

It's Not Just For Kids Anymore

((X)) An Online Newsletter Written for and by Adults with Tourette Syndrome

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Meet Citizen Can

I'm a twitchy guy. It's taken me quite some time to reach the comfort level where I can admit such a fact of life without cringing with disdain at my own willingness to "give up" and "accept" a "flaw" in my design. The quotes are intentional and appropriate, I think it turns out, happily, that many of the more educated folks with whom I like to mix think of Tourette Syndrome as more of a quirk of personality than a problem, and are curious to know what living with it is like. So I tell them, unpolitically correct though it may be, that being a Tourettic is not all that different from being a diabetic, or a homosexual, or HIV+. By which I mean that the condition is not likely to go away, so one can either hide it or learn to live with it; and in most cases, the former just takes too much effort.

I was interning, ironically enough, for Dr. Jehuda Sepkuty, M.D., in the neuromuscular laboratory at Johns Hopkins University in the summer of 2000 when I was told I have TS. The doctor who revealed the fact to me did so in the least professional way possible, and at first I denied it outwardly; though I undertook the arduous task of having the self-diagnosis confirmed by one of the foremost American specialists on TS, given my neuroscience background, I knew the signs (and symptoms) fit. Instead of lamenting my situation, I resigned to join TSA, and proclaim to the world that "Yes, you can be known for something other than your tics!" And even more profoundly, once you've found that at which you excel, you can use your newfound notoriety as a soapbox to explain the reality of living with a condition that is often maligned, mocked, and misunderstood (most commonly by being confused

with similar conditions like Attention Deficit/Hyperactivity Disorder and Obsessive-Compulsive Disorder). There is value to being able to laugh at oneself. Coprolalia, for instance, is a tragic Tourettic trait. But when comedian Rob Schneider takes a woman who swears uncontrollably on a date to a baseball game (where such a practice is more-than-acceptable) in *Deuce Bigalow Male Gigolo*, the film's audience cannot help but find him endearing. Deuce has managed to turn a weakness and insecurity into a strength, a uniqueness, and even-once outside the movie theatre—a point for discussion.

When I enlisted in the United States Army on September 11, 2001, I knew that having TS could disqualify me from service; a twitch in my shoulder that I developed after five weeks of rigorous Basic Combat Training coupled with very little sleep under the fierce-tempered eyes of a Drill Sergeant did eventually earn me a discharge. But the experience was by no means a waste, since besides gaining insights into the military's discipline and hierarchy—for better and for worse—I found myself explaining the reasons why I had to obtain a disability waiver to enlist. I clued my comrades into the protections afforded to Tourettics under the Americans with Disabilities Act, and showed them firsthand that even someone with scarcely controllable muscle spasms can score his platoon's fastest two-minute mile time.

When I left the Army, I worked for the Law Offices of the Public Defender

of the County of Los Angeles, the largest P.D. office in the country. I returned to school and became the first student in about seven years to be offered a combined Bachelor's and Master's degree from the prestigious University Professors Program at Boston University (I studied Psychology, Religion and Conflict Negotiations). And with a handful of friends-turned-business partners, I founded the HUMAN/intelligence Creative Group, Inc., which publishes the new content-driven monthly and national magazine *Citizen Culture*, the mission of which is to give talented new writers and photographers, critics and reviewers, poets and storytellers a foot into the publishing industry. And I'm proud: that we are the only magazine bringing smart content to both men and women aged 20-40;

that we have been picked up for distribution by some of the largest bookselling chains in the country; that experienced writers would rather publish in *Citizen Culture* than in the countless other, more established venues at their beck-and-call.

I've done fairly well for myself so far, and I know that most of my accomplishments would have been impossible if I had stayed in the Army, and I know that Tourette got me excused from service, so in spite of my staunch patriotism I'm glad to have had the chance to gain experiences of a very different sort. Yet I still wear my dog tags, proudly; they represent a surmounting, no matter that I never completed Basic. Because I've learned that even though my Tourette Syndrome—like yours—probably won't disappear, it takes dignity and integrity to patiently play the cards we've been dealt by life's twitchy hand.

**Jonathon Feit, 22
New York**



Finding Freedom Amidst So Much Confusion



Being a young adult with or without Tourette Syndrome can certainly be stressful but I have learned that TS is an aspect of life that has GOOD with the bad, freedom amidst confusion, and peace sprouting

through pain. Being a 24 year old female with Tourette, I look back and I certainly don't recognize the child I once was. Growing up my life was encompassed with facial tics, anxiety, depression and an "out of control" temper!

To cope with symptoms I became immersed in writing and art during my childhood. When I could focus; writing and art became a driving mechanism in development of freedom amidst so much confusion. I loved how painting and writing were sources in which ideas and emotions could be expressed which were built up for so long.

Currently I have been successful continuing to paint and write while studying at George Mason University.

Everyone has different ways they relate to and express their lifestyle with Tourette. I try to find a positive for every negative. For myself I know a positive of TS is it has enabled me to cherish my progress in life and be keen to others' needs. There is ability in disability!

Recently, within the past few years I have become more open about my TS and brought awareness of the disorder to my university. I held a seminar discussing Tourette and comorbid symptoms in university students. Life is a rollercoaster ride with uncertainty of the future but young adults with Tourette Syndrome realize that progress is a gift that life brings.

**Malinda Grace McGeough, 24
Washington, D.C.**

A Phond Pharewell

Welcome to "Lil' Twitchie's Dance Party." I am "Lil' Twitchie," or at least I am to a wonderful group of friends who reacted positively, albeit quite differently, to the diagnosis I received December of my sophomore year of high school. More often than not, my tics would (and do) manifest themselves as something akin to interpretive dance. I would be standing there, and voila, my arms would writhe around like a ballerina, or I would jump from one foot to another in time to the rhythm of a conversation. Before too long, Lil' Twitchie (the title affectionately dubbed upon me by a dear friend who thought my condition was just the coolest thing ever) was throwing her own "dance parties."

Whenever I would jump or twitch or otherwise move "abnormally," someone within this circle of friends would agree with my movement by saying, "bust a move!" Uttering vocal tics in time to the pauses in our group drum circles was just an added plus in their eyes.

Although I don't always do it intentionally, dancing has been an outlet of my Tourettic energy since well before my diagnosis. I took my place among the ranks of the "Phish Phamily" (a term of endearment

fans of the now-disbanded rock band Phish use to refer to the community that sprung up around the band) when I attended my first show in 1998 at age 14. I thought the concert was the coolest thing ever—nobody even blinked at my twitches—I was dancing!

For me the Phish Scene was an amazing community in which everybody was accepted, no matter how bizarrely their motor coordination was at times. The music would start and my spinal cord would "pick me up" as it and the music saw fit, and I would move accordingly. The frequency and severity of my all-out marathon twitching episodes, the bad ones, was determined by how recently I had attended a show. When I "danced" I unloaded all the potential energy that had been building up in my spine. Other phans would compliment my "dancing," ask me what drugs I had taken to make me dance that great (sorry, it's genetic, I can't share this stash with you!), or just smile and nod.

It was a beautiful thing to have had such an environment of total acceptance growing up. The bluntness with which my friends "teased" me allowed me to face people who had issues with me just as bluntly. I adopted a "please: stare, ask

questions, let me tell you all about it" approach to living with my genetic makeup. Religiously attending Phish concerts for the past six years (I've lost count of the exact number) gave me confidence in dealing positively with my unorthodox movements.

But a lot is changing; that confidence is wavering. I have left home for college, and with home I have left my open-minded group of friends who dealt so well with my being different and am now surrounded by strangers who don't know about why I do what I do like everyone at home did. These ones stare, point fingers, and whisper furtively amongst themselves; they don't even bother to ask me any questions about it. An especially hard blow came a little more than two years ago when a significant other announced to me that he couldn't stand my twitches and that they were "really annoying," and has consequently rendered me overly self-conscious whenever I have twitched publicly since. And I am writing these words the day after Phish played their final concert before disbanding. My tolerant Phamily has been scattered to the wind, I have lost my identity, and I don't know what to do.

**Megan Strang, 20
California**

IT'S ALL GOOD...



It's all good. Yes really, it is all good. To say just that might take a lot of effort for someone who has Tourette Syndrome. Diagnosed at the age of 18, I have, over the years had to face tauntless teasing, being made fun of and the like, but have learned to manage that through humor and learning to laugh—it not only makes the world a better place, but the world is a better place with people with TS in it.

This, was my second year as a volunteer counselor for the TSA of Ohio's summer weekend for children with Tourette Syndrome at Camp Willson in Bellefontaine, Ohio. These children have the most remarkable energy I have seen in any child. Every child is special in their own way, each offering something to give to the world. What happens in these children's lives can be difficult at that age. Going to school, not being accepted and made fun of, teased and common misunderstandings from yet even adults.

The medicine for these children does not come in a bottle, but rather it comes from seeing past the appearance of what appears to be tics and behavioral problems to seeing the light in a child's heart of

what they have to offer the world in their own special way. When children are accepted with unconditional love and loving them regardless of what may be happening, they can heal and the whole world can heal with them in coming to accept this condition that is known as Tourette Syndrome.

I believe as an adult with TS that acceptance and understanding begins in the heart, not in the mind. The exuberance of these children and all the happy faces when they saw that I returned as their second year counselor once again, lit up my life in ways that only a happy heart would know. To see the joy and happiness on their faces for a second year brought joy to my heart. I was not accepted myself as a child in other ways and my tics did not start until the age of 15, but I would never have considered going to a weekend camp at that age and can relate to these children and see how scary and frightening it can be for them. The weather was beautiful last year as well as this year without rain. Except, directly after camp concluded on Sunday in 2003, the rains came down to wash away all the seeming hurt and pain these children go through. I will never forget being the very last one to leave and how empty it was in the campgrounds at the time I left. Why, you might ask, was I the last one to leave? I cannot even answer that

one, but something on an inner level set that one up.

The Wednesday before camp this year, it was raining in my car as I was driving, yet the sun was out and Johnny Nash's song "I Can See Clearly Now," was playing in the car and one verse says, "Here is the rainbow I've been waiting for." Yes. There in the sky was a rainbow big and beautiful and long lasting in the southwest corner of the sky in the direction to Bellefontaine from where I live in Canton, Ohio. I knew this year was going to be even more special. To hear an entire camp cabin chanting my name in the mess hall, "Nelson! Nelson!" it's hard to hold back the tears and joy you feel. And of course, this wasn't a tic.

It's a never-ending battle it seems to fight the feelings TS people have inside and if we can just learn to channel our creative energies and abilities to help serve life and the people in it we heal these thoughts and feelings of what may be deemed inadequacy and pain to a better comfort zone in our heart.

Oh, and just to let you know this year at our weekend program for the children, the sun was out when parents came to pick up their children. And yes, once again I was the last one to leave. The sun will continue to shine!

**Nelson Freed, 35
Ohio**

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 March, 2005. The deadline for submissions is February 28, 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 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. Thank you.

How I Got Where I Am Today



Throughout high school, I always thought I didn't need to study, since I always got decent grades. When I

graduated, it didn't mean all that much to me, it was just another notch in my belt. My ADHD and Tourette caused many problems learning in school. I did come to have friends that more or less accepted my Tourette, but TS impeded my learning in that I found it hard to focus on lectures and in-class writing assignments. This was besides the problems that my ADHD caused. The ADHD caused lapses in attention, but when I was paying attention, I felt my tics were distracting to the class and myself.

After high school I went to Borough of Manhattan Community College (BMCC) for 3 years. I didn't know what I wanted to do with myself when I graduated high school, so I took courses that were unrelated to my official major (general science, then liberal arts) in order to "find a calling," and so the completion of my Associate's Degree was put off in favor of my search. I also had an attitude of doing as little studying as possible for my classes, thinking I could just absorb the material, completely ignoring the problems caused by my ADHD and TS. When I entered BMCC I still retained this attitude and I didn't seriously read the books I was assigned. I only did the homework when I wanted to or when it was easy enough. I was still acting like I did in high school and not taking college seriously. Nervousness about my TS kept me from socializing too much and made me undergo a lot of stress due to my workload and low confidence.

Somewhere in my time at BMCC I realized that I needed to be aware of where I was going, and thus my work ethic was born. From that point on, as I began to work harder and get better

grades, the stress from my workload diminished since my confidence was growing. By the end of my third year, I felt I had honed it well enough so that I wasn't just kidding myself anymore. I decided what I wanted to major in even though I felt I always knew on some level—Computer Science. I didn't experience the true calling I was hoping for though I had realized that what I wanted was to be struck by lightning and suddenly innately know with every fiber of my being what I wanted to do. Instead I actually had to do research into the various fields associated with computer science and only after that did I feel I had the insight to really know what I wanted to go into and the drive to get there.

I felt that I didn't have the room I needed to grow at BMCC, so I transferred to the State University of New York at Plattsburgh. I had no Associate's degree, but I did have a new major that I was determined to get a degree in. Due to only having a portion of credits transferred to my new college from my old one, and my need to take it slow and not overwhelm myself, I faced four more years of college. Although I was going to school full time (12-14 credits per semester), it was only just barely full time, instead of 15 credits a semester, which is what was recommended. I found that with the susceptibility to stress that the TS gave me, and dealing with the tics themselves, it made me want to go slower, to not bite off more than I could chew. I felt bad about that but didn't let it get me down and I didn't give up. I spent four more years at SUNY Plattsburgh learning how to deal with my own drawbacks in a social environment. In my last two years at Plattsburgh I began taking Orap and Clonidine for my tics, and I found them very helpful.

After working hard and further honing my work ethic at SUNY Plattsburgh, I attained a Bachelor of Science degree in Computer Science in May 2004. My last year was by far the most stressful.

Besides facing the hardest classes in my major, I went through the exhaustive process of preparing for and applying to graduate schools. Just before my graduation, I learned that I was accepted to New York University. I started classes in September in a Master's Degree program in Computer Science. As for the stress level, it's like senior year all over again. But I've pushed through it before. I can do it again.

Within the statement of purpose which I had to send with my graduate school applications, I wrote about my TS and how I worked very hard to overcome the many obstacles it imposed to graduate with a 3.39 grade point average. In my essay I talked about the fact that I am no stranger to challenges. I was diagnosed with TS and ADHD when I was 11.

Through steady work, much self-reflection over the years and a wonderfully supportive family and group of friends, I have been able to overcome these obstacles in order to get where I am now. Out of the eight schools I applied to, three accepted me. NYU was my first choice. I am not totally sure what area of computer science I want to focus on but I still have time to decide.

Jonathan Fried, 25
New York



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