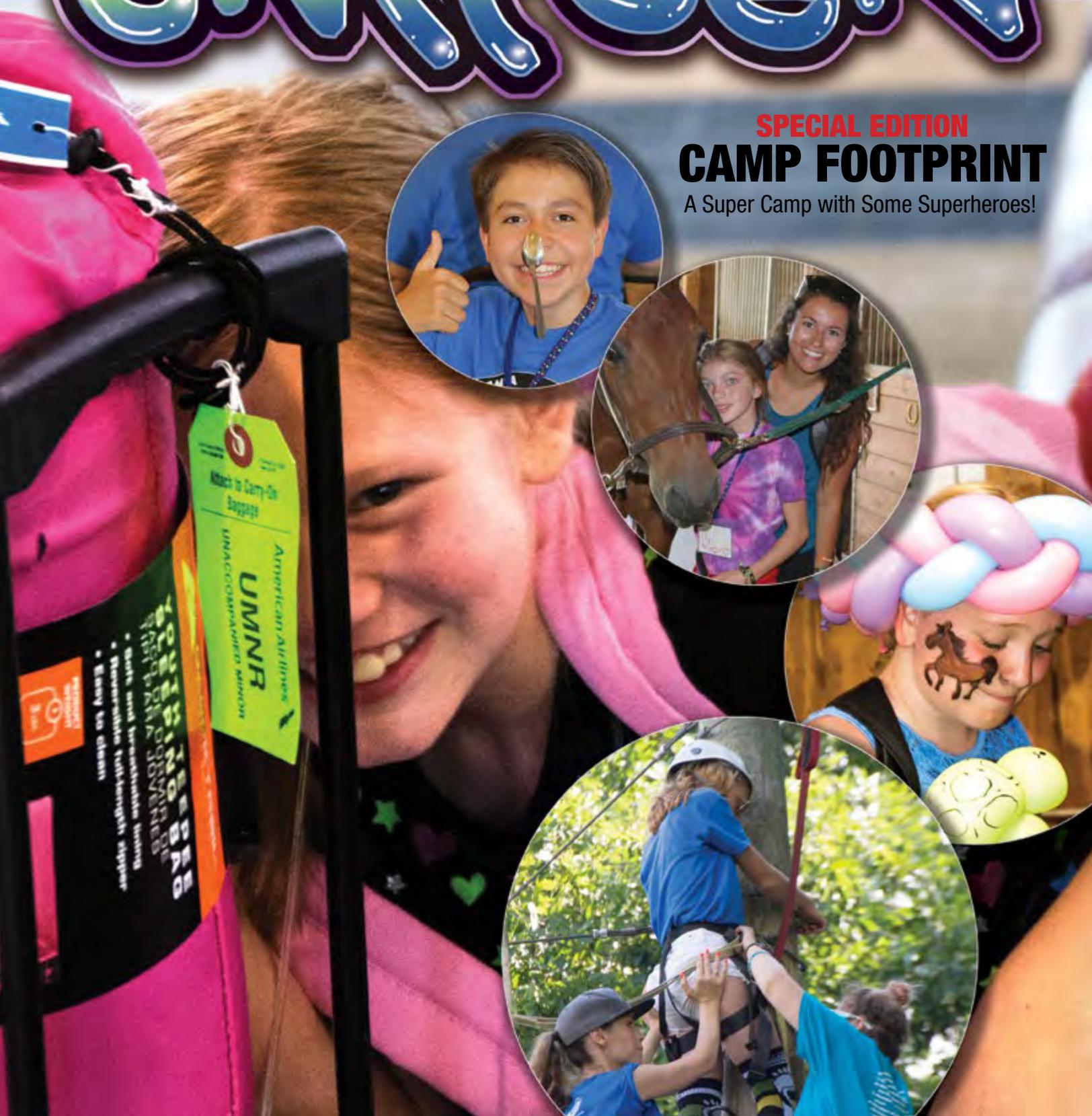


A MAGAZINE BY TEENS, FOR TEENS & ABOUT TEENS WITH DM1

DMTTeen

SPECIAL EDITION CAMP FOOTPRINT

A Super Camp with Some Superheroes!





what is a SUPERHERO?

Kids who deal with challenges by day, and more of the same by night.



Each cabin of campers had its own giant superhero banner, along with a name the campers decided on themselves.

The Making of a Camp Theme By Jonah Berger

What, my friends, is a superhero? What exactly should it be? Should it be a caped, broad-chested man who can leap straight over a tree? Should it be someone with tons of cash who can buy the fastest car? Should it be the girl on the Bachelorette, or a super-tall basketball star?

In the woods of Pennsylvania, I saw what superheroes should be. They are kids who deal with challenges by day, and more of the same by night. They stumble through every step of their paths with groove and courage and might. They support their friends and accept no shame, and in their wake, leave a courageous flame. They teach us all about how we should be, in the way they deal with CMT.

I saw counselors volunteer their time to guide, support and care. I saw them act like fools for the children's sake and take on any dare! I saw community in action and walls fall away. I saw greatness created through hard work and play. Yes, this is what superheroes are, and these are the people we should praise. They leave footprints of kindness when they walk, and hold magic in their gaze.



Camper Rylee Sweeney got into the superhero spirit as a masked and caped crusader!



All of our campers transformed into superheroes right before our eyes.

They teach us all about how we should be.

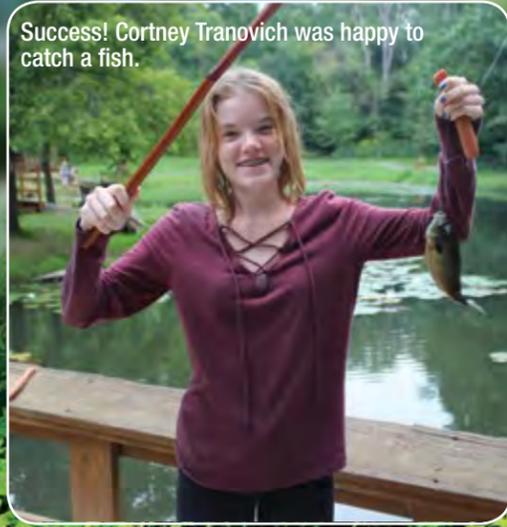


Our own Super CMTA CEO, Amy Gray, got into the spirit of things!

Our camp directors Jonah Berger and Jeana Sweeney were the best superheroes of all!



She caught one! Kathleyn Doyle shows off the fish she caught at Camp Footprint.



Success! Cortney Tranovich was happy to catch a fish.

Gone fishin'®

Many campers tried fishing for the first time.



The lush scenery was the perfect spot for campers who wanted to fish.

What Camp Footprint Means to Me

By Payton Rule, 18 years old, Belleville, Illinois

I was diagnosed with Charcot-Marie-Tooth Disease (CMT) when I was five years old. There is a lot of beauty living with CMT; however, there are also unique challenges. Because of my weak muscles and bad balance, activities most would consider routine and mundane, such as climbing stairs without rails or walking on uneven ground, are significant obstacles for me. This can make navigating unfamiliar surroundings and tasks daunting. So, as you can imagine, when the CMTA approached me with the idea of flying across the country to a camp I had never visited before and where I knew next to no one, I had my reservations. Still, I signed up, unaware of what I was getting myself into.

The first night I arrived at camp was fairly laid back as we spent time bonding and getting to know each other. However, the next morning we hit the ground running and didn't stop until my flight left at the end of the week. We started every morning with adaptive dancing and spent the rest of each day participating in a variety of activities including rock climbing, a high ropes course, zip lining, hiking, horseback riding and swimming. At first, I was extremely hesitant to participate. Would I be able to keep up? Was I physically capable of completing these tasks? As these thoughts raced through my head, I looked around and realized other people were experiencing similar fears to mine. That realization was extremely comforting. For one of the first times in my life, my concerns and physical struggles were the norm. I was not alone. Together, we were able to begin tackling these challenges. Everyone was really supportive of each other both physically and emotionally. If someone needed help walking or carrying something, both campers and counselors were happy to lend a hand. It was empowering to share experiences and conversations with people who understood the blessings and challenges of life with CMT.

My experiences at camp have taught me many valuable lessons and skills surrounding fear and perspective that I have carried into my everyday life. Through the challenges of camp, I learned the importance of stepping outside my comfort zone. The activities that required me to overcome fear were the ones that ultimately resulted in the most personal growth and satisfaction. The night hike is one memorable example. Hiking has never been a strength of mine. So, when I was told the cabins were going on a night hike in the rain, I was a little unsure. However, along with the other campers and counselors, I tackled and stumbled through the hike and was able to finish it. The fact that I was able to complete what I viewed as a daunting task built my confidence and showed me that if I am willing to push through my fear and hesitation, I am capable of achieving anything.

I am so thankful for the opportunity to attend this camp and for the friendships and wise and potent lessons I took away. This camp reminded me of the power of mindset. I can choose to view CMT as limiting and bad or I can choose to follow the camp perspective and celebrate and embrace my "funky feet" and all the other things that come with CMT. And whatever challenges I encounter, I know I will always have my CMT family behind me.



Payton Rule, left, and Gellie Hanson enjoyed camp together.



The campers in the Upper Boys Cabin bonded over sports, video games and living with CMT.

Band of Brothers

The Upper Boys - "THE GOATS" ...Greatest Of All Time!



The Upper Boys have kept in touch throughout the year through texting and Snapchat.

The Upper Boys showed off their GOAT tattoos.

Being a teenager is hard. Now, imagine having CMT and being a teenager. Finally, imagine that you're a teenager with CMT who has never met anyone else your age with CMT. That's a pretty familiar story for many campers when they come to Camp Footprint, including Anthony Herrera, now 16.

"I never knew anyone my age with CMT," says Anthony, who was diagnosed with CMT at 12 years old.

Fortunately, Anthony's grandmother learned about Camp Footprint. The rest is history.

"Once Anthony's grandmother found out about Camp Footprint, we started doing everything to make sure he had what he needed to get there," says Maury Herrera, Anthony's dad. "Although he had some reservations about going at first, I knew he would go and flourish. And he did - he loved it."

Anthony's mother, Beatriz, had long hoped that he would connect with some other campers.

"Anthony didn't quite understand what he was going through," Beatriz says. "I really wanted him to learn more about CMT and to understand that he's not alone. The fact that he's formed these long-term relationships with kids who have the same struggles he does really helps." Over the course of the week at camp, Anthony formed a tight bond with his "brothers" in the Upper Boys Cabin.

"All of us guys would hang out, throw a football around," Anthony says. "We talked a lot about sports, movies and games. And I found out things about CMT that I never knew before. We became like a big family."

Anthony's new friends also gave him the boost he needed to try new things.

"Trying new things, like the zip line, shook me up at first," Anthony says. "But the guys encouraged me. There was lots of daring and competition among the guys!"

The encouragement Anthony received at camp has followed him home, too.

"At camp, they really push the kids and show them that there's nothing they can't do," Maury says. "I know that he has to live with CMT all of his life and that he has to learn to handle it the best way he knows how. Camp gives him those tools and the enthusiasm and confidence to push himself."

Anthony plans to go to camp again this summer, and beyond that, he aspires to be a counselor at Camp Footprint someday. For now, Beatriz says, Anthony and his family are all soaking up the positivity that camp has brought to their lives.

"Anthony comes back from camp a different kid," Beatriz says. "He's not depressed. He's really happy and enthusiastic. Camp inspires him - and he inspires us."



Savannah Tranovich put aside her fears as she made her way up the climbing wall.



Campers of all ages found different paths up the giant climbing wall.



Maddie Wakeman waited for her turn to cruise across the zipline.



The zipline was a favorite for many campers.



Meghann McClung, Riley Williams, Brooke Bennett and Kathelyn Doyle were all smiles as they formed a line for the zipline.

Tyler Kulback enjoyed the view from above.



The Sisterhood of the Upper Girls



Like most people trying something new, Erin Black, 16, had some jitters before heading to Camp Footprint for the first time. But within no time, those feelings of nervousness had disappeared, replaced instead by gratefulness.

“Within two days, the other girls in the Upper Girls Cabin got me like no one has gotten me before,” says Erin, who was diagnosed with CMT when she was seven years old. “They’re my CMT sisters. The friendships I formed at Camp Footprint are so special, and I am so grateful for them.”

Though Erin says she is fortunate that her friends at home in Lakewood, Ohio have been very supportive and understanding of her CMT, she also says there’s truly something special about meeting other kids who have CMT, too.

“The only people who truly understand CMT are those who are living with it,” Erin explains. “To be around so many other people who are going through what I am going through is amazing. CMT can take over every aspect of your life, so it was nice to have a week where I didn’t have to explain what was wrong or how I was different. Everyone already knew.”

After days full of camp activities, like one would expect in a cabin full of teenage girls, there were a lot of late nights staying up talking.

“We would talk for hours, just about everything,” Erin recalls. “Within a couple of days, I was sharing the biggest things in my life with them.”

Though it’s still a few months before Camp Footprint kicks off, the CMT sisters of the Upper Girls Cabin don’t have to wait to keep in touch.

“We talk almost every day through Snapchatting and texting,” Erin says. “We’re so psyched for camp next year that we actually have a countdown!”



The campers in the Upper Girls Cabin loved getting to know each other throughout the week.



Savannah Evans, Rylee Sweeney and Mika Perez enjoyed their sweet treats by the campfire.



Time around the campfire as a whole camp provided a traditional camp experience.

Doug Frick, Evan Zeltsar, Ozzy Alfonso, Tomas Lopez and Hannah Roberts made s’mores around the campfire.



s'more fun

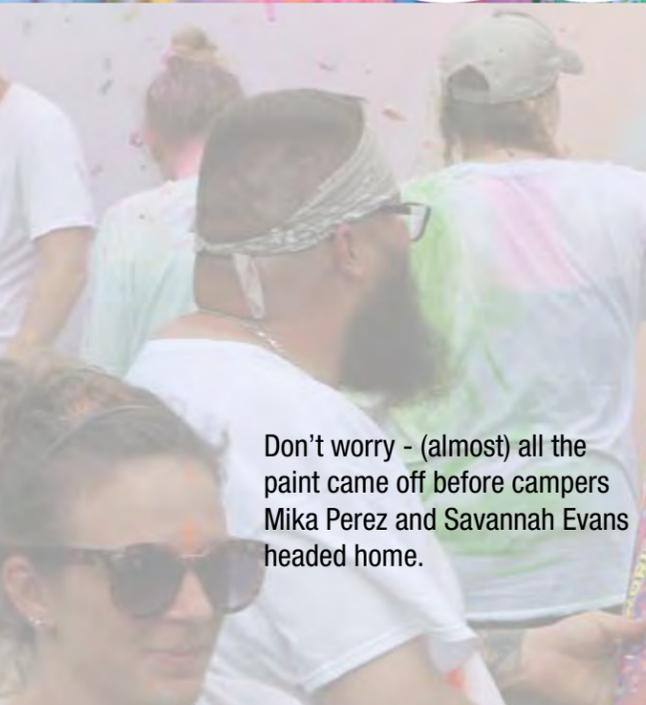




Grown-ups Ozzy Alfonso and Jonah Berger got in on the Color War action, too!

WE KNOW HOW TO
Color

OUR WORLD!



Don't worry - (almost) all the paint came off before campers Mika Perez and Savannah Evans headed home.



Emma Matheny, Jess Diamond and Genesis Felix weren't afraid to get a little messy during the Color War at Camp Footprint!



Vittorio Ricci and Charlie White got a game of basketball started between camp activities.



Nate Santa, Doug Frick, counselor Ozzy Alfonso, Ben Nelson, Sam Melville and Caleb Kinder stopped to smile and catch their breath after shooting hoops.

ALL THE **Right Moves**

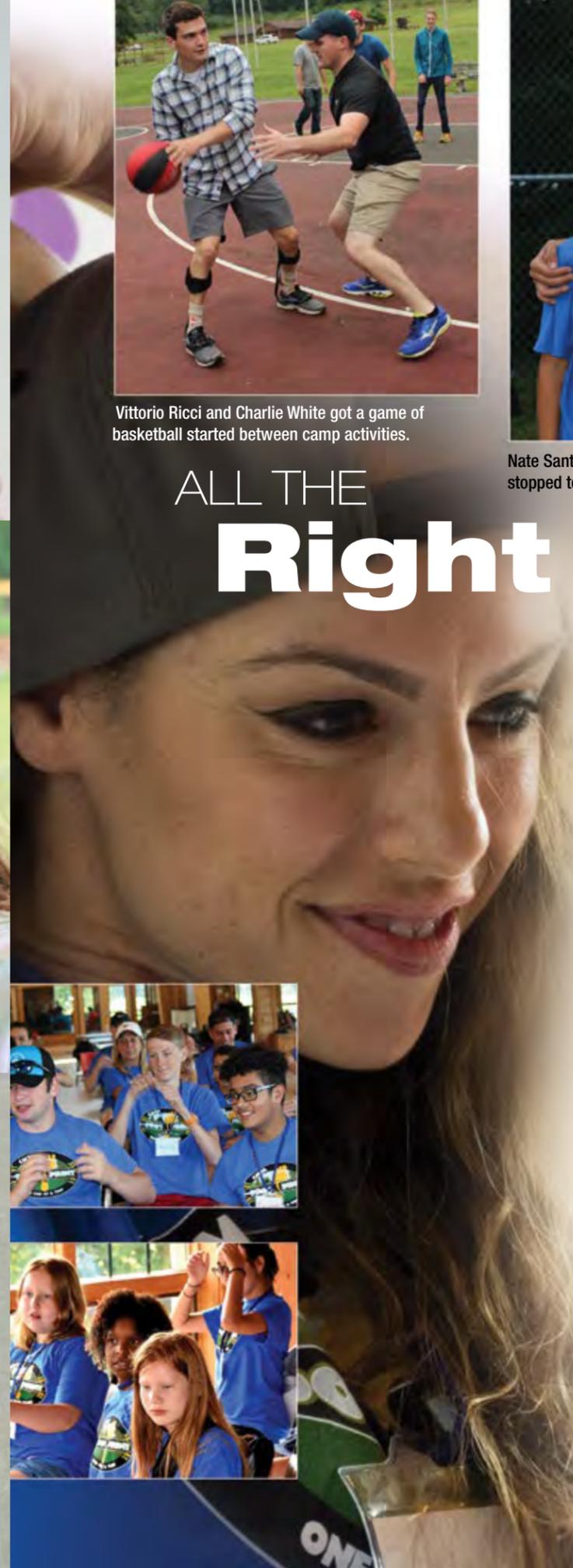
Chair Dance Gets Everybody Moving at Camp Footprint

Professional dancer and choreographer Bridget Savant developed a special inclusive chair dance program for Camp Footprint! Bridget has been dancing in Southern California for 27 years and teaching for about 15, all while battling CMT too! The stretching, body awareness and coordination that dance requires have not only helped Bridget physically, but have also given her confidence and opportunities beyond measure. Once Bridget heard about the first year of Camp Footprint, she knew she had to share this knowledge with other people who are living with CMT.

After observing how CMT affected everyone differently at camp, Bridget decided to teach everyone to dance while seated so that everyone could balance. Her goal was to make everyone sweat, feel good and connect with their bodies in a new way. She chose relevant music mixes that were relatable with pop culture and genuinely created moves on the spot. Campers and counselors replicated Bridget's moves as she taught through repetition and body language. Campers learned a fresh dance every morning to stimulate circulation, bond with other campers and release endorphins.

"The trick is to turn off the brain and trust the body to feel what it needs to," Bridget says. "Don't let your own mind get in your way! Just jam out and let go."

Professional dancer and choreographer Bridget Savant led the campers in a specially choreographed chair dance.





Friday Night Fever

Did you know that even superheroes like to dance? At Camp Footprint, campers, counselors and volunteers danced the night away!



Raul Molina (affectionately called Maui), Hannah Roberts, Brendon Burchard and Collin Stanton cooled off while hanging out at the pool.

IN THE Swim



Camper Genesis Felix enjoyed the pool at Camp Footprint.

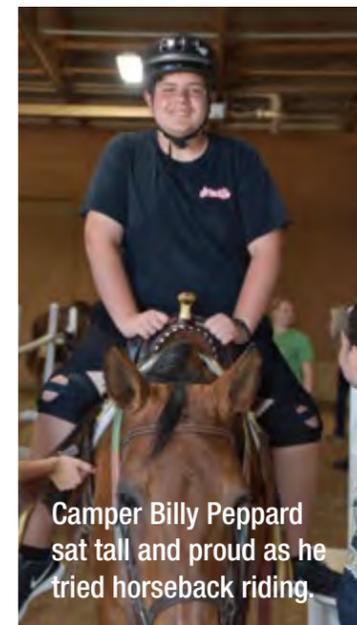


Elsa Groenink, Hannah Roberts, Genesis Felix and Hannah Miles caught the giggles and the waves at the pool.

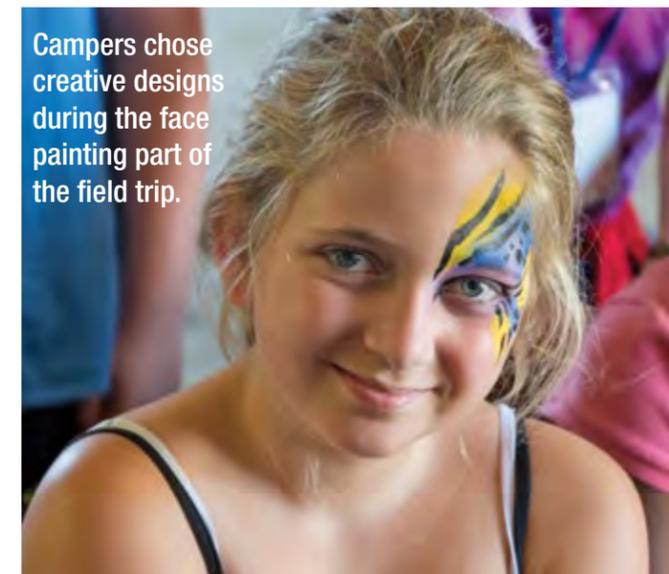


Camp Director Jeana Sweeney got in on the fun.

Field Trip of Dreams



Camper Billy Peppard sat tall and proud as he tried horseback riding.



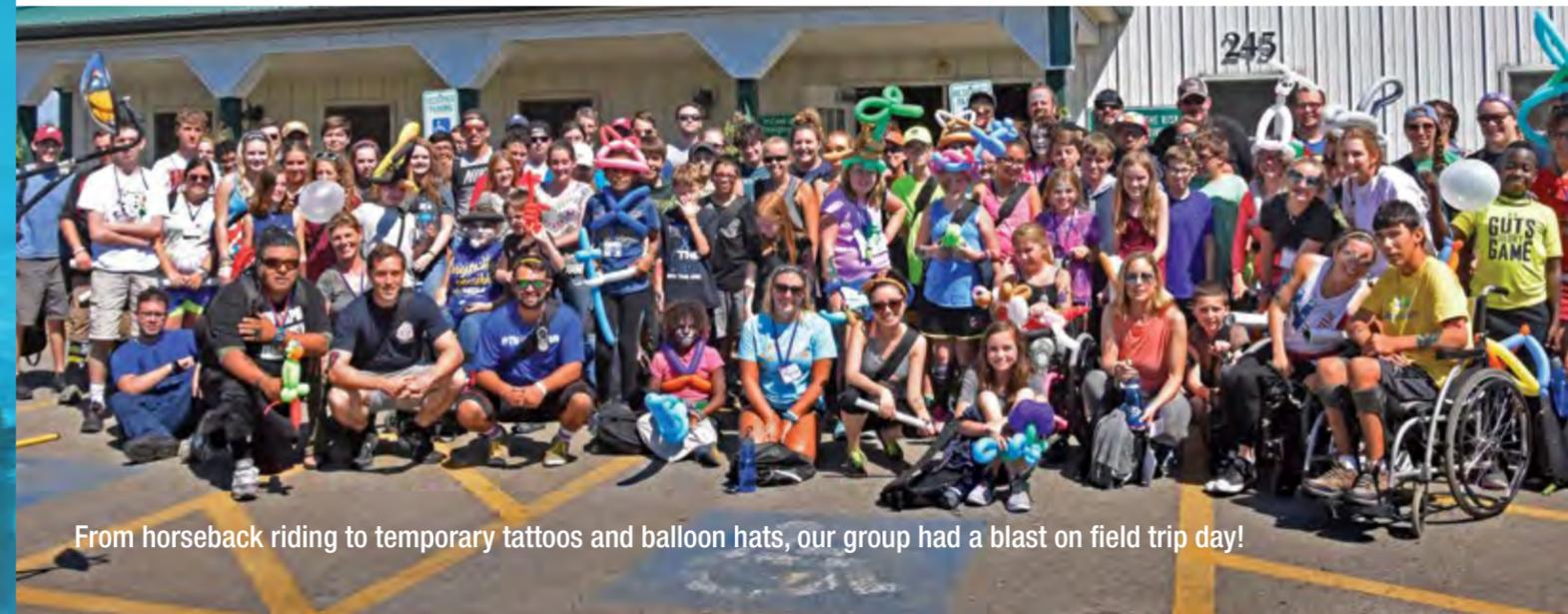
Campers chose creative designs during the face painting part of the field trip.



Doug Frick was all smiles while brushing a horse on field trip day.



Our field trip day was generously sponsored by our friends at the Hanger Charitable Foundation.



From horseback riding to temporary tattoos and balloon hats, our group had a blast on field trip day!



Stacey DeJoseph, Pennsylvania
 My name is Stacey DeJoseph. I am 28 years old, and I live in Pennsylvania. I have been living with CMT my entire life, and this past summer, I was involved in Camp Footprint. Camp Footprint was an amazing experience for me as a counselor. I have to admit that I was terrified at first. It was a completely new experience for me, and I did not know what to expect. But I am so glad that I was able to be a part of it, and I hope to continue to be a part of Camp Footprint.

It was great to be with a large group of people that all understand what it is like to live with CMT. I enjoyed everyone sharing their different stories and experiences. I made so many friends, both campers and counselors, that I will never forget. I was surrounded by others with CMT, all having a fun and eventful week. There were so many activities for us all to enjoy.

It made me so happy to see all the campers having so much fun. I wish that this camp was around when I was younger but I am so happy all the campers were able to experience it. I hope that Camp Footprint will continue so that others may enjoy this truly amazing experience.

Counselor Stacey DeJoseph, left, loved spending time with fellow counselors and campers at Camp Footprint.

OUR COOL CAMP Counselors

Counselor's Corner Reflections from Camp Footprint Counselors



Counselor Collin Stanton splashed around with campers during pool.



Counselor Ozzy Alfonso, right, formed a special bond with campers.



Counselors Casey Cardone and Stacey DeJoseph enjoyed the moment.

I can honestly say that watching these kids achieve their goals while also being silly and having fun made this adventure one of the best weeks of my life! So blessed to be a part of this family, and I can't wait to see everyone again next year!

Casey Cardone

Ozzie Alfonso, Belleview, New York

As someone who has CMT, I remember the daily struggles I faced growing up - mentally, physically, emotionally and socially. I wanted to come to Camp Footprint as a counselor, be myself and show the kids that "Hey, I'm just like you, I'm happy and I always keep my head up!"

As a teen with CMT, the biggest thing I have struggled with was social anxiety. Although most people who know me would describe me as an extrovert with an outgoing personality, I was nervous and shy because of the way I walked to the point where my legs wouldn't stop shaking. However, after I talked with someone, the question would come up. Once I'd explain CMT to people, my whole body would loosen up and relax. I'd feel a lot of weight fall off my shoulders.

Aside from being a father to my amazing son, being a camp counselor is the best title that's been put next to my name. The kids enjoyed my company, they didn't look at me like a guy with CMT and I didn't treat them just as kids with CMT. For a week, we were one big family who laughed with each other.

Camp gave me a sense of home away from home. We all experienced the same trips and falls and struggles. When we would see someone trip or go down, most of the time we would say, "Been there, done that - now get your butt up because we have somewhere to be!"

The biggest benefit the campers got, in my opinion, was gaining confidence and assurance through peers and mentors that everything is going to be okay - that this is not the end of the world, but just merely the beginning. Camp is important because it gives them a week of fitting in. It's a week where we all have difficulties with some of the activities we do, but where none of the campers have to be scared about other people judging them. Many campers conquer fears here. They figure out that they're capable of much more if they just step outside of the comfort box, which is what we encourage at camp.

I went into camp thinking that I was going to give these kids all I have in hopes that they can get something meaningful out of camp. But the truth is, I ended getting much more than I could ever imagine from the Camp Footprint experience.



Nurses Renee, Tina and Megan took excellent care of the campers all week long.





The CMTA's Camp Footprint* is the only camp in the United States just for kids with CMT! It is an annual, FREE, five-day sleepaway camp for youth (ages 10-18) with CMT where children with CMT are empowered with the courage, hope, skills and community for a lifelong journey of realizing potential and developing strengths.

Our mission is to provide each camper with an unforgettable week of adventure and fun with friends! Through participation in a community of youth with CMT, our campers make friendships based on shared experiences and understanding.

Register your camper today! www.cmtacamp.org



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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: frank@cmtausa.org.

* Camp Footprint is funded by the Pennsylvania Department of Health.