

Welcome to the WORLD OF CMT!



The CMTA is full of amazing people that will make this journey easier.

- Sign up for <u>Camp</u>
 <u>Footprint</u> and meet
 youth from all over the
 world living with CMT.
- Find a doctor that works for you. Check out the <u>CMTA Centers of</u> <u>Excellence</u>.

"I have been introduced to amazing people, and I have an amazing community. I have had many unique opportunities that most kids my age don't get." - Lily Sander





Join our tribe!

- Follow @cmtayouth on Instagram and Facebook
- Signup for the Youth
 Database

Additional questions? Email: jonah@cmtausa.org

STORIES FROM THE TRIBE

My name is Lily Sander and I live with Charcot-Marie-Tooth type 2E. I was diagnosed at the age of four by Dr. Shy. The road to my diagnosis wasn't easy by any scale. I spent months as a small child in countless specialists' offices, anxiously waiting for an answer. Fortunately, things looked up from there. I started back with physical therapy and found my CMTA family. They have been invaluable to my journey. I found a new passion, fighting for minorities' rights, focusing on disabled people. I am excited for the future as science advances towards a cure and our society advances towards more inclusion. I am working towards finding hope and light when looking to the future, instead of fear and darkness. – Lily Sander

I found out I had CMT la when I was 16. Until that point, I had thought a lot of my symptoms were just normal stuff that everyone experiences (wait... feet don't all look like this? Their loss). Everything was just slightly "off", but I didn't realize I could have had anything until I found out my dad had CMT. At my appointment to see if I also had it, I got to meet with a bunch of doctors who had dealt with CMT before. They told me all about the symptoms and an occupational therapist showed me a bunch of tools that could help me with everyday stuff. Soda cans no longer stand a chance against me. Since getting my diagnosis then, I've been able to get so much advice from websites and other people with the same disability. It was like a revelation getting to know what I had, it was honestly relieving. Everything finally made sense!. It also taught me that people are supposed to reflexively kick when the doctor taps their knee with the little hammer? I've turned it into a bragging right when a doctor can't get me to perform the reflex. It's something I'm proud of. – Hannah Hokenson



Life has paths, paths that are chosen and paths that are given CMT was a given path, a given path that sends people a sign that there heading in the right direction a sign that CMT opens a new door a door of new possibilities and new friendships

- Brooklyn

WORDS OF ADVICE

Use the resources available to you- they're there for a reason. Focus on what will make your life easier and less stressful

- Emmily Stufflet





Join a fundraiser to find a cure

- Dance 4 CMT
- -Walk for CMT
- Cycle for CMT
- Start your own fundraiser!

READY TO GET INVOLVED?

Get connected!

- Join our discord
- -Message the CMTA youth
- Find a CMTA branch near you

