THE FOOTPRINT
MAKE EVERY STEP COUNT
THE CMTA YOUTH REPORT

Welcome to the Inaugural Issue of **"The Footprint"**

A newsletter by the youth of the CMTA for the youth of the CMTA!

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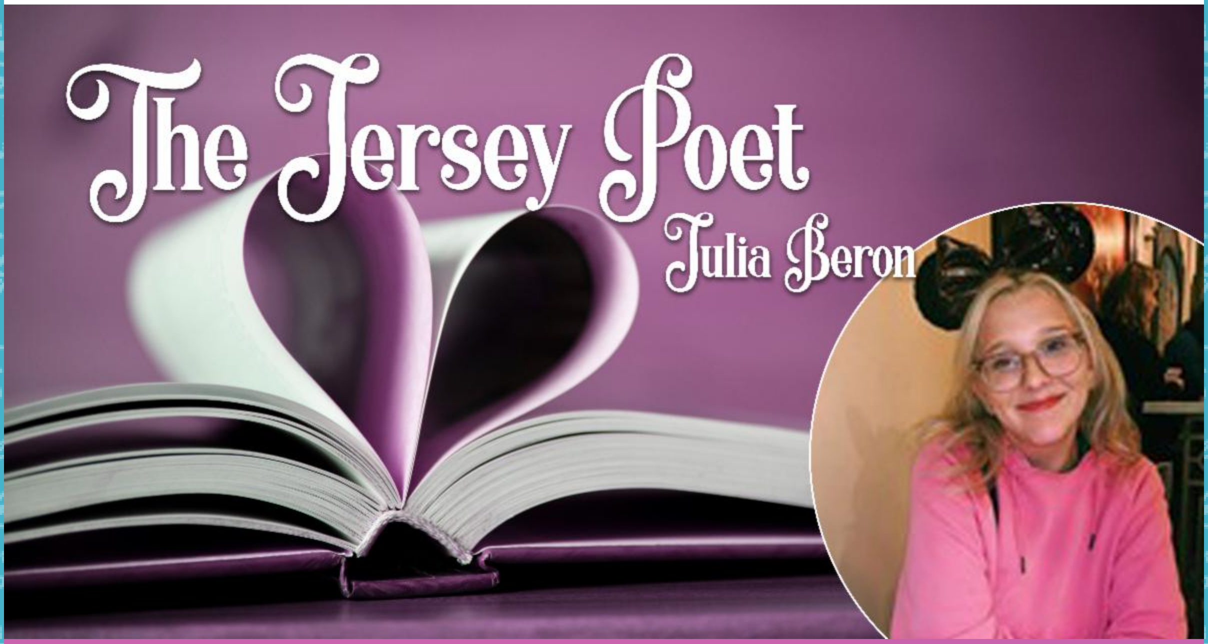
People often wonder, what does the future look like? How will things turn out and who will be the people that lead the way?? Well, we are here to tell you all that for the CMTA, **the future is super bright!** Why, because the future is **YOU!**

The youth movement in the CMTA has been building over time. And in the past year, it has officially launched as a branch of the CMTA tree. What does that mean for you? That means that **you are no longer alone.** You have a tribe next to you. You have an entire organization behind you. And **your voice has power.**

ALL YOU HAVE TO DO IS JUMP IN!

Get connected on social media, sign up for Camp Footprint, register on the youth database and put yourself out there! No one understands your challenge like the youth who have CMT!



You are you, And I am me, I am a youth with CMT!
Charcot-Marie-Tooth, to be exact.
No, there's nothing wrong with my teeth so don't even ask!

My hands and feet are a little weak,
but my mind is sharp like a mountain peak!

Some days are hard,
I will not lie But when I see my CMT family,
it makes me happy cry!

We are the Tribe of the Funky Feet,
It's an exclusive CMT family, the sweetest treat.

You may take for granted that you can run a mile,

but all I need is my tribe and I promise I will smile.

We are the youth with CMT,
And we are the strongest you ever will see!
One day we will all lead the way, One step at a time,
Youth of the CMTA.

Is my Disability the problem?

LILY SANDER

There is a serious issue with our society's view of disability. In the current medical model, inaccessibility is somehow seen as the fault of the disabled and blame is shifted from the designers and architects to those who use their products and buildings. It is my belief that a person is disabled by the way our society functions rather than by his or her diagnosis.

I remember one day in particular when I was out shopping. I was in my wheelchair, and there was a section of the store that was only accessible by stairs. I had to climb out of my chair and walk up the stairs. I knew at that moment that I was lucky that I could stand up and get to that area of the store. I also knew that many didn't have that option. I felt angry and as if I didn't belong.

Molly Burke is a Youtuber who explains the different models of disability. After watching her video, I began to perceive my CMT diagnosis differently. I began to see the world, and my disability, in a whole new light. Now I realize that I am not a burden, a problem or someone needing to be fixed. I am simply faced with challenges most people don't encounter because the world was designed without consideration for people like me. However, I am in charge of my journey and I will make the most of it!

RALLYING AROUND REAGAN

BY BRANDY ALEXANDRA BREEDING

Reagan Leigh Breeding, age 10, was first diagnosed with Charcot-Marie-Tooth Disease (CMT) Type 1A when she was 18 months old. At the time, there were very few resources and outlets that could provide Reagan the opportunity to meet other children who were experiencing the same symptoms and life challenges CMT imposed. It was through networking and my own research that I came across the Charcot-Marie-Tooth Association (CMTA).

When Reagan turned 5 years old in 2015, she attended a week-long summer camp in Rockport, TX with the Muscular Dystrophy Association (MDA). Reagan loved MDA Camp; however, she was the only child there who was diagnosed with CMT. It was not until 2016 when I first learned that the CMTA established Camp Footprint - the first camp in the US for children living with CMT. I still have the CMTA Camp Footprint email, dated May 3, 2016, which stated, “The Wait is Over.”

The wait was finally over for Reagan on January 6, 2020, when I registered Reagan for Camp Footprint 2020.

Reagan was immediately welcomed into the Tribe of the Funky Feet by individuals from the CMTA Youth Council and other individuals within the CMTA leadership.

When it was announced that Camp Footprint was going “virtual,” due to the COVID-19 pandemic, Reagan was extremely upset. And yet, the first “Camp Footprint Information Webinar” that Reagan and I attended was filled with laughs and a unique sense of energy. I could tell that everyone on the Zoom call treated it as if it were a family reunion. The energy was contagious! As soon as we exited the call, Reagan turned to me and said, “I feel really happy. It is like I already have a huge family with them.”

The day UPS dropped off Reagan's Camp Footprint's Camp in a Box was a day filled with excitement and wonder.

Reagan felt, "overjoyed with the items I received because they were special to me. I felt like I belonged because CMT was written on everything, and that's what I have.

It made me feel like I had a place."

Talk about taking all the stress and anxiety away – the CMTA Board of Directors and the CMTA leadership had all the bases covered! All I had to do was help Reagan with a few push pins and then sit back and relax.

Those push pins aided Reagan in transforming her room into a fort infiltrated with blue and orange decor, footprints, and Reagan's very own glowing campfire! Camp Footprint pulled off something truly amazing, which I never dreamed possible. Reagan was engaged all day, every day. "The interaction was amazing, and we could all talk. We would then have personal time to talk one-on-one with our Cabin. The activities that we did were so fun! It felt like I was actually in-person. I made lots of friends within my Cabin and with other campers," says Reagan.

The community and acceptance that I saw Reagan experience was nothing that I had ever witnessed.

Reagan was in the hospital at the tail end of Camp Footprint, and the outpouring of love and support showed by her fellow campers as well as the CMTA leadership was truly spectacular. Reagan's Cabin Counselor, Erin, went out of her way to not only gift Reagan with her own iPad prior to camp starting so Reagan could easily access The Virtual Experience, but Erin also sent Reagan a corgi themed care package once Reagan was discharged from the hospital.

CMTA Camp Footprint definitely left a positive, long-lasting impression with our family. Its impact on Reagan has been remarkable. I am blessed to have witnessed Reagan develop a sense of independence and self-confidence and experience belonging and acceptance among the Tribe of the Funky Feet. I saw those newfound skills carry over into the school setting and other areas in Reagan's life. I am confident to say that I will definitely be registering Reagan to attend Camp Footprint 2021. I already know Reagan is on board because according to her, "I think it was the best camp that I have ever gone to, and I would love to do it again!"

Respectfully,
B. Alexandra Breeding

Register Now for 2021 CAMP Footprint

So many people with CMT have trouble accepting their disease and living a truly happy life.

Growing up I've always been a very happy kid. I was always smiling and having a good time playing outside or going to the beach.

But when I got older and was diagnosed with CMT my view of happiness changed. It felt like I was trapped and restricted from everything that I loved to do in life.

This is a very common thing for people to feel and it can be hard to overcome.

> ***The secret to living a happy life with CMT is to always enjoy the little things, have lots of good friends, and live everyday to the fullest.***

If you do these three things, you can start to live a truly happy life. In the end there are no secrets to being happy. All it comes down to is to do what makes you happy everyday no matter what is holding you back.

COMING SOON!

THE CMTA YOUTH BOOK

"STAY TUNED"

YOUTH ZOOM HANGOUT!

SUNDAY, JANUARY 24
FROM 7PM – 8:30PM EST

REGISTER TODAY

Have a story to share, we want to hear from you.

[CLICK HERE]

CMTA
Charcot-Marie-Tooth Association

YOUTH
empowering youth

TREATMENT DRIVEN • COMMUNITY POWERED

We are the driving force behind CMT research

follow us on social media :)