

VOLUME 1 ISSUE 3

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

# DMTTeen

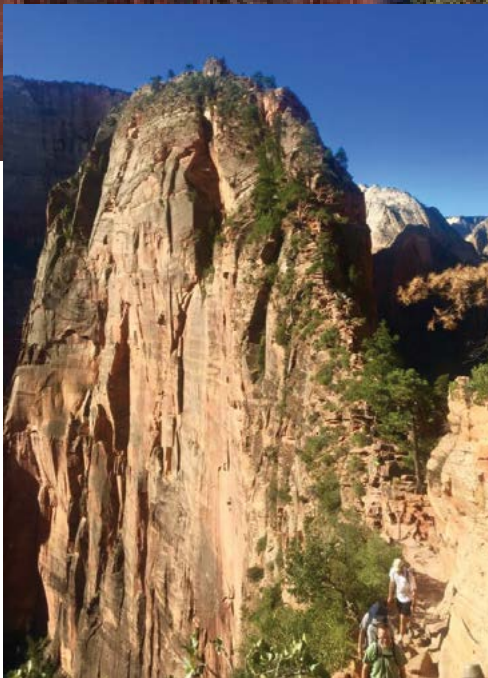
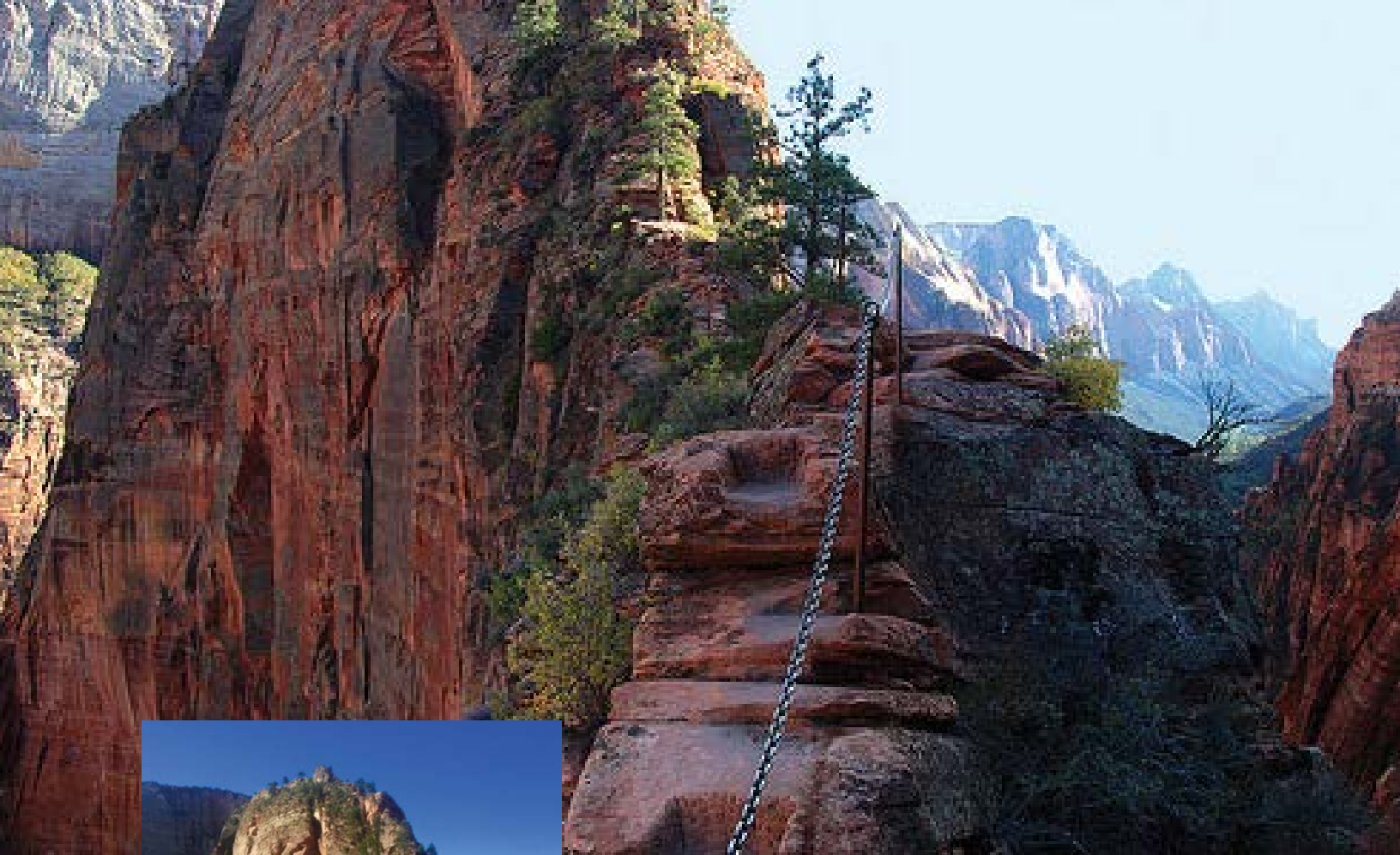
MY FIVE  
WEEK BACKPACKING  
ADVENTURE

#ChairLife Wheelchair Motocross

A WHOLE LOTTE LOVE GOING ON!

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Climbing to the Top:

# My Five-Week Backpacking Adventure

By Zoe Phillips

This summer, I went on a five-week teen travel hiking trip throughout the western United States. Being the only kid on the trip with a physical disability, I was hesitant.

Since Charcot-Marie-Tooth disease isn't commonly known, I knew I would have to teach people what they could do to help me.

MY MOM, AUNT AND GRANDMA all have CMT, so we had always suspected that I might as well. When I was a baby, I was late to walk and never crawled, just scooted. I have extremely high arches and my feet turn inward when I walk. I wear orthotics that I keep in my shoes at all times.

My mom and I went to a neurologist a while ago to talk about what I will need in the future. He said that I could choose to wear braces now, but I will for sure have them in the future. We agreed that I did not want to rely on them at such a young age. I recently had an EMG to prove what we already knew was true. Sometimes I get nervous for the future. Since CMT is progressive, I know in a few years I might not be able to do the things I do now. That is the main reason I wanted to do this trip—I know I can't control the future.

At first, there were problems. I climbed the Colorado Rockies with nothing but orthotics, taking a break every other step. I then invested in hiking poles because of how much trouble I was having and that helped a lot. On the way down from hikes, I could rely on the poles and not put as much pressure on my legs. They also helped with balance issues. In Arches National Park, I passed out from a heat stroke. By the time we arrived at Zion National Park in Utah, I had almost everything figured out. I knew my limits but still stepped outside my comfort zone.

Angels Landing in Zion National Park was the most challenging hike of the entire trip. The National Park Service describes it this way: "The route to Angels Landing involves travel along a steep, narrow ridge with support chains anchored intermittently along the route. Footing can be slippery even when the rock is dry. Unevenly surfaced steps are cut into the rock with major cliff dropoffs adjacent. Keep off when it is wet, icy or thunderstorms are in the area. Plan to be off before dark.

Younger children should skip this trail; older children must be closely supervised." I can proudly say that the Angels Landing trip was the hardest thing I have ever accomplished, and I climbed all the way to the top—the full 1,500 feet on my own two legs.

It didn't matter to me that all of the other campers waited for more than an hour for me to finish. It didn't matter how I did it as long as I got the job done. I didn't care if I was tired or if my legs were about to give out. I just kept going. All I could do when I reached the top was look around me. Look at the view, look how far I could see into the distance, look at what I did. Less than three hours before this, I had been at the bottom. Less than three hours before this, no one, including myself, would have believed I could do this.

This trip made me realize that I want to inspire and be inspired. My determination to hike and climb mountains no doubt inspired some of the campers and counselors on my western trip. I've concluded that a disability itself isn't a limit. It's all in your head and I promise, the possibilities are endless.

Movie director Tim Burton said, "Every story has a beginning, middle, and end. Not necessarily in that order." The minute I got to the top of Angels Landing was my beginning.

Zoe Phillips, 15, is a high school sophomore in the metro Detroit area. In addition to hiking, she likes to play guitar and sing. She has CMT1A.





# Shh! Watch out Northeastern, Vittorio is Coming

*By Emma Ricci*

## I KNOW A LOT ABOUT CHARCOT-MARIE-TOOTH DISEASE.

I know about tests like electromyogram (EMG) nerve conduction and genetic testing, and the neurologists who perform these tests. I also know about carbon fiber AFOs with names like Noodles, Toe Offs and Blue Rockers. I've written papers on CMT in biology and English classes. I don't have CMT, my brother Vittorio does. I'm his younger sister Emma.

This fall, I'll be a sophomore in high school. Four years ago, my brother was diagnosed with CMT going into his freshman year. While my family struggled to understand CMT, Vittorio was okay with the diagnosis and seemed to come out of his shell. Throughout elementary school I was the talkative one while Vittorio was very shy. That has reversed now. I'm really proud of my brother and I'm working on trying to come out of my shell too.

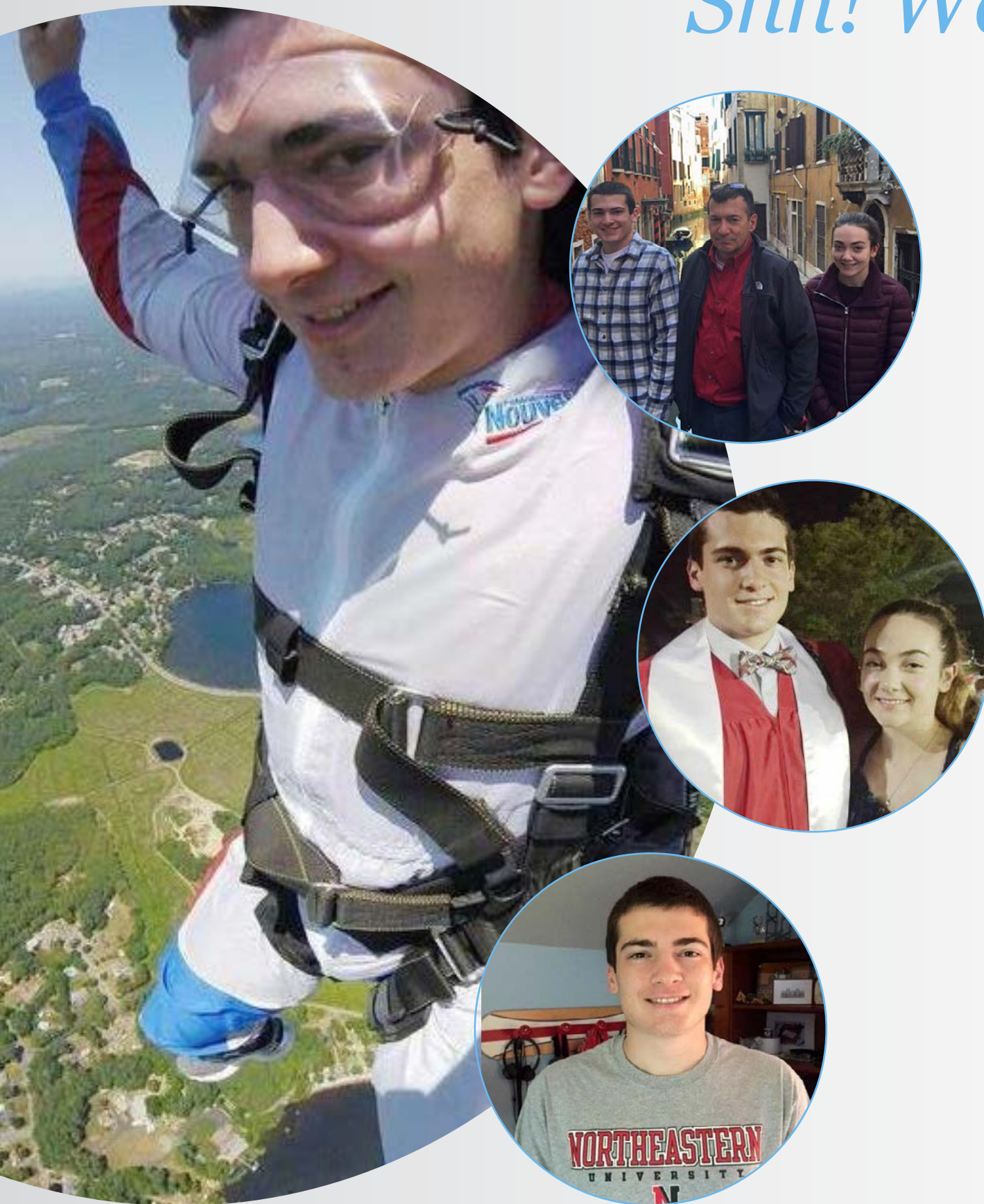
High school is different for girls. The "groups," social media, what you wear and how you look are all very important. I have grown apart from and have been left behind by many of my friends. It's difficult enough being a teenager and trying to figure out where you belong without the pressure from school, friends and society.

I enjoy art, watching YouTube, coffee, and my dog Gio. I want to use my high school years to find my passion. For me, new experiences are definitely out of my comfort zone. I have seen my brother change in the last four years and I know I will find my place too.

So, watch out Northeastern, Vittorio is coming and he will make an impact like he did at my high school and in our community. I am planning on taking over his bedroom, and turning it into a walk-in closet. Maybe I should be an interior designer.

This is step one.

Emma, 15, is a rising sophomore at Masconomet High School in Boxford, Massachusetts.







## CMT No Barrier for Musical Prodigy Henry Cassidy

By Emily Cassidy

Have you ever listened to a Broadway performance and left the theatre wishing that you could go home and reproduce the show over and over again in your own home?

Well, Henry Cassidy can do just that.

MY BROTHER HENRY'S CMT MEANT he was never the first to cross a finish line or shoot a basket. He cultivated his passion in something else-music. From early childhood, Henry displayed a talent and fervent affection for music. Growing up with a musician for a father, he was surrounded by classical symphonies and sonatas by composers like Bach, Mahler, Beethoven, Wagner and Brahms. When he was 18 months old, he threw a fit in the car if the local FM station was changed to a popular station, and continued to cry until it was changed back to classical. Even now, although he doesn't cry about it anymore, he much prefers classical music to Twenty One Pilots or Adele.

Henry started playing piano when he was very young, using a one-and-a-half octave toy keyboard. He began by reproducing songs that he heard in the media or that he was exposed to as the result of being the child of a middle school band director. His first "hits" were "Dead Man's Chest" and other themes from the Pirates of the Caribbean movies and "Axel F" (the Beverly Hills Cop theme song). A stickler for perfection, he played the same tunes for weeks until they were carbon copies of the original.

As Henry grew older, his keyboards grew longer, and he spent hours practicing music from films like "Star Wars," "The Nightmare Before Christmas," "Star Trek" and "Indiana Jones" with his headphones on. Henry also loves musicals like "Les Miserables" and "Phantom of the Opera" and entertains his classmates by playing and singing large sections verbatim. Although he has never learned to read sheet music for piano, he's never needed to. His perfect pitch (a rare ability to recall individual pitches from memory) has given him the unique ability to play back almost anything he hears in its original key and its original voicing. Currently, he is attempting to learn impressionist composer Claude Debussy's "Arabesque." Why does he like it? "Because it's good stuff," he says.

Henry has always been successful in his school music programs. He played the French horn in middle school, but took up vocal lessons in high school and joined the choir instead. After the first semester of his freshman year, he was promoted to varsity choir, where he sings bass. Although he is still undecided about where he wants to go to attend college, he plans to pursue a degree in music composition.

Henry, a high school junior in League City, Texas, also enjoys playing multiplayer video games on his Steam account, learning about military history, shooting firecrackers and watching "Doctor Who" and "The Office."

Emily, 22, is a senior at Sam Houston University. She is currently doing a music therapy internship at a psychiatric hospital in San Antonio, Texas.







# Lessons from the Feet

By Isabelle Tate



Izzy, 13, is in the eighth grade at Grassland Middle School in Franklin, Tennessee.

**MY NAME IS ISABELLE TATE**, but most people call me Izzy, which is also my stage name. Before I started the seventh grade last year I was diagnosed with an extremely rare form of CMT and tight Achilles tendons.

My feet have given me such a good perspective on life: Don't stare, don't judge a book by its cover and appreciate every single thing you have. You don't truly learn these things until you've experienced them firsthand.

Like a lot of girls, I love shoes. In my case, though, my feet decide what I can and can't wear. Ever since I was a child I have walked on my toes, though I could still walk on my flat feet. Up until a year ago I could slightly spread my feet apart and stand on my flat feet and I was still walking pretty normally.

Going into seventh grade last year, I wore flats, but eventually I could only wear wedge heels. By the end of the year, I couldn't wear flats, I slid down the stairs, and I had to hold onto things to keep my balance. At first I was made fun of because all I wore the entire school year were wedges or brown wedge boots. I remember looking so forward to wearing high heels and... now they've lost their fairytale magic.

Towards the middle of the school year, my heels started curving in, causing me to fall sometimes. At the beginning, some people stared, but not everyone. I still felt

pretty normal. It meant I couldn't go out as much, or play sports. It was hard to walk relatively short distances. People stared and worst of all I was scared that my feet would keep me from my dream of becoming famous. It's hard because especially as a 13- almost 14- year old teenage girl ... you feel magnified.

I had surgery on both my feet on July 25, 2016. The surgery went great, but it was painful and overwhelming. All I remember is going into the operating room and breathing through a mask until everything turned black and I told myself "Okay, I'm out." I feel much better now—like my old self—but it took about 5-6 days to feel back to normal. Since then, I've mastered the use of my wheelchair at home and at school. With the wheelchair, I have a new sense of freedom. It lets me go to the mall, around the neighborhood, and to the supermarket—all places I couldn't walk to before my surgery. After six weeks in casts, I'll wear leg braces. With physical therapy, I hope to resume walking fairly normally.

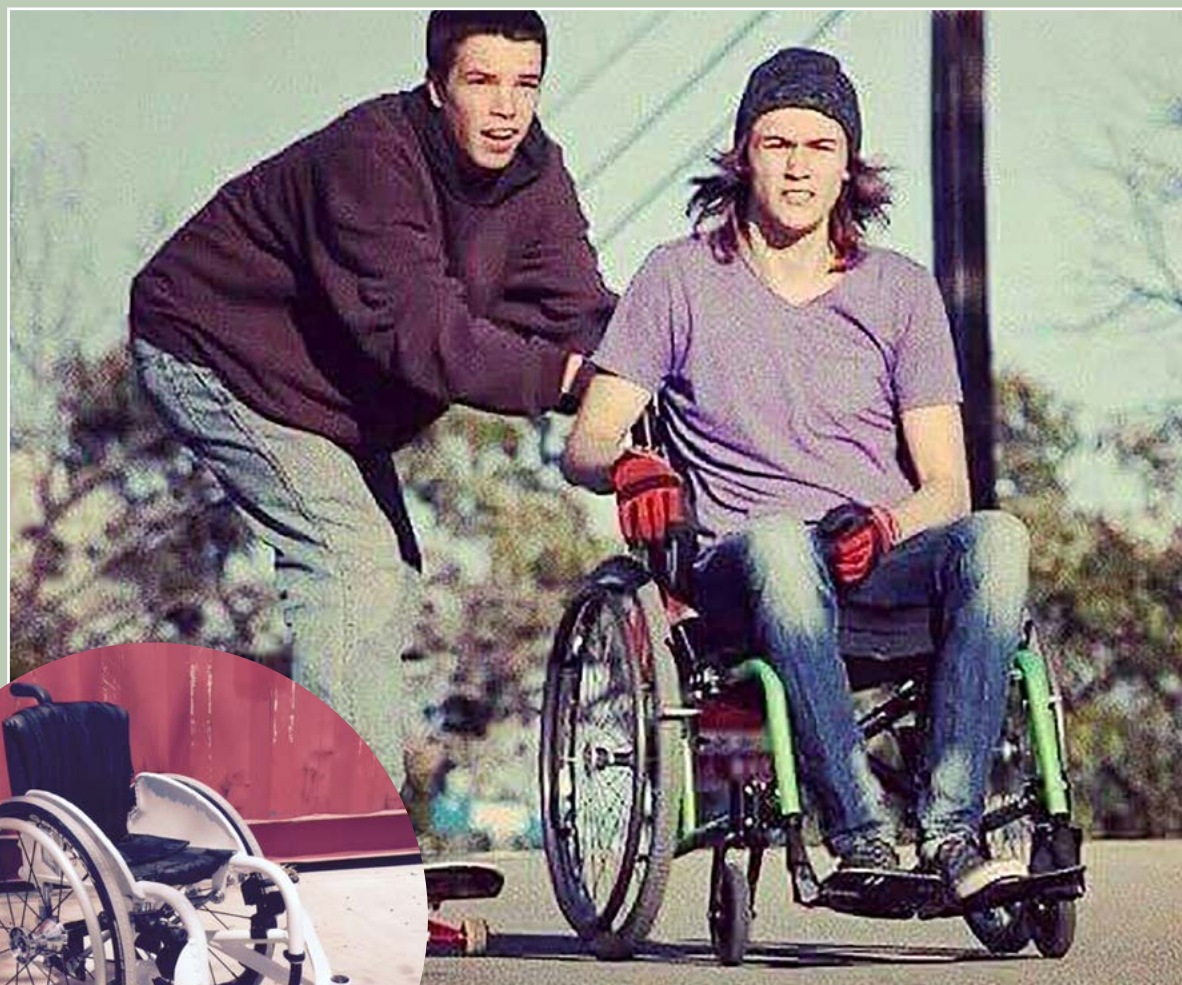
Once that happens, I hope to get back to my "career." My father is a professional singer/songwriter, so I grew up in the world of singing and acting. I did two commercials—one print and one TV—before my CMT took over and I've been singing on stage since I was 3. I love to act and if I can do anything about it, my feet **WON'T** stop me because I am determined to beat this.

Luckily for me, I have the best and most supportive family, who give up so much for me. My sister who's always there, my dad who talks me through it and my mom who saves me. She's my hero and she sacrifices everything for me.

I also have the best and most supportive friends. Like my best friend Georgia, who sticks up for me even if I don't want her to, and who carries me two miles when my feet are hurting. I may not be lucky in my appearance, but I'm lucky with the people who surround me every day! Our family friends Eileen Bray, Kesha (yes, that Kesha!) and Kesha's mother Pebe started a gofundme page [www.gofundme.com/2fxx2vuc](http://www.gofundme.com/2fxx2vuc) to support me and show their love.

It's frustrating sometimes because no one understands what I'm going through. They try, they really do, but they don't understand. I finally met someone named Nicole who is 43 years old and was diagnosed at 26 with CMT. She teaches yoga at a place called Yoga Harmony and I have started attending her classes. She's a big inspiration and it's nice to have someone around going through something similar to me. My feet are a hard challenge in life but I believe when everything is said and done I will be a better person because of it. I know in my heart that **EVERYTHING WILL BE OKAY!!**





## #Chairlife: Wheelchair Motocross

By Chase Myers

“I found my calling when I discovered my idol, Aaron ‘Wheelz’ Fotheringham, an extreme wheelchair athlete who does tricks adapted from skateboarding and BMX.”

# WHEELCHAIR

I HAVE BEEN WHEELCHAIR-BOUND since my junior year of high school in 2014. I was born with CMT, but it didn’t start making an impact until around sixth grade. It was a lot to comprehend at a young age, but I didn’t think of living life any differently. I played baseball from second grade till seventh. I used to BMX (bicycle motocross) and try to skateboard. I studied karate from second grade till fourth. I’d climb trees and try anything. My reality was a nonstop adventure!

I’ve always had pretty intense social anxiety and that only got worse throughout middle school and high school, but I survived. Barely, but I still managed. In middle school I made a couple of friends that I can say I’ve had the pleasure to know, inspire and learn from. I was a rebel and a problem in my younger years and lived in in-school suspension.

I have a strong interest in many fields—philosophy, genetics, spiritualism, frequencies of energy and physics in general. It makes a lot of sense that I love skating and WCMX (wheelchair motocross), considering it’s all physics.

I found my calling when I discovered my idol, Aaron “Wheelz” Fotheringham, an extreme wheelchair athlete who does tricks adapted from skateboarding and BMX. Aaron, who has spina bifida, is the godfather of the wheelchair scene and basically created WCMX. He was the first to do a double backflip in a wheelchair and to jump many mega ramps. He’s created a legacy from his sick and fearless way of life. He rides in a Box chair forged in the flames of love and hope, carved to perfection by Mike Box himself, the builder of the most radically advanced action sports wheelchairs in the world.

The Box chair has a sweet suspension system to help with standard stair sets and jumps conjured by Satan himself. It also has a grind bar under the axle and grind pad under the

foot rest, a seatbelt and leg belt that let me become one with my steed, wheels that actually air up and scooter wheels in the front to go faster. The chair is ultra-lightweight, a good thing in WCMX.

I’ve been attempting stunts for two years now. I’ve jumped curbs, two stairs, three stairs, dropped into half pipes and attempted to grind. In these ventures, I’ve had some gnarly spills from face planting to rolling after flying out to catapulting and bouncing. Once my tooth went through my lip.

I love WCMX because of how intense and hard-core my accomplishments are. A lot of people have asked why I do these things. Once a lady said to me, “Chase why do you try? You know you’re going to fall.” That only fueled me to ignore the spills and temporary pain and the people who can’t comprehend a passion as deep as mine. My mindset is that I can do whatever I set my mind to and achieve my goals no matter how many times I fly out of my chair. All is temporary in this physical realm, whether it be life, happiness, pain or depression. It is all temporary. I am ready to go full speed into this life spreading the two things that are forever—love and hope.

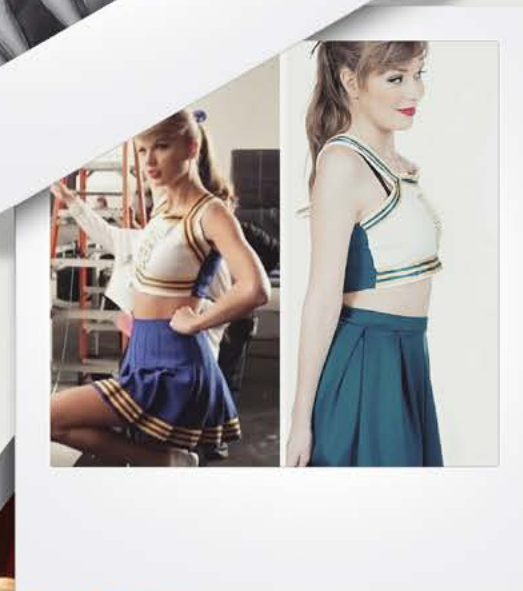
No one should hold themselves back or put themselves down because of anything they perceive to be negative. Every action you do or conscious decision you make is the result of willpower and those of us who go through semi-obstacles just to survive see the beautiful glimpses of life far more.

So with this article in mind, I challenge all readers to push yourselves more every day you wish to encounter something truly beautiful and magical.

Chase Myers, 19, lives in Texas. He’s raising money for a Box wheelchair at [www.gofundme.com/2gktofw](http://www.gofundme.com/2gktofw).

# MOTOCROSS





# Dutch CMTeen Earns **24,000** **INSTAGRAM FOLLOWERS** With Copies of Taylor Swift Tour Outfits

**DUTCH CMTEEN LOTTE LUTJE** says her family knew she had CMT pretty much as soon as she was born. Her sister has it as well.

Lotte has always been into creativity and making pretty things. Her friends (and pretty much everyone her age) enjoy sports and physical activities, but sports were never really her thing, for obvious reasons. She felt left out and she hated her body for it. That's partially what made Lotte fall in love with Taylor Swift and her music-it always made her feel better.

Being the creativity addict that she is, Lotte made loads of fanart and attended lots of shows. For one, she and her friends all decided to dress up in one of Taylor's tour outfits. These weren't for sale anywhere so it just seemed logical to Lotte to try and make them herself. Her grandma helped her and Lotte fell in love with making and designing clothes. She recreated more and more of Taylor's iconic outfits and started seeing how much other people liked them and appreciated her work and skill. And so she went from feeling pretty useless to having over 24,000 instagram followers looking forward to more of her work!

Lotte says it made me realize that her body isn't useless "and also that one can look fierce as heck, even with CMT." She knows now that she doesn't need athletic skills in order to be important or appreciated. Lotte's philosophy is: "Doing what you love and doing it your own way is all you need."

Lotte, 18, is currently studying design at a California university.





# The Making of a Paralympian

By Millie Cass

*“I hope to represent my country in Tokyo in 2020.”*

**GROWING UP, I NEVER THOUGHT SPORTS** would be my thing. I was diagnosed with CMT1A at 3 years old; I struggled through PE at school and I basically wrote sports off from a fairly young age. By the time I reached the age of 13, my CMT had worsened and I could no longer manage the walk to school without tripping.

My Dad and brother, both keen cyclists, suggested that I ride to school. I enjoyed it so much that I got a road bike and pursued cycling as a hobby, never realizing where it could take me. Later that year my dad contacted British Cycling and got me booked onto a Talent ID day. The day involved a two-hour track session, an interview and power testing to find athletes with potential in the sport.

Since then I have worked with Team Great Britain and trained with people who recently competed in the Paralympics in Rio. It quickly became my dream to become a professional athlete. I am now training five days a week and competing at the international level. I hope to represent my country in Tokyo in 2020. I also go to the gym twice a week and with the help of a coach I have started weight training, something else I never thought I'd do.

Off my bike, my CMT still affects me in many ways. A few years ago I was prescribed leg braces to help me walk. I am tired most of the time from training

but it's worth it when I get to compete. I have pain that I'm sure you're all familiar with: shooting pains, achy muscles, nerve pain and sore joints. It doesn't stop me, though. I always say I'd rather be in pain and have achieved something than just be in pain.

Without sports I think my CMT would be much worse than it is. So I encourage you to try lots of sports, find one that suits you and let it help you get stronger. Try researching Paralympic sports and governing bodies in your area that may well be looking for the next Paralympians and give it a go!

Even if you find you don't want to compete, the difference that sports will make can be dramatic—maybe even better than medication. Sports with CMT is hard but you've got nothing to lose and it could make your symptoms better. I know cycling has helped me avoid surgery!



**\*Millie, 17, competes on track and road. She goes to school at Silverdale School and live in Sheffield, South Yorkshire, England.**





## Reflections on High School: Lessons Learned from CMT, By Vittorio Ricci

**MY NAME IS VITTORIO RICCI.** I am from Massachusetts and recently graduated from high school. I was diagnosed with CMT when I was 14. I've learned a lot about myself because of CMT and feel compelled to share my high school experience with anyone who might be struggling.

Like many teens, I was very shy and introverted. I had a hard time making friends and tended to stay close to the ones I had. I spoke softly, kept away from large social circles and generally avoided attention.

Middle school came around and my friends were getting very competitive in sports. I signed up for cross country, but my undiagnosed CMT made me much slower than everyone else my age. You can probably tell where this sob story is going. I couldn't keep up with everyone else, I was left behind, etc. Finally, after a few months of testing, I was diagnosed with CMT.

After the diagnosis, I felt re-invigorated and I started talking. I had a story to tell. CMT gave me a purpose. I joined my first high school team—cross country and I ran. When my leg braces broke, I ran without them. When someone could do more pushups than I could, I started doing pushups every single day. I made the effort to go outside my comfort zone to make new friends. I went to football games, joined clubs and tried to make myself a memorable friend to all of my classmates.

Now that I've graduated, I can honestly say that I am proud of the changes I've made, but I still have far to go.

Today, a person with CMT is never alone. There are so many people with this disorder going out into the world and making a difference, whether it's through art, science or athletics. Some compete in triathlons, some give huge

public speeches, some paint impactful images and others start hashtags to spread the word about this disease.

There are multiple roads to happiness in high school; the key is finding what you love and pursuing it unapologetically. When I first started playing ice hockey with my friends, I couldn't even stand up on the skates. Instead of saying, "I can't because I'm disabled," I just kept practicing. Now I've got the slap shot of Wayne Gretzky (not really, but maybe someday).

The point is, stop making excuses. Some people are born on third base and just have to run home. People like us, we are born last in the batting lineup, get called up to play only for exhibition games and get shoved to the ground by everyone when the moms bring out orange slices for half time. We are also the ones who stay after practice to perfect our swing and run an extra lap. Enjoy all those high school moments. Don't let

fear stop you from doing something worthwhile.

Vittorio, 18, graduated from Masconomet High School in Boxford, Massachusetts, in May. He'll be attending Northeastern in the fall. In July, he and his family hosted the 4th Annual (Vittorio's Funding the Fight) CMTA Fundraiser, bringing the total raised over the years to just over \$140,000.





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