

VOLUME 2 ISSUE 2

A MAGAZINE BY TEENS, FOR TEENS & ABOUT TEENS WITH CMT

CMTTeen

Summer of '17: On the Move



Diary of **SCOOTER BOY:** “Hold the door open please!”

ENTER MY LIFE: My dad was the first member of his family to be diagnosed with CMT1A. **LUCKY ME**, I am the second. I kind of knew at a young age, when I was falling **A LOT**, that I might be like my dad.

*By Sean Tyree**



I remember being 5 years old in the grocery store with my mom and falling and getting back up and telling her I thought I needed leg braces.

At 7 years old, my parents told me I had CMT. At that time in my life, I could still keep up with my friends physically and was even on a swim team. However, as I started to grow and my body began to change, I began to notice how CMT was affecting my physical appearance and how it was making me feel physically and emotionally. I started to become **EMBAR-RASSED** about my “different ability” and hid it from my friends. Those friends I did share with just didn’t get it, so I stopped explaining. Many of my own immediate family members still don’t get it. It gets old, frustrating and upsetting to constantly explain. Sometimes I just want to SCREAM ... if you really care about me, look it up!

ENTER JUNIOR HIGH: What can I say ... the absolute **WORST** time of my life thus far. The years of my “un”-corrective foot surgeries for my CMT high arches and a big toe hammertoe fusion. I refuse to get my other toes done at this point. I spent my entire seventh grade, as my grade school friends slowly began to fade away from me, using a knee scooter to get around school.


ENTER SCOOTER BOY! Sounds like I should have been wearing a cape and mask. Being called **SCOOTER BOY** was absolutely mortifying! As I was using a scooter and losing muscle, my jock

“friends” were beefing up. I began to stay home a lot. Being an only child staying home with your parents constantly can get pretty lonely and boring. Let’s just say I watched tons of YouTube videos to keep myself entertained. I also stopped wearing shorts so I could hide my “skin-ny” legs and AFOs as my other nickname was **CONCENTRATION CAMP BOY!** Talk about body image issues. Am I really so skinny that I look like a Holocaust concentration camp victim? **ENTER TEARS! ENTER ANGER!**

ENTER HOBBIES: I started metal detecting, target shooting and woodcarving. As I look back on this now, I realize these are metaphors for my soul searching. In metal detecting, you are looking for treasures buried under the earth. In woodcarving, you are carving objects out of a blank piece of wood. I was trying to find the treasure of who I was outside of my physical appearance and trying to carve the identity I would be comfortable with and able to show the outside world with confidence.

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**“I know myself
and I am tough..
exit
SCOOTER BOY”!**

ON TARGET!

ENTER ADVOCACY: - I was given an opportunity last summer to participate in a George Wolfe internship at the Topeka Independent Living Resource Center (TILRC), where a group of teenagers with “different abilities” were mentored by TILRC staff. We got paid to help make Americans with Disabilities Act (ADA) accessibility plans and recommendations for the Topeka Zoo; we also learned how to self-advocate and become educators.

ENTER ME: I am no longer afraid or embarrassed or get angry when I have to speak up for myself and my needs at school, home or work. I know my rights through my 504 plan and the ADA and I know that nobody should be treated mean because they are different.

Most importantly,

I KNOW MYSELF and I AM TOUGH.....EXIT SCOOTER BOY!

Although most people in my life don’t understand the physical pain I experience every day with CMT, what I know is

I CONTROL MY CMT, IT NO LONGER CONTROLS ME!

I have had so many opportunities given to me this past year thanks to the help of my parents, Kaw Valley Woodcarvers, Topeka Treasure Hunters, Boy Scout Troop #175, TILRC, Families Together, Kansas City CMTA Branch, MDA and MDA summer camp, and others. Now, I get to look forward to meeting some of you at **CAMP FOOTPRINT** in PA this summer too! **THANK YOU CMTA!**

Sean Tyree, 15 years old, will be in the tenth grade in the fall.



What I Did on My Summer Vacation: A Visit to a Biomedical Research Facility

By Vittorio Ricci*

While many families head to the beach for summer vacation, I visited a research laboratory that distributes mice models of human diseases, including Charcot-Marie-Tooth.

On June 22, my family and I had the amazing opportunity to tour Jackson Laboratories in Bar Harbor, Maine. For those who don't know, Jackson is the world's largest nonprofit biomedical facility that researches genetic disorders and breeds lab mice. The lab offers educational programs for high school, college and graduate students with housing on-site. There are 40 labs and one is attempting to use gene therapy to stop the progression of CMT2D. Our guide was the head of this research study, Robert Burgess, PhD.

To get there, we drove a scenic six-hour coastal ride from Boxford, Massachusetts, to Bar Harbor, Maine. I made sure we stopped at a few of the countless flea markets along the way.

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Our first day was spent exploring Acadia National Park, driving to the top of Mount Cadillac and stopping at the family-Christmas-card-backdrop of Sand Beach.

Jackson Laboratories is located next to Acadia National Park, making it one of the most photogenic places I've ever seen. We met Dr. Burgess in a lobby that seemed right out of the opening scenes of Jurassic Park. He led us throughout the main facility, stopping to discuss portraits of past Nobel Prize Winners and see a replica of all the lab buildings, including the mice breeding facility. We stopped outside a sterile room where afflicted lab mice are examined to track the effect of their treatments. But the research facility was the most anticipated stop of the tour. Burgess's lab was packed full of equipment I half-recognized from high school biology—centrifuges spinning down mysterious fluids and interns pipetting liquids from vial to vial. It was the kind of messy, complex space only a scientific researcher could find manageable.

Lastly, we sat down in Dr. Burgess's office to talk about CMT and his research on type 2D. He explained to us how he is using gene therapy to stop the progression of CMT2D in lab mice, and results were looking good. Specifically, his team is working with Dr. Scott Harper at Nationwide Children's Hospital, using a specially manufactured

virus to prevent the CMT2D afflicted mouse's cells from creating the faulty protein, effectively stopping the progression of the disorder. The virus contains a small, specific strand of the afflicted mouse's DNA that includes the mutation, which causes the immune system to respond and prevent that strand of DNA in the mouse from making proteins. Those faulty proteins are what cause the mice's nerves to degenerate. We watched several videos of CMT2D lab mice with and without treatment. It was exciting to watch a video of active mice and not see signs of CMT disease.

As a person who lives with CMT - I was amazed by the enormous efforts taking place at Jackson Labs. Thank you to Dr. Burgess for his time, his work and explaining it all to me and my family. Nothing gives me more hope than to hear someone say, that a mouse once had CMT.

**Vittorio, 19, is a rising sophomore at Northeastern and a member of the Boston MA CMTA Branch run by his mother, Jill.*



SC Middle School Raises \$1,072 for CMT Research



Joseph Matthews, far left, with the Northwood Middle School Student Council.

Hello, I'm Joseph Matthews from the Northwood Middle School in Taylors, South Carolina. I decided to raise Spirit Week money for CMT this school year because my younger brother, Jeffrey, has the disease and I watched him struggle with certain things as he was growing up.

For Spirit Week, my fellow Student Council members and I created two games and sold water bottles to raise money. In "The Wishing Well," contestants dropped a pebble from above down into a cup. The second game involved guessing how many pieces of candy two filled jars contained. The one who guessed the closest won the candy inside. We raised a total of \$1,072 and donated it to our local CMTA branch. They were so happy with what we accomplished and so proud to see that people truly do care about CMT.

The Story of Life

By Zach Geary*

Life is a racetrack,
And you're the car.
You never know when your tire will pop
Or when your engine will smoke.
You're afraid of spinning out on every sharp corner,
Or your wheel getting stiff after a while
And not being able to steer your way around the track.
No matter what bumps or crashes you've been through,
Or ups and downs,
You may not achieve first place
But you were in the race.



*Zach, 11, is from Southampton, Hampshire, England.



CMTeen Reader Poll: Do Stories About Disability Have to Be Sad?



You can buy “Mia Lee Is Wheeling through Middle School” on [amazon.com](https://www.amazon.com).

Middle schooler Melissa Shang is an author and activist. She also has CMT. In 2016, Melissa published “Mia Lee Is Wheeling through Middle School” because she wanted to read stories about people like her. “There are very few stories about kids in wheelchairs, and there are even fewer with a disabled person who is cheerful and happy,” she says. When she tried to sell her book, publishers told her that her main character, Mia Lee, was just too happy for a girl with a degenerative disease in a wheelchair. So she self-published.

In 2013, Melissa gathered 140,000 signatures and petitioned her favorite doll company, American Girl, to make a doll with a disability. The company did not grant her petition, though it does make doll accessories like a wheelchair, crutches, a hearing aid and a diabetes care kit. According to Melissa, there’s also a secondary character in a wheelchair, a boy in the hospital with polio, and a girl with a stutter. “But these were not the characters I wanted to see,” she says.

In a June 21 piece in the opinion pages of The New York Times, Melissa, 13, questioned whether stories about disability always have to be sad. “For once, I want to see the disabled kids not in the hospital, but in the school cafeteria eating lunch with their friends. I want young readers to think of disabled kids not as miserable people to be pitied, but as people living normal lives in spite of their challenges. I want young readers to see disabled kids as friends, people to gossip with, to take selfies with and to go see movies with on the weekends. Not having books that show disability in a lighthearted way makes it harder for everyone else to see disability as a normal part of life.”

What do you think? Do you agree with Melissa? Would you like to see more happy stories about being a CMTeen with CMT? If so, tell us why. If not, tell us why not. Send your thoughts to marcia@cmtausa.org and we’ll publish them in the next issue of CMTeen.

The Adventures of Rui Rui and Tango



Lia Bleifus, known to her friends and family as Rui Rui, wanted a dog. Her parents, Sherry and Ethan, wanted a dog too. Because Rui Rui, 13, has CMT, they also wanted a companion to help her with her balance and leg strength issues. The answer turned out to be Tango, a lovable black Goldador (Golden/Labrador Retriever cross) mobility assistance dog.

Tango came from Can Do Canines, an amazing organization in New Hope, Minnesota, that provides mobility assistance dogs at no cost to clients with mobility challenges, hearing loss or deafness, seizure disorders, diabetes complicated by hypoglycemia unawareness or childhood autism.

Can Do Canines trains 50 - 60 dogs a year, many adopted from local animal shelters. The dogs' initial training is done by federal prison inmates, who live with the dogs 24/7. The dogs are then handed over to volunteer trainers who slowly introduce the dogs to their new owners.

For Rui Rui, Tango is not just a beloved pet, but also an invaluable companion whose harness provides her with balance assistance and who can pick up things that she drops, although often with an added layer of slobber. Tango also helps Rui Rui make new friends and provides an introduction to discussing her CMT. With a big head and a semi-goofy disposition, Tango keeps Rui Rui and her family amused and entertained. Rui Rui reports that Tango likes to cuddle with her rabbits, gets along well with the family cat and enjoys eating snow. He doesn't seem to mind the cold weather in Minnesota and will happily walk with Rui Rui in 10 degree weather.

In addition to swimming and hanging out with Tango, Rui Rui loves acting and recently performed in a production entitled Aphrodite Loveletters in which she played a sassy nymph. For more information on Can Do Canines, visit can-do-canines.org.





Working Around the Weakness

BY Diane Wittenberg*



Part of me feels guilty for passing along the CMT1A gene to my son. But the other part of me sees that it's made him who he is today—an amazing, strong (mentally, if not physically) and confident young man.

Daniel is now 22. When he was in middle school, he was bullied relentlessly. I know how that feels, because so was I. When he came to me at the end of eighth grade and stated, in no uncertain terms, that he was going to play football in high school, my first thought was, “NO! They’ll kill you!” But then he explained: “Mom,” he said, “they won’t and here’s why: 1) it’s a no-cut sport so I don’t need to worry about tryouts; 2) I’ll learn how to work out and lift weights the right way; 3) you don’t have to worry about me getting hurt because I won’t really be good enough to get much play time and I’ll be on the bench during games, and 4) I’ll never get picked on again because I’ll be hanging out with the football players.”

I was impressed. This was from a 13 year old! He had some very good points. Although I was still nervous, I was never the kind of mom to stop my kids from making their own choices, as long as the thought process was right. So off he went! And his plan worked perfectly. From the first day of school, he had friends that he’d made during summer practices. Sure, the football players still gave him a hard time, but in a friendly, teammate kind of way, not a bullying kind of way. Even today, his best friend is someone he met freshman year on the football team.

Another thing that might be worth mentioning ... at that time he didn’t know he had CMT. He just thought he was weak, uncoordinated and un-athletic. I knew, but I didn’t think he was mature enough to approach it the right way back then. I waited to tell him until his junior year of high school so he could address it with confidence and strength, and never use it as a crutch or an excuse.

I’m writing this article instead of Daniel because he doesn’t like to even acknowledge that there’s anything different about him. I think his attitude is that everyone has something, and you just deal with it and live your life. Don’t dwell on the negative. Figure out how to best work around whatever “weaknesses” you have and move on. This doesn’t define who you are. For every ounce of physical strength that CMT takes away, you can gain mental strength to move your life forward in whatever direction you choose. You choose what to do with your life.

*Diane is a partner at a CPA firm in Orange County, California. She’s married and has three kids, one of whom inherited her CMT.