

VOLUME 1 ISSUE 2

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

# CMTrean



A CONSUMER  
FORGOTTERS

FIGHTING

SURGERY:  
MAKING THE  
TOUGH CALL



# Paratriathlete Charlie Stanton-Stock:

## The Road to Tokyo in 2020 & Beyond

**Hi,** I'm Charlie. I was diagnosed with CMT in May 2014, when I was 13. I had always been active playing rugby and cricket, running, and riding horses, but after my diagnosis I decided to give up rugby as I just couldn't keep up. To try and keep fit and strong I decided to have a go at triathlon. I found a children's paratriathlon event to try in September 2014. It went well and I met some of our Great Britain para triathletes. Inspired, I began training through the winter with my local tri club and at the start of 2015 planned my first youth triathlon. I realized I would have to compete against able-bodied athletes as para events are few and far between. I planned my first youth triathlon at my club (WaldenJNR). I also decided to fundraise for CMT UK while I was at it. I had a really good first triathlon. Everyone was so supportive that I decided to continue with my fundraising and just raise the bar, something I then continued to do for the rest of the season. By September 2015, I had completed my first open-water tri, completed two triathlons in a weekend and completed two triathlons in a day. My last event of the season was my first sea-swim triathlon (in a very choppy grey sea)! In 2014/15, I raised almost £3,000 (\$4,300) for CMT UK.

In October 2015, I was invited to attend a para-talent weekend with British Triathlon, which classifies me as a PT4, the classification for ambulant athletes with a lower level of physical impairment. I met other paratriathletes and had a great weekend. British Triathlon then asked me to train with one of their triathlon academies. I now travel down to Oxford once a month to train with their elite academy and other paras in my region. I also received my wonderful personalised GB Tri-Suit, which I am so proud to wear. More recently, during February half-term I did a week's fitness camp in Oxfordshire with able-bodied elite athletes from all over the country. It was a tough week for me. Many

of the athletes run, bike and swim several times a week, but with CMT fatigue and school I normally do just two bike sessions and the two-hour tri training on Saturday morning. At fitness camp, we started each day with a two-hour swim (I hate swimming!), breakfast, and then a two-hour bike session followed by a run or conditioning session in the afternoon! I was shattered at the end of the week, but felt so much fitter and stronger!

My transitions (when one changes between events) and running were the hardest part of the triathlons through last season. The hospital gave me some foot-up braces to try, which were good but not ideal for someone trying to put them on with cold wet CMT hands. My mum had been posting my progress on CMTAthletes on Facebook and came across a man named James Cuizon. James was running marathons and Ironman competitions, which are long-distance triathlons. [Editor's note: James completed his second Boston Marathon on April 18!] James really liked his Turbomed braces for running, so in November I fundraised via "Go Fund Me" to buy the same kind. They have been amazing and have aided my deteriorating foot drop, stopped me falling over at school and really helped my running. James followed my

*[Editor's Note: Paratriathlon—which combines swimming, cycling and running--will make its debut at the Paralympic Games in Rio de Janeiro, Brazil, this summer. The next Paralympic Games take place in Tokyo in 2020.]*



continued on next page



*Paratriathlete...*

triathlon progress over the summer and suggested I apply for a grant from the Challenged Athletes Foundation (CAF). The grant for the CAF opened in December and I just thought I would give it a go, so I filled in the forms and told them my story. I was truly speechless a couple of weeks ago to receive a grant for \$1,000 from CAF! Someone having the faith to invest this much money in me has truly amazed me! It will help me to buy all sorts of kit: The top of my list as a skinny CMter is a big dryrobe to keep me warm before and after races and at open-water swim sessions. Help with strength training is also on my list.

What motivates me? Well, lots of things. The people, for one. I receive so much amazing support within my local club, town and even the other competitors. And also the fact that I really am getting stronger. After my diagnosis I could stand on one leg for six seconds. A month ago I managed the same exercise for 48 seconds. Although I won't ever walk a tightrope, falling less and keeping stronger for longer is my ultimate goal (as well as an Olympic medal, which would look good in my trophy cabinet!). My plan for this year is to improve my transitions, as well as working on swim, bike and run. I also want to raise some more money by completing 10 triathlons this season. Wish me luck!

Thanks for listening,  
Charlie

\*Charlie, age 15, lives in Saffron Walden (near Cambridge) UK, and is the only one in his family with CMT. If you'd like to sponsor him, all the money goes towards CMT research. You can make donations at <https://www.justgiving.com/Charlie-Stanton-Stock1>.

# A Vegan Treatment for CMT

*By Alexandra\**

CMT is different for everybody. But I found a treatment that works for me. Becoming a vegan allowed me to live without pain or medication. Here's how I did it. When I was 8 years old, I was diagnosed with severe scoliosis. I was quickly fitted for a brace to straighten my spine, which I wore for five years. At that time, no one suspected more than scoliosis. No one in my family has (or had) CMT. We had never even heard about it. Life went on, but as my symptoms progressed, the doctors began to think there was something else.

Sometime before my thirteenth birthday, I finally got the genetic test to determine if I had CMT. I remember sitting with my parents when the geneticist told us, and already knowing the exact characteristics of my type because we had been doing so much research. It wasn't an unexpected diagnosis, as the symptoms I experienced matched pretty well with those of CMT. A few months later, I needed two surgeries on each of my feet to relieve some of the pain from my high arches. Unfortunately, after I recovered from the post-surgery pain, the nighttime nerve pain began.

This nerve pain would wake me up between two and six times per night, and force me to get out of bed and walk around to get rid of it. My doctor put me on medication for the pain, but it didn't work. He switched

the medication, and it worked 70 percent of the time. The other 30 percent however, I was awake and in pain.

One night, out of boredom, I read "The China Study" by Dr. T. Colin Campbell. I learned about how many diseases are linked to diet and about instances in which diseases such as autoimmune diseases, neurodegenerative disorders, cancers, diabetes, heart disease, obesity, osteoporosis, arthritis, kidney stones, and so many more were either greatly lessened or eliminated completely as a result of diet change.

"The China Study" talks about a vegan diet as the most potent medicine on the planet. This "vegan diet" is a diet based on plants alone: No meat, dairy, fish, eggs, or any other animal product are allowed. At first look, that seems really extreme.

CMT is widely known to be a genetic disease, and most people believe that there is no cure. I knew this, but I wondered if adopting the diet this book preached would be beneficial in any way to my condition. So, I tried it.

On June 15, 2015, I stopped eating animal products. Within two weeks, I made the decision to take myself off of medication. Since that day in June, I have not had any pain associated with CMT. I can go weeks without even thinking about my disease, which is an incredible change from pre-veganism.

If your first thought is "I could never live without my [insert animal product here]!", I understand. I always thought that I could never go vegan because I loved cheese/milk/bacon too much. But, there's vegan cheese, vegan milk (almond milk, soy milk, coconut milk, etc.), and vegan meats available that taste very similar to their animal product alternatives. Being vegan is easy, as long as you have the willpower to do it. And, once you experience the benefits of a plant-based diet, you won't be tempted to go back. As the health benefits are becoming more and more widely recognized, I hope more people (with CMT and without) will realize the powerful effect that eating plants can have on the body.

If this is something you are interested in, please read "The China Study" by Dr. T. Colin Campbell. Watch documentaries on Netflix, such as "Forks over Knives," "The Engine 2 Kitchen Rescue," and "Cowspiracy." If you need more convincing on the health benefits, watch some of the videos on [nutritionfacts.org](http://nutritionfacts.org), which is a website with videos that draw conclusions directly from scientific research.

\*Alexandra, 16, is a high school student in Middletown, New Jersey.





# NOT ALONE

*By Hannah Frazier\**

This is a message for everyone who fights every day to hide how they feel so no one asks them what's wrong. To all those who hide their bruises so they will be treated like other people.

My name is Hannah Frazier. I'm 16 years old and I was diagnosed with CMT1A about three years ago. Before that, I was just a kid who worked hard in school, was sick a lot, and dreamed of being the next J.K. Rowling.

My message is for everyone who struggles with something that is as hard for them as CMT is for me—my friend with MS, my friend who is going through chemo, people who are dealing with mental or physical abuse, people who deal with suicidal thoughts, my friend who is transgender and struggles with who he is every day.

You are strong. You may not see it. I didn't. But it takes so much strength to do what you are doing every day. I know this. I have been there. There are thousands of everyday people like us dealing with something and hiding it because they don't want to be treated differently, or "tip-toed" around. All of us who keep getting back up are amazing. Even if to someone else what we go through looks small in comparison, it still takes great strength, great will, not to just let go. For some of us, the thought of suicide may have been real at some point and we chose to stay. We **CHOSE** to stay! That's what makes us strong. We found a way around it, time and time again, and stayed in this world by choice. The bullies will never go away, but those of us who make the choice to stay will never go away either.

When I found out that I have CMT1A, the neurologist explained that my nerves fire at 10 meters per second (mps) instead of the normal 60 mps. At that moment, I knew that my life would never be the same. I had been planning on so many things for my future, but then this happened. It changed a lot about my life because I needed to do everything I could to preserve what I had left. But I wasn't ready to let go of the things I dreamed of doing. I struggled and felt lost. I stopped jumping around and skipping when I was happy.

When I explained this to my friends they got lost in the science of it and the changes that would be coming and started distancing themselves from me. Even my closest friend stopped coming

around as much. The next summer, my family and I moved to a small town in Washington. I was happy about moving because I thought it would be a chance to start over. Instead I ended up being forced to attend an alternative high school because even though I was a 4.0 student, I missed more than half of the eighth grade. I was worried it would put my college at risk, but I had to accept it and find a way to live with it without becoming angry and bitter.

Things didn't get any easier from there but eventually I figured out how to keep going. I just had to believe that things would get better and that I would persevere and come out of these experiences a better person because of the way CMT has affected and still affects my life. I refuse to let CMT stop me from becoming who I want to become. Even though I lost that happy and energetic girl I used to be, I'm still me, I'm still strong, and the fact that I'm still here means that I still have a purpose in this world.

To this day I stumble in my strength and find myself crying on my bedroom floor, but then I find the strength to carry on and I get back up. It hasn't been easy and it never will be, but it helps knowing that I'm not the only one dealing with CMT—or chemo, or MS, or anything else—at my age. Even though I have a lot left to face in life still, I want to help people who are dealing with similar situations because it's not easy to go through any of this alone.

**STAY STRONG  
BECAUSE YOU ARE  
NOT ALONE!**

*\*Hannah, 16, is a high school sophomore in Prosser, Washington.*







# The D-WORD

By Jonah Berger\*

You're figuring out who you are, dealing with pressures from family, friends and society, and most of all trying to find your place in the world. On the path of life, the teenage years present some of the sharpest curves. When you add CMT to the mix, it only gets more complicated. Looking different, walking different and BEING different make it even harder to fit in.

The dating scene is a tricky one to navigate when you have a disability. I know because I went through my teenage years trying with all of my might to be cool when, at the end of the day, there were things about me and my disability that simply were not cool. I spent some of my time trying to cover up my leg braces and pretending to walk in a more normal way so that I wouldn't seem different. I spent the rest of my time trying to accentuate my non-CMT qualities to compensate for my funky walk. It was exhausting and it got me no closer to what I was looking for.

Enter Megan, my fiancé. It took me 42 years to find her and I promise you it was worth every second of the wait. Why? Because she is as beautiful as a sunrise, her laughter is infectious, and she is kind to everyone she meets. Yet one of her most important qualities is that she purely and completely accepts my disability and all that comes with it. I have dated several other women over the years, but none of them accepted me for exactly who I was. And even though it sucked to have to wait so long for

Megan, I'm so glad I did. Because the only way you should share your heart and your life with someone is if they know you fully and accept you truly. I thought it would be interesting to get Megan's perspective on this topic, so let's jump in:

*Jonah:*

*What was your first impression of my disability?*

*Megan:*

*I first met you at the summer camp where we were working. (We were friends for almost two years before we started dating). I remember that from the very beginning of our relationship you were very honest about CMT and how it affected you. You talked very openly about it and because of that, I understood it and it became less of a thing for me.*

*Jonah:*

*Once we started dating, what were your concerns about being with someone with a disability?*

*Megan:*

*Having been together for over two years now, I've learned that we have an easy way of working through any concerns when they come up. I express them to you as soon as they come into my mind so that you and I can work through it together. For example, I remember wondering if we would be able to go hiking together. I asked you about it and you told me that we could totally hike together, but that you may need some help from me in certain parts. I told you, "No problem I'll probably need help from you in certain parts too."*

*Jonah:*

*What advice would you have for teenagers with CMT as they enter into the dating world?*

*Megan:*

*1) Be positive. Attitude goes a long way. Because you are so positive and unwilling to let CMT slow you down, I am less concerned for you. 2) Be open. As a result of your openness I was able to learn quickly about CMT before I had the chance to wonder what it was all about. This meant I was dealing with the facts that you had given me instead of the assumptions I would have come up with. 3) Be willing to laugh at yourself. Part of the reason we have always been able to deal with CMT is because we laugh about it whenever we can. Trying not to take it too seriously has helped it to not become too serious.*

If I had to boil this down into one piece of advice, I would say: Be yourself. And I mean really be yourself. Don't change who you are to fit in because there's nothing cooler than being authentic. Own and be honest about every single part of you: the wonderful parts and the funky parts. Practice telling people about CMT. Admit the parts of CMT that simply suck. Share the positive parts with people. Help those who cross your path to understand that "normal" doesn't exist. We each have our own challenges and our own joys. The more openly you share those with others, the more success you'll have, especially when it comes to someone who makes your heart beat faster!

\*Jonah Berger is a member of the CMTA Advisory Board and the director of the CMTA's Camp Footprint.



There isn't a human being walking the face of this earth who would deny that being a teenager is one of the hardest things to do.





drawing by Julie Morton

## Two Feet, Three Surgeries: Making the Tough Call

By Julia Beron\*

**Surgery.** The topic that scared me the most. The night before. The morning of. The waiting. The anxiety. Anesthesia. Pain. Recovery. I absolutely hated every single thing about surgery. At doctors' appointments, I would pray that I wouldn't need surgery. But here's the catch - I knew that I did.

**I had my first surgery** (on my right foot) when I was 8. I couldn't walk. My foot was so turned in that it had developed a huge callous on the side. My foot was facing major deformity. I was so scared. I didn't know what to expect. However, I was a little girl and I couldn't make my own decisions like I can now. On October 23, 2008, my mom, dad, brother and I drove to Children's Hospital of Philadelphia for the operation.

The surgery came out amazing. That was more than seven years ago. My foot is still just as beautiful as it was the moment my cast came off. Two years later, doctors noticed my left foot was turning. What was the answer to that? I bet you can guess: Surgery. I wasn't as scared because I knew this time around what was to come. Or at least I thought I did. I thought that the surgery on my left foot would turn out as great as my right. I was wrong.

Five years later, two days after my sixteenth birthday, I finally admitted that I needed another operation. My left foot was a mirror image of my right foot before I had my first surgery. Deformed. I couldn't walk. I was wheelchair-bound. But this time was different. As a 16-year-old girl, I am obviously way more mature than I was at 8 or 10. High school is not an easy time for anyone, especially someone with a disability. My friends started going out to parties and dating boys. I asked myself: Am I ever going to be able to have a completely normal life? Will a guy ever like me although I have an obvious physical disability? Trust me, these are topics that I still have a difficult time with, but I was willing to go through another surgery, with the hopes of being more independent as the outcome.

Exactly one month after I admitted to needing another surgery, I underwent my third operation, the second one on my left foot. I was so unsure, so scared, constantly turning to the comfort of my friends and family. Was it going to work? I really had no idea, since the last one was less than perfect. But as scared as I was, I was equally excited. Six weeks

later, it was time for the big reveal. Time to cut off the cast. There's nothing like the first hit of fresh air that hits your skin when you take a cast off, trust me. And the best part? My foot was perfectly straight and while it looked disgusting from being in a cast for six weeks, it was also beautiful. It was so worth it. I would have another surgery in a heartbeat if I needed it. Don't wait five years and be miserable and in terrible pain like I did.

Surgery is scary; I'm not going to lie. It might not always work, but you have to keep trying and keep a positive attitude. The outcome is worth every bit of anxiety, every tear you cry and every ounce of pain you feel. Almost three months post-surgery, I am walking on my own, I am standing tall, and my foot is in no pain at all. CMT sucks, but as crazy as this sounds, I wouldn't wish not to have it. As much as it has brought me down, it has opened my eyes to things around me that you could never get out of a textbook. I have CMT, but it does not have me. Don't ever let it have you. Always be a star.

\*Julia, 16, is a high school sophomore in Montville, New Jersey.





# MY SPARTAN RACE EXPERIENCE

By Becca Livney\*

On April 9, my family and I participated in a Spartan race to raise money for the CMTA. Spartan races are intense, miles-long endurance tests with obstacles like climbing cargo nets, crawling through mud pits and under barbed wire, and leaping over fires.

Watching my dad and our team overcome these obstacles, I learned many things about determination

and strength. Walking into the tents at the beginning of the race, I did not know what to expect. I pictured short walls to climb or small mud puddles to jump over. To my surprise, the easiest obstacle was a six-foot barrier that I had to be launched over. I wasn't worried about my dad—who's the head of the CMTA—being able to conquer this race. Even if I failed at obstacles, I never doubted his ability to complete these challenges. I knew that his determined and competitive personality would lead him to success. Throughout the day, I saw my dad prove to everyone that his disability cannot and will not hold him back from the obstacles that life throws at him. Besides individual courage, the race showed the importance of teamwork and how we need support from others to be successful. My dad was surrounded by family and friends he could depend on for help throughout the race. The whole time, he had a group of people who stayed close to him to make sure that he was able to complete each challenge. But my dad was not the only one who had support. The whole team worked as a unit

to help each of us over the obstacles. For me, being terrified of heights, the cargo net was my biggest challenge. As I was climbing upward to the top of the net, I was overcome with fear and doubted that I could finish. But my teammate extended her arm to me and ensured my safety. I was able to climb over of the net and finish the obstacle. Each of us was able to finish the race with confidence because of our teammates and their support.

I believe that my dad completing this race was an inspiration to others with CMT, showing them that their obstacles can't stop them from completing the obstacles life puts in their way. I am so proud of the way my dad and our whole team fully overcame this race and the challenges that it threw at us. It showed us--and others--that with determination, anything can be achieved.

\*Becca, 15, is a high school freshman in Winnetka, Illinois.







# THE “B” WORD

By Madison Hill

**The B  
stands  
for  
braces.**

I was diagnosed with CMT at the age of 14 and today the thing I struggle with the most isn't the pain, it's the braces. I don't want to look different. I don't want people to see them and think I can't do things like other people. But I'm moving past it and focusing on the fact that my braces are going to help me. And if they do, then who cares what anyone else thinks of them.

Like many people with CMT, I fell a lot during my childhood. At the age of 2, I walked on the inside of my feet. The doctors told my parents that they wanted to surgically break my feet and cast them to fix the problem, but because I was so young they decided that I might actually grow out of it. Unfortunately that wasn't the case. They didn't know at the time that it was CMT.

At the age of 14, I loved being active, playing, having fun and climbing trees. But I started to have a lot of sharp stabbing pain in my feet and my back that left my parents and my doctors confused. It took two MRIs and a CMT specialist to finally diagnose me correctly. Doctors showed me the braces right away because I was already 14 years old and my feet were starting to curve in unnatural ways.

When I first saw the braces, I refused to wear them because they kept me from doing all the things I love. I was still healthy and I felt like I was fine. Then all of a sudden I wasn't. I went from being active and running and playing to lying in bed with sharp stabbing pain. The doctors told me that I would have this pain for the rest of my life—that it's never going to go away. It took me a year and a half to bring the braces home. I didn't even want to look at them, much less wear them. No matter what anybody said to me, I told myself that I was fine and didn't need them. The doctors kept trying to convince me that at any moment my ankles could just give way and I could dislocate my knee. Unfortunately, that's what it took for me to finally realize that I have to wear braces if I want to live without pain.

The day I dislocated my knee was probably the scariest day of my life. I thought my leg was broken, but instead my weak ankles had rolled. After that, I talked to my doctors again and they told me that I really, really needed to start wearing my braces. I almost started crying.

**Madison, age 16, is a high school sophomore in San Diego, California**

I'm 16 years old now and I've been living with CMT for two years. When I was 14, I kept telling myself that I was fine and that CMT wouldn't restrict me from doing anything. Two years later, I began to have a lot of pain. I finally brought the braces home and I've been practicing in them, but not as much as I should. I rarely wear them to school and if I do, I wear long pants that cover them. I don't know what the other kids think when they see me wearing big bulky braces on my legs and that's the part that scares me. I've gone from being the kid who was super active and playing and running and jumping to the kid who has to ride in a wheelchair when she goes to an amusement park because too much walking takes a toll on her.

I'm still getting over the insecurity of wearing braces and have only worn them out in public about five times. I normally just wear them when I'm at home or with family. Being 16 years old now, I'm realizing that this is never going to change. I just have to face the fact that I have CMT and move past it. Even though it might cause me a lot of pain, I think it makes me special and motivates me to push through and just not care what other people think. I tell myself whenever my CMT gets me down that it could always be worse. We have so much support and an entire association dedicated to helping us with CMT and giving us ways to fit in with society and show other people that no disease can stop us.







# THE WAIT IS OVER!

# CAMP FOOTPRINT

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**Any Questions, contact Camp Director Jonah Berger  
at (303) 827-4218**

