

Welcome to the SECOND Issue of "The Footprint"

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

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Who's Zooming Who • Dying to Tie Dye • Willkommen Josephine Sam's Secrets • How I Found My Voice



These are strange times we are all living in...

and Zoom has been one of the best ways to stay connected to our friends and family. The Youth Community of the CMTA has started using Zoom to keep connected from so far away.

CMTA Youth Zoom Hangouts

have happened twice so far and they have been awesome. We had over 70 youth join our last hangout and it was a blast.

We get a rockin' newscast from the youth council, we have lots of updates on the youth movement and Camp Footprint, and we did a few activities to help us get to know some new friends. The best part of all is that everyone on the call has CMT, so even strangers understand! Don't miss the next one coming up on

Sunday, April 25 from 7:00-8:30 p.m. EST





I started my tiny tie dye shop, Ashlyn's Tie Dye, in August of 2020 to help raise money for the CMTA. I was still a little new to the CMT community, and, the previous week, I attended Virtual Camp

Footprint, which was an amazing experience. I had never been to Camp Footprint before, and I was looking forward to going that summer. Of course, COVID hit, but I was NOT disappointed in virtual camp! I cannot imagine what in-person camp must be like. Anyways, I wanted to get involved somehow, and I felt like I was being called to help the amazing CMT community.

I was brainstorming ideas for raising money. I wanted to have fun with it, and I was doing a lot of tie dye that summer. I thought it would be the perfect idea to incorporate tie dying into a small business. I was inspired to get started by Julia and Chains by Jules who was also raising money, and I was encouraged to help everyone who had CMT! I wanted to take part in the cure for CMT, and I thought this would be the perfect opportunity to be able to.

When I made my first Instagram post on Ashlyn's Tie Dye, I only expected to get 1 or 2 orders. I was wrong about that, and I have been blessed to receive more than just a few orders! I always try to tell any of my customers how much I appreciate and thank them, and I hope that they know that it means SO much to me! Being a part of the CMT community is truly a blessing. Everyone is so kind, and I am so grateful for everyone I have met through having CMT. The best part is that we all understand what each other are going through!

Nilly owner Dusseldorf Germany



Hey! My name is Josefine and I am from Düsseldorf, Germany. I got diagnosed with CMT a year and a half ago, so everything is still quite new to me. I really wanted to get in touch and exchange experiences with people who have CMT as well and are about the same age as me. Unfortunately there are very rare opportunities in Germany for young people with CMT to get connected.

To stay positive I try to not let CMT rule my daily life, of course it affects me in some aspects, but I always try to see the best in every situation.



by Season Ciriello

Since I was little, I've always been a natural performer. The whole world was my stage, as far as I was concerned. Some of my earliest memories include breaking into song in the middle of the street, jumping up on makeshift stages and entertaining passersby with improvised standup routines, even joining bands on stage during local music events and providing backup. (Yes, I've actually done that several times.) I had this instinctual need to perform and to entertain. I definitely wasn't the shy kid.

Naturally, my parents put me in theater classes at a very early age, where my dramatic spirit thrived. Since then, I've been part of several local theater groups, where I've gained valuable skills and made some wonderful friends who are just as wacky and dramatic as I am.

About a year and a half ago, everything changed for me when a curveball known as CMT was thrown my way. Having no family history, it obviously came as quite a shock. What followed will sound familiar; doctors, specialists, travel and lots of tests.

Essentially, I felt my life was a mess.

It was also around that time that I started feeling different. Performing became more fatiguing, I started to lose my ability to learn simple dance steps and I found myself tripping over my own feet frequently. So as shocking as the diagnosis was, it also came as a relief. I finally knew why I was feeling so weak. Deep down, I knew something was fundamentally wrong, but I had no idea what it was. At least this knowledge gave me something to work with, a new starting point.

About six months ago, we scheduled my first, and very extensive, surgery. I had recently performed in a huge production with my theater group and between the way I was feeling physically and the knowledge that I was facing a rough and lengthy recovery, I knew it would be my last performance for a while. This realization was both a relief, because stage performing was becoming so physically taxing, and a profound loss, because performing is a vital part of who I am.

During a recent movie binge session, I had a revelation. Perhaps I could combine my current limitations with my passion to perform, by pursuing voice acting as a career! I may not be able to dance, but I can sing. Can I run across a stage? No. But I still have a voice, and a very dramatic one at that!

I remembered back to when I was younger and how fascinated I was by voice acting. Now, I wanted to be someone's favorite character.

I wanted to see my name listed in those end credits.

To be honest, I was terrified to start, afraid that my theater skills would not translate into this new method of performing. What if I discovered I wasn't any good? How do I even begin? It all seemed so daunting. Then I decided to JUST DO IT.

It's been a few months since that revelation and I've taken classes, worked with a professional VO coach, created a home studio and recorded my first demo. And to my great surprise, voice acting comes very naturally to me!

Fast forward four months.... I've got a new foot and a new career path. A path I may never have pursued if not for my diagnosis.

If I can offer a takeaway to this story, it's that life will invariably throw you curveballs or put limitations in your way, but there is always a way to adapt. You don't have to give up on your dreams; you just may have to take a different path.

Sometimes that path will surprise you and lead you to places you never thought you'd go.



Register Now for Virtual 2021 Camp Footprint!

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In my day-to-day life there are so many struggles that I have to deal with as a person who has CMT. Even from the point of when I first wake up in the morning and have to stretch. Stretching is just one of the ways that I battle my CMT and make myself stronger. Every day I also lift weights and do some type of exercise.

It is so important for people with CMT to stay active and try their best to stay ahead of struggles.

It is also important to make sure that you give your body proper rest and recovery so that way you never injure yourself. Overall, holding an active lifestyle that fits your needs is just a little secret to living with CMT.



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

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