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One TIC at a Time

Growing up with Tourette Syndrome

By Dylan Peters

I just turned 10, which means I have now lived with Tourette Syndrome (TS) for 6 years. I was diagnosed at the age of 4 after I began jerking my head side-to-side, staring and repeating words.

My parents explained to me that Tourette Syndrome was a neurological disorder where my brain tells the muscles in my body to move over and over again. These actions are called tics. They told me there was no way to stop these actions or sounds – no medicine, no therapy and I could not tell my brain to stop sending these messages to my muscles. Since I was only 4, I had a hard time understanding what they were telling me, yet I knew my head was jerking, I was staring and repeating things like saying, “Mom, I am going to go outside.... go outside.” I would always whisper the words I was repeating and it seemed no one ever noticed.

I was scared of what people would say or how they would react when they saw me making these strange actions or sounds, so I told my parents that I did not want anyone to know. We did tell our close family members but that was it – no teachers, no friends, no parents, no coaches, not even my dentist.

Once I started school, I began to worry that my friends would notice my tics and by this time I had several different ones. I managed to get through kindergarten, first grade and second grade without having to tell anyone. At the end of my second grade year I knew that my time keeping this secret was limited. Several of my friends started asking me why I was opening my mouth so wide all the time or why I rolled my head around my shoulders constantly.

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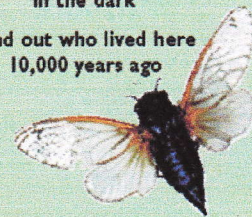
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So, at the beginning of third grade I knew the time had come. I had several tics, both vocal and motor. I had an eye blinking tic that was really bad and was happening constantly. My mom and I met with my new teacher and we came up with a plan to tell my class. I was terrified my friends would treat me different and make fun of me. I was worried they would think I was weird and would no longer want to be friends. When my mom dropped me off at school I told her, "I am going to have faith in my friends and everything is going to be okay."

Later that morning the class gathered in a circle and our teacher discussed differences and how those differences make each of us unique. She then introduced my mom and told them that I had something to share..... I stood up and told my friends I had Tourette Syndrome. I explained what TS was and about all the tics and made sure they knew I could not stop them from happening. I told them I am the same Dylan today that I was in kindergarten, first grade and second grade. The only difference is now you know I have Tourette Syndrome and have tics that you may see or hear. Challenges, disorders, syndromes, glasses, braces – none of these are things to be ashamed of, they simply make you... YOU. I wished that everyone could have friends

like I have. I was amazed at how they all understood and even shared some special secrets about themselves.

Over the past 6 years I have had numerous motor and vocal tics. Some of the motor tics include: head jerking, eye blinking, hands motioning in the air, rolling my head around on my shoulders, opening my mouth really wide, taking in large breaths of air and others. The vocal tics that I have had are: repeating myself or others, saying slogans over and over, throat clearing, gurgling noises, sniffing, humming, gasping for air, snorting, gulping and making at "t" sound. We never know what tic I might wake up with in the morning or how long the tic will last. Some tics stay with me

for weeks, others for months. I have also had several tics all at the same time. I have also gone weeks with having just one that doesn't happen very often – these are the best weeks. Tourette Syndrome and the tics that go with it wax and wane – so some days are good and some days are bad. In the last several years I have tried many different medications and combinations of medications. Recently we found a combination that has been very successful for me in reducing my tics. I have learned that medication that helps me today may not help me tomorrow. There is no cure and Tourette Syndrome will probably be a

"We never know what tic I might wake up with in the morning or how long the tic will last."

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part of my life forever.

We have learned that stress and anxiety make my tics worse. Last April was especially rough for me. I began having an abdominal crunch tic that occurred nonstop and I was wrenching my side at the same time. It was as if I was doing ab crunches all day, every day. I became very sore and was in a lot of pain. We tried some medication that eventually helped slow the tics down but I had to stop the medication because it made me feel like a zombie. I did not make it through a day of school for 2 weeks. That tic went away after about 6 weeks. It was awful and I am thankful that I have only had one of those full body tic episodes. I have learned many kids with TS have an increase in their tics when they are stressed or anxious.

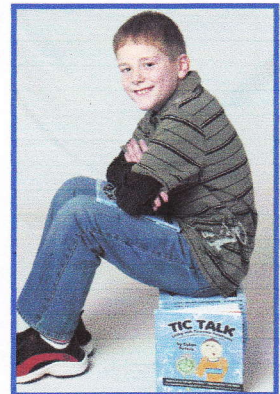
Finding a neurologist who specializes in Tourette Syndrome made sure that I would get the best treatment and the most accurate information. It was important to my parents that we always feel comfortable with our doctor and be able to tell them what we wanted and didn't want and what we agreed with and did not agree with.

One of the biggest positives that came out of sharing my secret was the communication between me and my teachers. Chewing gum sometimes helps with my tics and so she will allow me to do that in class. Also, if I am having a lot of tics and need to leave the room to take a break, I can just give her "the signal" and leave quietly. We usually know in April or May who

my teacher for the next school year will be and my mom and I meet with her to go over the TS and my tics. We talk about how she manages her classroom and how we will work together to make the year successful. This has made a huge difference in my stress level at the beginning of the school year. During the year the open communication between me, my parents and my teacher is a big reason that I feel comfortable at school.

I have made it my goal in life to "Create acceptance and tolerance one tic at a time." I recently wrote a book called TIC TALK – LIVING WITH TOURETTE SYNDROME – A 9-year-old boy's story in his own words. I hope that my story brings awareness, acceptance and tolerance of those who have Tourette Syndrome and provides reassurance to others with TS that they are not alone.

Dylan Peters is a 4th grader and the author of Tic Talk – Living with Tourette Syndrome – A 9-year-old boy's story in his own words. His favorite subjects are math and science. He plays the piano and enjoys computer and video games. He hopes to one day be a surgeon. Dylan's website is: www.tictalkbook.com.



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