.

But at that point in life I had taken the "why me" approach as the easy way out.

What struck me was how seemingly effortlessly he persevered through this uncontrollable hailstorm not letting it deter him or better yet, get the most of him. Like a pilot commandeering his plane through a rough patch of turbulence, he continued on hoping to strike a chord in me, if nothing else.

He told me about an interview that he went on for a job and how the secretary also suffered from it but tried her darndest to hide it, even denying it when questioned by him. "I mean, Christian, it was so noticeable that I truly felt sorry for the

girl," he said as his last words got caught in his throat only to be forced out by this uncontrollable enemy.

I sat and talked with Frank, expressing my emotions over being the victim of such a cruel joke, "Why, I ask myself all the time, I just can't deal with it at times," I remember telling him as my voice began to chirp with emotion.

He told me how he learned to cope, how he researched the disorder feeling a need to learn about this horrible tenant who was impossible to evict that lived inside him, and books that he'd read all the while fighting his best to maintain some form of control yet at the same time fighting a losing battle. He gave me a book entitled the "The Unwelcome Companion," which I still have to this day as sort of my own personal bible. I had so many questions and worries regarding how I would ever cope with this for the long haul that my frustrations became visibly evident.

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"To think that my dad's father, who ran out on him when he was born never to come back is the one responsible for doing this to me," as the anger in my voice echoed off the thin walls of the small cozy dining room. "I mean what bothers me more than anything, a guy I don't even know has done this to me. I even find myself blaming my father for this, cause he has it too." But my anger soon faded to contentment as I continued to talk and more importantly listen.

On this day, I truly felt comfortable with this monster that lived inside me. It didn't consume me as I opened myself up and let my emotions run free. I realized that it was reassuring to hear this victim speak because

never before had I come face to face with someone like myself, so to speak.

I had always struggled to cope with this on my own and now I understood that there were others going through my battle. He showed me that I was not alone, and he did this just by expressing feelings that I chose to try to bottle up.

That dinner will go down as merely a footnote, if that; in my life yet in terms of self-esteem and the will to overcome it was more than a building block that has since become a foundation of strength. Reflecting back on it now, that encounter proved to be a rebirth for me. I realized that there was no sense in proclaiming myself a victim; rather I had to stand up and exercise my will.

To this day Tourette Syndrome affects {in my opinion} millions of people in this country yet there is no cure. TS is not only a disorder that affects the body with involuntary movements and vocal tics but more importantly it is a disorder that affects the mind. Many people with TS simultaneously suffer from various forms of depression due to the psychological impacts caused by living with such a socially hindering illness.

I am one of those people. I suffer from Tourette Syndrome. I have suffered from it for years, since I was a child in grammar school. For years it went away or so I thought only to rear its ugly head again in high school and later college.

This disorder, unfortunately, is a part of me. It is who I am, therefore, I guess in a sense it defines me. And I am forced to live with it hoping it lies dormant for as long as possible. Yet there is not much I can do to quiet it when it wakes, since it has a mind of its own answering to no one. I can only refer to it as my monster. It is my monster within.

**Christian Falcone, 26  
New York**



## My Twin and I: In This Together

**M**y twin brother Jeremy and I were diagnosed with Tourette Syndrome during our fourth grade year of school. Spring Hill is a small town and no one understood what we were going through. Jeremy had a much more severe case than I did and my parents had to battle with the school to allow him to finish his years at the elementary school. Neither one of us has verbal tics much, but we do have some physical tics. My brother also had a lot of violent rampages that my family began calling "storms." The administration at the school could not understand Jeremy and he was isolated in a home-bound schooling program the next two years.

During middle school I was a straight A student, but was faced with my fellow students teasing and making fun. I had a tic where I would suddenly jolt my head toward one side to the other. It almost seemed like a horse waving its mane to shake off a fly. It was embarrassing because there was no way I could prevent it or know when it was going to happen. I decided to deal with it by educating. Our class of 150 sixth graders were all corralled in the gym of our school, and, for an hour and a half, Jeremy and I educated the

sixth graders with our knowledge and the knowledge we had researched. After that neither of us had to face such horrible times.

My brother and I took medication for seven years, nine pills a day, and were just removed of the medication as we parted from high school. I think I am a reason that any kid with TS should take the initiative and educate the bullies or the people that just don't understand. How can they, without the knowledge to do so? I graduated high school with a 3.9 GPA and am majoring in park management and conservation. My brother also graduated and now has a full time job with a landscape company. Anything is definitely possible you just have to take the initiative and get it.

**Zachary Roberts, 18  
Kansas**



**Zachary (left) and his twin brother Jeremy on Graduation Day**

## The Cold Loneliness of the Tourette

They think that I won't notice  
When they try to avoid me in the street.  
Or how it feels to want to break out  
From under an intangible sheet.  
The mocking still haunts me behind the glass  
As my eye tics and my face erratically creases.  
Besieged with a mouth that has no control  
Of the words it untimely releases.  
I see a group of teenagers laugh at me.  
As I yelp, bark, swear and shout  
Taking turns to point at me.  
And saying "Oh no! The madman is about."  
But they must think that I am blind  
Or born emotionless to all the odd stares I get  
But I just wish they would look a little deeper  
Into the cold loneliness of the Tourette.



**Daniel North, 27  
UK**

*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, 2005. The deadline for submissions is August 29, 2005.

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](mailto: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.

# My Life...So Far



**M**y first TS symptoms occurred when my mom entered the hospital for radiation treatment for Hodgkin's disease, which is a cancer of the lymph glands. I was just six years old. The first tic or "habits" as I called them, was blinking my eyes very rapidly. For the next twelve years I had one tic or another. A tic would appear out of nowhere for six months and then it would disappear just as quickly. The tics ranged from deep coughs, shoulder shrugging, and teeth grinding to grunting, rapid-eye-blinking, and biting the inside of my cheeks repeatedly. During those twelve years I was in constant pain and suffered mightily. My friends never said anything to me. I guess they were able to live with the tics, but I wanted to crawl out of my skin nearly all of the time.

When I was a senior in high school, one of my friends finally did say something. He asked me why I always blinked my eyes a lot. I said that I got sunscreen in my eyes. That is all that I could think of at the time. I didn't know why I blinked so much, so how could I tell other people why I did. My parents were worried and they took me to psychologists, psychiatrists and learning specialists, but no one diagnosed the problem.

When I was nineteen-years-old and in my first year of junior college, the tics went away. Six months later they all came back in full force. I was performing every tic that I had ever had several hundred times a day. I had to leave each class many times a day to go to the restroom and do my tics. School became difficult and I dropped out in the middle of my first year of junior college. I was fired from my customer service job. Every time I talked to customers I blinked and did all of my tics. My boss thought that I was too stressed out

and couldn't handle the pressure, so he fired me. For the next year I felt so depressed, I could barely get out of bed.

One night my mom was at a neighbor's party and a lady was talking about her son's Tourette. It had been diagnosed by a neurologist. A neurologist diagnosed me as having Tourette Syndrome. I could finally put a name to my problems. Later I found I also have obsessive compulsive disorder. The neurologist started me on Orap. I thought that this would be the end of the problem but this was just the beginning. I began by taking a couple of pills a day. They totally knocked me out and made me feel like a zombie all day. If given a chance I could sleep for eighteen hours a day.

I was first diagnosed with Tourette Syndrome when I was twenty-years-old. I am now thirty-four and still working on correct dosage. I take eight pills a day, which is more than I ever have. I still get very tired on occasion, but it is a lot better than it used to be. I just keep thinking that I would much rather be tired all day and be able to function than to go back to how I was before I began taking medication and not be able to function at all.

I have had many jobs; none of them for more than a year. Many of them end after being late too much or missing work entirely. Many times I am so tired in the morning I just can't get up. I've used many excuses to explain my absence.

I still live with my parents. I have tried moving out, but always end up back there, because I lose my job and run out of money. I have also fallen for many get-rich-quick-schemes and some people would say I can't manage my money. I have never dated, not in high school or today. I guess I figure that if I date someone they will no longer want to go out with me when they find out that I have Tourette. Even if I did date, I don't think there is a chance that I will ever get married. The thought of giving this

disorder to my children is horrifying. If I ever gave it to one of my children then I would be devastated.

Many of the so-called experts on Tourette say that the symptoms decrease as you get older. I am still waiting for that day.

I am in the process of writing a book of personal stories by people with TS, similar to the "Chicken Soup for the Soul" series. I hope other young adults with TS will find it interesting and comforting to know others are experiencing the same things and feeling they are.

**Chris Mason, 34  
California**

## FRIEND

*I love my friend  
My friend, he loves me.  
Sometimes he is near  
Other times absent.  
Although I cannot touch him  
His shrill voice I hear.  
I often ponder if he'll be with me  
always  
Maybe he'll leave me forever.  
My friend is Tourettes  
That friend is me.*

**Anthony Ianni, 39  
Nevada**



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