

# **A FAMILY'S QUEST FOR RHYTHM**

LIVING WITH TOURETTE, ADD, OCD  
AND CHALLENGING BEHAVIORS

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## THE IMPORTANCE OF BALANCE

Picture a Norman Rockwell painting of a town hall built in the late 1800s. The hall is filled with the town's residents sitting on folding chairs and old church pews while people of all ages are on stage singing, playing musical instruments and dancing. Even the members of the volunteer fire department are performing their rendition of "Little Bunny Foo Foo."

This was the scene in which Matthew, at the age of five, had his first drum solo performance. The audience could see only the top of his head from behind the drums. It was the first time we saw audience members' facial expressions change from "Awww, isn't he cute" to "holy mackerel, that kid is *good*."

His interest and talent for percussion instruments first became obvious when Matthew was two. We always had music playing in our house. This particular day, the Moody Blues record "I'm Just a Singer in a Rock-n-Roll Band" was playing on our turntable. I walked into the living room and saw our little boy keeping perfect rhythm while air drumming.

We bought him a \$25 child-sized drum set for Christmas. The drum set didn't last long, but it provided us with an opportunity to see his natural talent. Matthew not only enjoyed drumming, but had incredible talent for it as well. For his fourth birthday, we bought him a beginner's drum set. When he wasn't drumming on this or hand drums, he drummed on anything and everything in our house. Fortunately, distressed furniture fit into the décor of our log house.

At five, Matthew began taking lessons from local high school students. One of his young teachers, Shane, went on to be

a percussionist for Yo Yo Ma. As an adult, I have heard Matt share with audience members that one of the valuable lessons Shane taught him was to have fun and enjoy the music. After every lesson, they used the last 5 minutes to jam—Matthew on the drum set and Shane on the guitar. Shane knew the importance of his not only learning the mechanics of performing, but also developing a love and a sense of joy for *making* music as well. Thank you, Shane!

When Matthew was eight, we brought him to the Eastman School of Music to meet with Ruth Cahn, who was the lead percussionist for the Rochester Philharmonic Orchestra. She immediately impressed me by speaking directly to Matthew—not his parents. It showed respect for her future student and the fact that her relationship with him was of primary importance. They discussed his love of drumming, and then she played rhythms and asked him to repeat them. After approximately 15 minutes, Ruth looked at Matthew and told him that she would be honored to be his teacher if he were interested in being her student. He enthusiastically said yes as only a youngster can. She was his teacher and he was her student for the next eight years.

What an incredible positive turn of events for our son. Doing an activity that he loved with a highly respected teacher in one of the most famous and glamorous buildings in Rochester. Without realizing it at the time, a critical component of his not being ‘disabled’ by his significant symptoms was unfolding. His extreme symptoms were balanced by his extraordinary talent. Quite incredibly, however, some of the therapists and counselors who worked with us suggested that if Matthew was *bad* or *inappropriate*, we should take away his drums and his lessons!

I am aware that the common philosophy for raising a child involves punishment. This assumes that not only will the objectionable behavior cease, but it will be replaced with a behavior that society recognizes as acceptable. Let me be clear, there were many times that we punished Matthew, but to take away his drums as punishment seemed ludicrous. His life was extremely difficult, to say the least. His drumming was his joy,

his passion and one of the few things in his life that was positive. Why would I want to use it either as a punishment or as a reward?

A young man told one of my co-workers, “Don’t ever tell *them* what you like because they will either make you *earn* it or they will *take* it away.” This wise statement nails it. What a shame! Instead of adults encouraging a child’s strengths as a balance to the difficulties, we make children *earn them or we take them away*.

I guess Matthew may have come by his oppositional behaviors naturally because I became oppositional. I ignored advice that suggested I take his drums away. Instead, we celebrated and nurtured his talents, because it just made sense. By doing this, people saw him not only as a youngster with Tourette syndrome, but also as a gifted drummer. Because other people recognized this, Matthew did as well.

We adults tell children that they are more than just their diagnoses, but I believe we need to practice what we preach. Because of his gift for playing percussion instruments, Matthew was able to have more than a one-sided identity. He was (and is) a great deal more than the person who has a diagnosis of Tourette. He has always had a sense of the importance of balance. I believe it is a critical component of his growing up and becoming the person that he is today.

This ‘balance’ was most apparent when Matthew was at RPC and taking lessons at the Eastman School. Every Saturday I picked him up at the children’s unit and walked past the ever-present reminder of the adult forensic unit being next to the children’s facility. I had to walk between the fenced in yard topped with razor wire to my left and the yard with swing sets and slides to my right. Amazing! Matthew constantly asked me if we were bringing him to jail. I still feel the stabbing pain and the tightening of my chest thinking of my son living in this building.

Eastman Theater and RPC. Two such totally different buildings were central to his childhood. One was a building that represented talent, success and self-worth; the other a building

that represented isolation, depression and extreme sadness. It was a tangible example of the extremes of Matthew's young life. Incredible talents versus significant symptoms. I picked him up at a depressing and frightening building and brought him to a stunningly beautiful representation of architecture, which housed the talents of musicians from around the world. It was a reminder of the bizarre but extremely important balance for Matthew.

Matthew's symptoms were seen as extreme by everyone who witnessed them. When he drummed, he was respected by adults and his peers while he enjoyed his favorite activity—producing music. He had regular appointments with doctors and therapists who attempted to help reduce his symptoms. Every week he entered this prestigious building to spend an hour learning from one of the most respected percussionists in the area.

I should take this away? I should tell him that if he wasn't 'good' he couldn't go to his lesson; couldn't practice or couldn't play his drums? I was to prevent him from entering this prestigious building that weekly reinforced the fact that he was a member of an exclusive and talented club?

One Saturday morning as we walked through the expansive entrance hall, a young woman in her early twenties said "Hi" to Matthew and *not to me*. She acknowledged Matthew; my nine year old son. I remember thinking that this was due to the fact that *I wasn't* a member of this exclusive group—but he was! It sounds like an unimportant event, but I remember it as one of many moments that would remind me how his talent had such a powerful and positive impact on the way other people viewed him in spite of his symptoms.

I decided early on that the most important job I had as his parent was to get him to adulthood with his self-esteem intact. I wanted him to enter the adult world knowing that he had potential and could accomplish greatness—not to feel like a failure who never did anything right.

While some people told us we should use the drums either as a reward or punishment, others made comments such as "he must practice all the time." They were certain that it must have calmed

him when he practiced the drums. I smiled and agreed that he did practice and that it was calming for him. I didn't tell them that while he played the drums frequently, he practiced very little. Yes, his tics were quiet when he played the drums, but that things could also get nasty when his drumming wasn't going "just right."

I am very glad that I decided to disregard professionals when they suggested that I take his drums away. As an adult, Matt not only has good self-esteem, he has an incredibly unique talent from which to make a career. I am committed to the importance of balance. Kids need to know that their diagnoses are only *part* of who they are—and definitely not the most important part.

Many children with these types of difficulties live outside the box and have natural abilities and talents. They often are creative thinkers, writers, artists, musicians, dancers, athletes. Some have the ability to be hyper focused on developing skills, interests and talents. But when their talents are not nurtured, or even worse, when they are used as threats or punishment, the desire to engage in the activity often fades into the background.

These young people have mountains to climb: physical, emotional, social, academic; dating, getting and keeping jobs, finding careers and having a family. Often even everyday activities such as grocery shopping, taking a bus, or going to the movies can be difficult.

They have many struggles, but also may have one area in which they excel. Matthew's experience taught me the importance of putting as much time and energy into developing his strengths as I did into understanding his disorders. Was this tiring and exhausting? Yes—but so incredibly important and rewarding.

Every year the local Moose Club sponsored a talent show for school-aged children, Kindergarten through twelfth grade. They actually had cash prizes! The first year Matthew entered, he was in the senior division, even though he was only in sixth grade. I let friends know that he would be playing his drums in the show, and they asked me who would be playing with him. When I told

them that he was doing a solo drum performance, they were confused as to how a drum solo could possibly be entertaining.

Every year, Matthew worked for a month or more on writing, practicing and rewriting his song that he would perform. As he practiced, I heard the various combinations of rhythms. It wasn't until he played in front of the audience that the song came alive and, much to many people's surprise, he created music by playing a drum solo.

That first year, my close friend Brenda attended the show with us. She knew how difficult Matthew's life was. There was also a group of girls from sixth grade sitting in the front rows. During his performance, they screamed as if he were a rock star. At the end of the song, he stood and bowed from the waist as his teachers had taught him. The girls screamed again; so as a true performer, he walked behind his drum set and did an encore drum roll. He is a born entertainer with a natural sense for giving the audience what they want.

That evening there were a few dancers, some singers, four rock bands and Matthew in the show. It came time to announce the winners. Since he was competing against high school students, I wasn't confident that he would win. When they announced Matthew Giordano as first place, Brenda and I both leapt to our feet cheering. I wanted to yell out, "THAT'S MY SON!" The judges had no idea of Matthew's diagnosis or his difficulties; all they knew was that this young boy had blown the audience away with his drumming performance. There were many similar moments over the years and they were all as fantastic as that first time.

Matthew continued to enter these shows until the year he graduated from high school. One year, he said he was thinking about not entering so someone else could win. He wasn't boasting—it really was out of kindness, although I suspect that there may have been a certain girl in the competition who he wanted to win.

Too many children have talent in a specific area and for, some reason or another, are prevented from participating in the



activity. For example, there was a young boy who had a natural ability for diving. He also had some major sensory issues and could not endure the sensation of being in the water long enough for him to swim any more than it took to reach the side of the pool after a dive. For him, being in the water longer than that was torture. Last I heard he wasn't diving in any organized group because everywhere he went, they insisted that he must also swim laps to participate in diving; very regrettable for both this young boy and the sport of diving.

We have seen the impact of teaching Matthew the importance of balance in his adult life. For instance, when he was first living on his own, there were times when he found it necessary to call me when he knew he was off-balanced. We developed a code. If when I said hello, he said “evergreen,” this was our signal that the briefer this conversation, the better. I made minimal comments and asked only the most necessary of questions.

He would call me later in the day—usually after he had eaten something, exercised, played the drum or just woken up more—and apologize. We then had a more complete conversation. It was important that when this occurred, my focus was on the *strategy* and not why any of this was happening. I didn't ask questions; I didn't take it personally...that is what was and what worked; at least for that moment.

Matthew has never been one dimensional. In order to maintain a balance, all areas of his interests, his talents and symptom must be considered. A close friend of mine once described Matthew as being a beautiful and unique mobile. All mobiles have a delicate balance. If one section of a mobile becomes off-balanced, all of its parts are impacted, resulting in the mobile becoming twisted to the point of becoming nonfunctional. This was also true for Matthew. We learned over the years that he required certain fundamentals to maintain a balance. When he was ‘out of balance,’ his symptoms increased and he became similar to the twisted mobile, unable to function.

## FINAL THOUGHTS

During the process of writing this book, it became increasingly evident to me that we were extremely fortunate to have so many remarkable, talented and kind people who made such a positive contribution to our lives. Influential people, famous people and people who, because of their innate kindness, aided us on our quest: Dr. Oliver Sacks, Sheriff Meloni, Ruth Cahn, Matt's teachers, therapists, doctors, friends, family, and even strangers.

I owe a great deal of gratitude to the families who remind me daily how important it is to let parents know that having a child with challenging behaviors isn't their fault or the fault of their child—and that they are *not* alone. My sincere wish is that parents recognize and encourage your child's talents and interests, disregarding what anyone else thinks or says. Also, no matter how difficult, it is important that you *try* not to take symptoms personally and instead help your child discover ways to manage his or her difficulties. Love them even when it's hard to *like* them. And know it's very likely that someday you will look back at these times as being the hard years that are long past.

I am grateful for the critically important contributions of the people who volunteered to read numerous drafts of this book. This is especially true of four people. Liz Greenberg: without her subtle—and not-so-subtle—nudging, this book that I have talked about writing since Matt was a young boy would most likely never have been written. My co-workers, Jackie Yingling and Roger Nellist spent invaluable hours before work, during lunch, and even during their vacations, looking over each page with me. Jennifer Rowe provided us the exceedingly

important professional and technical help we needed to finally get this to the publisher.

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