

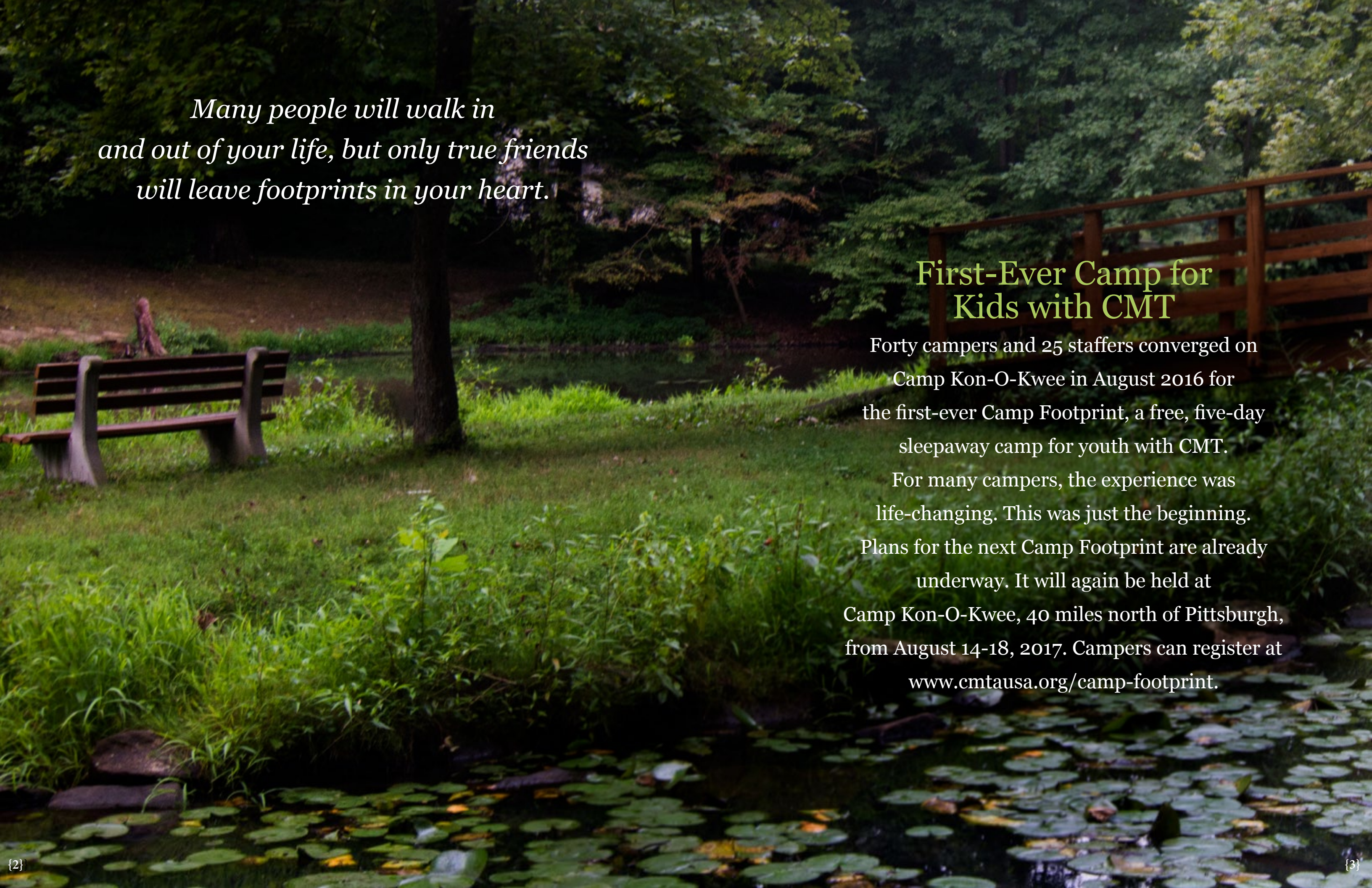
VOLUME 1 ISSUE 4

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

CMTTeen

Camp Footprint...Special Edition!



A serene outdoor scene featuring a wooden bench on the left, a large tree in the center, and a pond with lily pads in the foreground. The background is filled with dense green foliage and a wooden fence.

*Many people will walk in
and out of your life, but only true friends
will leave footprints in your heart.*

First-Ever Camp for Kids with CMT

Forty campers and 25 staffers converged on Camp Kon-O-Kwee in August 2016 for the first-ever Camp Footprint, a free, five-day sleepaway camp for youth with CMT.

For many campers, the experience was life-changing. This was just the beginning. Plans for the next Camp Footprint are already underway. It will again be held at Camp Kon-O-Kwee, 40 miles north of Pittsburgh, from August 14-18, 2017. Campers can register at www.cmtausa.org/camp-footprint.



The Sloth is My Spirit Animal

By Carly Ann Blaukat Sizemore*

I NEVER THOUGHT I'D FIND SOMEONE who would understand what it's like to have CMT. Then my mother saw a little banner on Facebook about Camp Footprint, the first annual camp for kids with CMT. I was shocked, but without hesitation I said, "Let's do it." In no time, I was booking a flight to Pennsylvania.

I've known I've had CMT almost all of my life. It affects my legs and now it's starting to slowly affect my hands. I've never let that stop me from being an adventurous person, but I hid my CMT from the world because I thought no one would understand. When I tried to explain, people would ask if CMT stood for Country Music Television or look at me puzzled, like maybe I stuttered.

I'm a naturally slow person. If I had a spirit animal, it would be a sloth. When I go fast I can hurt myself or look like a fool. But like my mom says, the world "doesn't revolve around Carly" so I've adapted and overcome. With every ankle sprain and fall, I've learned to get back up and laugh along. I held back the tears from all the apathetic people and looked down to see where I was going so I wouldn't fall again.

Camp Footprint was different. All through the week I felt something I've never felt before—empathy. All around me

were people who understood my pain, my weakness and my troubles. We all had a joke when we started talking about CMT. Someone would freak out and say, "Wait, you have CMT?? I have CMT! This is crazy!" Then another person would chime in and say, "I do too!" and we would all freak out because almost everyone there had it.

Every day was something new and never once did I ever feel alone, degraded, or like someone wouldn't understand if I needed to take a break or if I fell down on some air. Nothing was rushed, we could be sloths and that was okay because everyone was a sloth. Many people came into camp wanting to go backhome on the first day, and then cried the last day saying they would pay rent and "clean the green trolley" if they could stay. Jonah Berger, the camp director, told us on the way from the airport to the camp that we might be spread out on the bus on the first day, but he promised that going back to the airport we would be a family. Just like he said, the last day we were all huddled together, three to a seat.

Every night at camp we had "foot time," when we all got together in the common area to care for our feet and have foot baths and massages. Every day we had little talks about CMT. Every single person had

empathy, love, compassion, and something to offer. It was truly a little miracle.

Without this camp, I wouldn't be as confident with my CMT as I am now. I wear my shirts and bracelets loud and proud. I talk about it constantly. I want to make people more aware, find a cure, and get this thing done. Without this camp, I also wouldn't have known what true

friends are. I've made friends who will be in my life forever and ever. I have friends in Australia! I still fall, but what keeps my slow self going is that I always have something to look forward to. And that would be seeing my CMTA Camp Footprint family again.

*Carly, 17, is from Missouri.



Camp Changed Me Forever

By Julia Beron*

ONE OF MY BIGGEST PROBLEMS WITH CMT is that I am the first one ever in my family to have it. Since only one in 2,500 people have this disorder, it's difficult to find someone with CMT to talk to. I don't feel like many people understand the full picture of living with CMT. That has always been a huge issue for me.

When my dad told me that there was going to be a CMT sleepaway camp for kids with Charcot-Marie-Tooth, I instantly said "no way." I had never been away from home before and the idea scared me. However, after some convincing from the amazing camp director, Jonah Berger, I decided to give it a shot. I mean going to camp with a bunch of kids who know exactly what I go through every day? It felt like a dream. Although I was excited, I was also dreading it, not ready to leave my home for a week in the woods.

The night before I left finally came, and I was begging my parents to let me stay home. But I packed my suitcase with the hopes of leaving this camp a new person. The one thing that kept me calm was that I knew that no one would judge me because we all have CMT. That morning, waking up and going to the airport, I was so excited to be given this opportunity.

While I was excited to go, my Camp Footprint experience began with many, many tears. I wanted more than anything to go home to my family and friends. I must have cried 10 times in less than 24 hours. I begged my parents to let me leave even a day early. They told me, "You need to stay. This is a great experience for you."

On the second day, I did the unthinkable: I went canoeing! Now for a "normal" teenager, it might seem odd that I'd be so excited about that, but I never would've thought I could do it. That night, I did a night hike with no flashlights! That was the beauty of this camp. There was absolutely no excuse not to do the activities because everyone had CMT and we all did everything together. We cheered each other on every step of the way. That's what this family is all about: support. The rest of the week flew by and we all grew extremely close. We truly became a family. On the last day, I texted my dad and said "I'm going to cry when I leave these people, this place." And I did just that.

Now I have tons of people who I'm close with who know 100 percent what I deal with every day. I can't imagine not having them in my life. This camp changed me forever, in the greatest ways. I can't express how grateful I am that I was given this opportunity. Countdown is on for the second year of Camp Footprint! Till August 14, 2017.

*Julia, 16, is from New Jersey.



Friends for Life

By Brendan Conroy*

CAMP FOOTPRINT WAS THE WEEK OF A

LIFETIME! My brother Brody and I both have CMT2A, but before camp we never really knew anyone else who has it. Meeting other people with CMT made a huge impact on me because I know we are not alone and there are others who understand our struggles.



In the past I have had to use a wheelchair, but with lots of physical therapy I am walking independently again. I have neuropathy and bouts of dystonia, which means that my muscles move without my telling them to, but thankfully that is being controlled with medication.

There were so many fun activities at camp. My favorite thing was the high ropes course. I also enjoyed doing the zip line. Both were challenging, but lots of thrilling fun! My brother's favorite thing was taking a walk in the dark of night, when we had to depend on other senses to make it through. That was awesome. We both loved going swimming every night. The water was amazing and so relaxing.

Camp came to an end in no time, leaving us with fantastic memories. One of the best things I took away with me were the friends I made. We stay in touch and I hope to see them next year.

*Brendan, 18, is from Pennsylvania





Pranks and Glitter at Camp Footprint

By Timothy Lauriault*

I BELIEVE THAT KIDS WITH CMT SHOULD GO TO CAMP FOOTPRINT.

Camp has fun activities and all the kids and counselors have CMT so they make the same mistakes you do. They can do all the things you can and can't do.

Camp Footprint has fun activities. They have a zip line, high ropes course, swimming, cabins and a night hike. The night hike might seem scary at first, but it's very fun.

My personal favorite thing about camp is that you get to pull cool pranks. One time the girls put glitter all throughout the boy's cabin. Then they tried to scare the little kids and the boys poured water on them.

Another cool thing at camp was the scavenger hunt. We dug in the ground until the whole game board was showing and we found a rope. The counselors put the rope on this big machine and lifted a giant chest out of the ground. The chest was filled with a bunch of bags with every person's name on them. I found mine and inside was a bunch of stuff like fuzzy socks, a jacket, a key chain (which is now on my backpack), CMTeen magazines with a bunch of information about CMT, and a bunch of other cool stuff in it!

*Timothy, 10, is from South Carolina.

Words Cannot Describe

By Jeana Sweeney*

EXHILARATED. HAPPY. LOVED.

TIRED. These were just some of the words that the kids at Camp Footprint used to describe it. The kids got to experience so many things that those of us with CMT long for, but I think that the most important was freedom—freedom to fit in, to be themselves and to try what they thought was the



impossible. Trying—and succeeding at—canoeing, fishing, swimming and so much more—gave the campers self-confidence and a sense of independence. Within this bubble of freedom, campers and camp staff built bonds that will never be broken. Thanks to social media, those relationships will be maintained.

CMTA staff started talking about doing a camp several years ago. CMTA CEO Pat Livney was passionate about the idea because of his experience as a counselor at a Muscular Dystrophy Association camp for kids. He wanted children living with CMT to have the same experience. The CMTA lobbied the state of Pennsylvania for funds to start the camp (not an easy task) but lo and behold, we got a YES! The state granted the CMTA \$100,000 to hold Camp Footprint, helping the CMTA make history!

For many campers, the feeling of fitting in was a new one. One child's experience is typical.



This camper had never really felt like she fit in with her peers and often sat alone reading a book during lunch time at her school. She thought things would be the same at camp. She had no expectation of fitting in there either, so she packed a book with her things. As the week went on though, she began to open up and talk to those around her. Asked to name her favorite part of camp, she said, "Everyone here knows my name." She returned home happy, her book still unread.

* Jeana is the CMTA's community services director.





Campers, Counselors Share Deep Connection

By Jonah Berger*

A LOT OF ENERGY WENT INTO PLANNING CAMP FOOTPRINT, and the results far exceeded expectations. United by excitement and enthusiasm, the dedicated staff of volunteer counselors came together for training the day before the kids arrived, decorating the cabins, getting to know each other and mapping out the week. The campers arrived at the Pittsburgh airport on Monday, August 23, from every corner of the United States, as well as Mexico and Australia! The first day was all about getting to know each other and soaking in what it's like to be surrounded by others who deal with similar challenges and hold similar wisdom.

Over the next five days, campers accomplished a lot: kayaking, canoeing, swimming, wall climbing and traversing high rope obstacles. They also sang and laughed without limit! On Wednesday evening, when the sun went down, the group gathered at the edge of a thickly wooded trail. What happened over the next hour was pure magic: The entire group of imbalanced and funky-footed campers and

staff set out on a night-time hike in the total dark, with not a flashlight to be found. Campers and staffers alike faced fears, built trust and made it to the other side. It was a highlight of the week!

The final night of camp found campers on a treasure hunt, complete with a buried treasure chest full of camp goodies. A local restaurant catered an amazing luau afterward, with dancing, awards and reflections on the week spent with this amazing community.

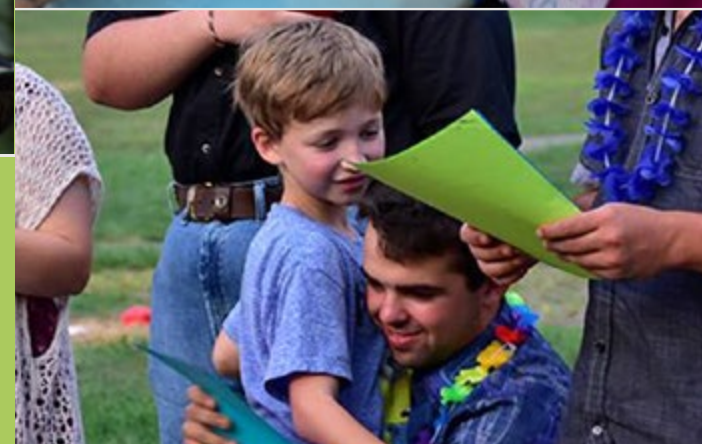
In looking back over this fantastic week, a number of things stand out—the activities, the devoted staff, the beauty of the Pennsylvania woods, and the bravery of the campers to take on feats that most would deem out of their range of ability. What stands out far above the rest, though, was the connectivity of the campers and staff and how quickly the shared challenge of CMT brought them all together. By the second

day of camp, friendships were forming, leg brace comparisons were abounding, and stories of life with CMT—the good and the challenging—filled the air.

A collection of individuals aged 10 to 18 connected into one group, united by their CMT. They looked out for each other, helped each other over tough terrain, encouraged each other to participate in all of the activities, and most of all, felt normal. For once, they were not the one person in their family, among their friends or at school dealing with difference. When they looked around, they saw that everyone was struggling and overcoming struggles in the same way. It was a profound connection that affected every person there.

Jonah was the 2016 Camp Footprint director.





Dear Camp Footprint, I want to thank you for the gift you gave me last summer at the first-ever camp for kids with CMT! I don't know how I got lucky enough to be a part of something so special, but you will forever hold a place in my heart!

I was first in line to volunteer to be a counselor, and then almost immediately felt hesitant! The doubts and fears crept in and questions popped in my head about how I would be able to keep up with a whole group of kids excited about camp. I decided that I would "figure it out," which ironically became the motto of the week for all of us! It's crazy to think how close I came to missing out on one of the greatest weeks of my life!

Camp Footprint, you brought together a diverse group of adults and kids who all share a common bond that has now developed into life-long friendships. I was wiped out that week for sure! I would like to say it was due to my CMT, but I think my age played a bigger part! In fact, CMT didn't keep me from a darn thing! For the first time in my life, I was able to fully participate in every activity that was available!

Camp Footprint, you gave us all the opportunity to be FREE! I saw myself in every camper that week. I remembered exactly how I felt at every age level, and how I would have thrived if given an opportunity like this when I was a kid. I am so grateful for all the people I met that week, who have now become my family! Thank you for amazing memories, friendships, opportunities, FUN & FREEDOM!

Until we meet again Camp Footprint,

Erin Gaul
Camp Footprint counselor (and Harrisburg, VA branch leader)

Lessons from Camp: Never Give Up

By Cortney Tranovich*

I AM 14 YEARS OLD AND I HAVE CMT1A.

Last August I attended Camp Footprint, a place where you could just be yourself without anybody judging you. Jonah Berger was the director of the camp. He is a really nice and very funny person. He was such an inspiration to me and other people who have CMT. I also made a whole lot of other friends with CMT. These friends weren't just any friends: They are the only friends I have who actually understand me and my problems with CMT. The staff there also had CMT. They were so nice and were always there to help you. I couldn't have asked for better staff!!

Two other things I loved about Camp Footprint were all the fun activities and the yummy food!! At first, I wasn't sure if I wanted to go to camp or not, but I am so glad that I did. That camp helped me to learn to never give up!! If you have CMT and you are reading this, NEVER GIVE UP!! If you have a goal in your life then keep trying to achieve it until you do. Yes, I know that having CMT is hard sometimes, but you have to think of the good things about having CMT. I mean if I didn't have CMT, then I would have never had the opportunity to go to Camp Footprint and meet all of the wonderful people I did. I can't wait to go back next year!

*Cortney is from Pennsylvania.

Many thanks to the Hanger CHARITABLE FOUNDATION

...for funding two grants for Camp Footprint. Because of its generosity, 15 campers were able to travel to camp without any personal expense. The Hanger Charitable Foundation also funded Transcend CMT Day, dedicated to enabling campers to overcome their physical challenges for a day.





State of Pennsylvania...You Made it Happen!!!

Project Funded by the Pennsylvania Department of Health

Thanks to the Pennsylvania Department of Health for its support of Camp Footprint, a camp and a week like no other! With the department's help, the kids of the CMTA experienced a week of growth, bonding, normalcy, friendship, joy and community. This experience will live on in all these campers (and counselors and staff!), giving them a renewed sense of hope and opportunity and bonds of friendship that can never be broken.





Like what you've read in this issue of CMTeen? How about contributing something for it?
We're looking for articles, poems, art & photography on anything that interests you — from braces to bullying to smart comebacks.

Please send submissions or ideas to:
marcia@cmtausa.org