FALL 2023

THE CMTA REPORT

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CAMP FOOTPRINT x 2

The Minneapolis Branch Walks 4 CMT

SEPTEMBER IS CMT AWARENESS MONTH— GET INVOLVED!

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THE CMTA REPORT | FALL 2023

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Email the CMTA at info@cmtausa.org

40 YEARS STRONG!

In a remarkable achievement for a nonprofit, the Charcot-Marie-Tooth Association turned 40 years old in 2023.

Not many nonprofits make it to the 40-year mark. According to the National Center for Charitable Statistics, some 30 percent of nonprofits don't exist after five years. If one looks at a nonprofit's impact, rather than mere existence, the percentage is much higher, by some estimates up to 90 percent.

The Foundation Group, a nonprofit consultancy, lists five top reasons that nonprofits fail: the lack of a plan, unrealistic expectations, lack of leadership, lack of money and failure to adapt. The CMTA has avoided each of these pitfalls on its way to 40 years, and today it does far more than just exist: It's having more of an impact than ever.

The first reason nonprofits fail is the lack of a plan. From the beginning, the CMTA had a plan—to accelerate CMT research by capitalizing on advances in scientific knowledge and technology. That initial plan was formalized in the CMTA's Strategy to Accelerate Research (STAR) in 2008, which allowed the identification of the genes that cause CMT, permitted the replication of the genetic mutations in cellular and animal models and utilized rapid drug discovery and preclinical technologies to identify therapies that modify the CMT disease process.

To reach those goals, the CMTA assembled teams of top scientists recruited from an international body of scientific and clinical key opinion leaders in CMT. The STAR program's unique character stems from the willingness of the scientists to come together to advance CMT research collaboratively, sharing and communicating ideas, discoveries and research findings.

The five core principles of STAR remain the same as they were in 2008:

- **Develop a strategy** based on knowing the cause of the disease and where to focus.
- **Find the best researchers in the world** and task them with implementing projects that support the strategy.
- **Create accountability** and hold those researchers accountable for achieving their goals.
- **Demand collaboration,** bringing researchers out of their silos to work with each other.
- **Encourage partnerships**—It costs between $400 million and $1 billion to bring a new drug to market. Because the CMTA does not have this kind of money, we work with pharmaceutical companies that have the resources to develop drugs and can carry the ball over the line for us.

The second reason nonprofits fail is unrealistic expectations. The CMTA has always had realistic expectations for STAR. Because we knew from the beginning that it typically takes 15 years to bring a drug to market and that a lot of work needed to be done, we began with building the infrastructure necessary for clinical trials.

According to the Foundation Group, another reason nonprofits fail is lack of leadership. Successful nonprofits like the CMTA almost always have a strong board of directors who take an active role in strategically guiding the organization, keeping the mission top of mind. All the members of the CMTA board are affected by CMT in one way or another—either themselves or a family member or friend—deepening their commitment.

A fourth reason nonprofits fail is, unsurprisingly, lack of money, which is often caused by lack of a plan, unrealistic expectations and/or poor leadership. The CMTA is powered by an extraordinary community and in 2022 had the biggest year in its fundraising history, demonstrating that people give to causes that resonate with them, even in tighter economic times.

The final reason nonprofits fail is that they don't adapt to changing circumstances. One of the best examples of the CMTA's ability to adapt was how it handled the COVID pandemic. The organization had a distinct advantage because all employees already worked remotely. We quickly pivoted to putting many community programs online, and made thousands of "wellness calls" to community members.

The CMTA remains strong as it celebrates our 40-year milestone. We thank every member of our vibrant, giving, helpful community of patients, their families and friends, doctors, researchers, staffers, board members and volunteers for the parts they played.

CMTA 40 years of serving our community! 1983–2023
Charcot-Marie-Tooth Association

2023 CMTA PATIENT & RESEARCH SUMMIT

SATURDAY
04 NOV 2023

9:00 AM - 5:00 PM

Steven Scherer, MD
University of Pennsylvania

Reza Seyedsadjadi, MD
Mass General Hospital

Michael Shy, MD
University of Iowa

John Svaren, PhD
University of Wisconsin

Steven Gray, PhD
UT Southwestern Medical Center

The 2023 CMTA Patient & Research Summit on Saturday, November 4 will offer life improving presentations on living well with CMT as well as a comprehensive update on STAR research. Spend the day learning how to manage CMT and hear what you can do to be involved in advancing CMT research through clinical trials and studies.

World-class CMT experts, scientists, biotech partners, and STAR advisory board members will share updates on the remarkable and life-changing progress being made in STAR research. Neurologists, physical/occupational therapists, orthotists, and others aim to share information that will improve day-to-day CMT challenges.

To register and learn more about all the speakers and sessions, scan this code

SCAN ME

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CMTA Youth Outing!

On November 4, youth with CMT (age 10+) and their siblings are welcome to join us as we tour the city of Boston, have lunch together and check out a candy shop! It's an amazing way for youth with CMT to meet other youth and learn that they are not alone!

CMTA Youth Empowering Youth

CMTA HAILS NOVARTIS ACQUISITION OF DTx PHARMA AND ITS CMT1A THERAPEUTIC PROGRAM

On July 17, the CMTA hailed the news that global healthcare giant Novartis is acquiring DTx Pharma and its CMT1A therapy DTx-1252 as a significant step forward for the acceleration of novel CMT treatments capable of reaching the peripheral nervous system. Under the terms of the agreement, Novartis will make an upfront payment of $500 million and additional payments of up to $500 million upon completion of pre-specified milestones.

DTx-1252 is a first-in-class FALCON siRNA therapeutic that represses PMP22, the causative gene for CMT1A. The FALCON (fatty acid ligand conjugated oligonucleotide) platform enables the delivery and activity of small interfering RNA (siRNA) therapeutics to tissues beyond the liver, enhancing biodistribution and cellular uptake. By repressing PMP22, DTx-1252 reversed CMT1A in a mouse model that faithfully recapitulated the genetic and clinical manifestations of the disease. DTx-1252 treatment induced remyelination of axons to normal levels and increased muscle mass, grip strength, coordination and agility.

Artie Suckow, PhD, co-founder and CEO of DTx Pharma, said, "I am thrilled that Novartis will be moving forward with our CMT1A therapeutic program and the FALCON platform. With its resources and capabilities in neuromuscular diseases, Novartis is well positioned to accelerate the development of DTx-1252 and provide hope to patients, who are desperately in need of therapy." He added, "DTx Pharma owes a lot of its success to the CMT1A community; patients initially inspired our efforts to tackle this debilitating disease several years ago and continue to inspire us today by sharing their stories with the DTx Pharma team. DTx is excited to pass the baton to Novartis and Bob Baloh to continue development of DTx-1252."

Robert Baloh, MD, PhD, global head of neuroscience for the Novartis Institutes for BioMedical Research, said the acquisition "underscores the Novartis commitment to bringing life-changing medicines forward for patients with neuromuscular diseases and other disorders of the nervous system," adding, "We are excited to drive forward these promising preclinical programs and explore the potential of the FALCON platform."

According to CMTA Chief Research Officer Katherine Forsey, PhD, the acquisition highlights the progress made in positioning CMT as an attractive proposition to pharma, the founding principle of the CMTA's Strategy to Accelerate Research (STAR). The CMTA has been increasing its collaborative work with DTx Pharma team members as they prepare for the commencement of first-in-human clinical trials of DTx-1252, Forsey said, adding, "We are excited by the prospect of continuing this work with the Novartis team and applaud their commitment to bringing life-changing medicines forward for patients with neuromuscular diseases like CMT."

Noting the CMTA's long history with Baloh, who served on its Scientific Advisory Board from 2015 to 2020, Forsey said "We look forward to working with Dr. Baloh and Novartis to further accelerate progress. The CMTA is committed to supporting clinical trial readiness and roll-out for CMT and we look forward to the next chapter of this treatment's development."

DTx Pharma announced June 7 that it had been granted orphan drug designation for DTX-1252, signifying the Food and Drug Administration's recognition of the drug as a promising treatment option for CMT1A.

DRUG TREATMENTS AND GENE THERAPIES FOR CMT2D SHOW EXCELLENT RESULTS IN MOUSE MODELS

Robert Burgess, PhD, and his team at The Jackson Laboratory are working with an experimental drug to switch off the stress response that worsens symptoms in patients with CMT2D.

CMT2D is caused by mutations in a gene called glycyl tRNA synthetase (GARS). Five other genes closely related to GARS cause other forms of CMT, suggesting that they cause the disease in a similar way. Working with mice, the team at the Burgess Lab found that mutations in GARS, or the related gene YARS1 (which causes dominant intermediate CMT type C, CMTDIC), turn on a stress response in nerve cells.

When they used an experimental drug to switch off this stress response, the CMT symptoms improved. The drug also has benefits when treatment is started after CMT symptoms have developed. Maintaining the benefits requires continued treatment; if treatment is stopped, the symptoms return.

The Burgess lab is talking with drug companies about further developing this experimental drug into a treatment that can be safely used in humans. In addition, the lab is also piloting a novel gene therapy approach for CMT2D with very promising results in mouse models. Having "multiple shots on goal" with both gene therapies and drug strategies will improve the chances of having viable treatment options for CMT2D patients.

CMTA UPDATES LONG-STANDING NEUROTOXIC DRUG LIST

> With two exceptions for anticancer drugs, the reviewers concluded that the vast majority of the drugs are as safe (or as toxic) for CMT patients as for anyone else.

The Charcot-Marie-Tooth Association (CMTA) in June announced the results of a review of its long-running list of medications known or suspected of being toxic to the peripheral nervous system. With two exceptions for anticancer drugs, the reviewers concluded that the vast majority of the drugs are as safe (or as toxic) for CMT patients as for anyone else.

In 2022, the CMTA commissioned Guido Cavaletti, MD, and Paola Alberti, MD, PhD, to do a systematic review of the currently available published data in order to provide a scientific basis for the list. Cavaletti is a professor of human anatomy at the School of Medicine and Surgery, University of Milano-Bicocca, while Alberti is an assistant professor there.

The two potentially toxic drugs—anticancer drugs vincristine and paclitaxel—are both administered only in very specific diseases by physicians who are well aware of their possible peripheral neurotoxicity and the need for careful monitoring. That is not to say that people with CMT will not experience side effects from any other drugs included in the review, just that their risk is not greater than for people who do not have CMT.

The reviewers emphasized the importance of not denying patients with CMT treatments that may prolong life expectancy for cancer or improve their health status if affected by non-cancer-related diseases. Close and accurate monitoring of peripheral nerve function in CMT patients treated with any neurotoxic agent is essential to detecting the earliest signs of neuropathy worsening and any non-typical outcomes.

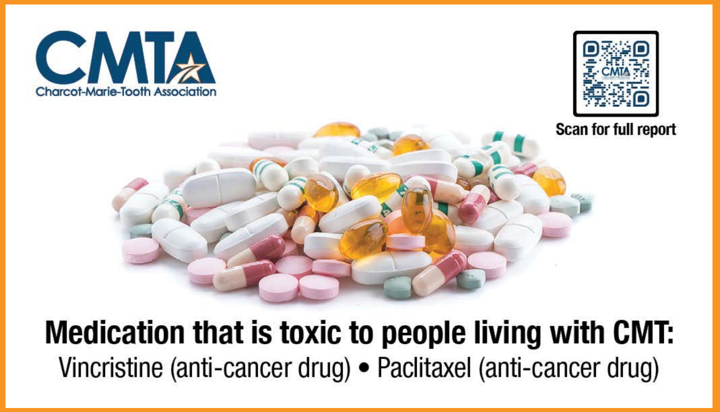
Members of the CMT community should ensure that all their treating physicians are aware of their disease and will discuss the risks and benefits of any treatment for non-CMT-related conditions and the potential impact on pre-existing condition(s). The list of neurotoxic medications is not intended as medical advice, nor is it a list of drugs that individuals with CMT should avoid. Rather, it is intended to help patients and their healthcare providers make informed medication decisions.

Neurologists monitoring CMT patients as part of their normal care package or for natural history studies should keep detailed records of exposures to potentially neurotoxic medications and support reporting of accelerated neuropathy progression if observed.

Dr. Cavaletti commented, “The results of this revision provide clarification that CMT patients are not exposed to any additional risk of peripheral nerve damage when compared to people who do not have CMT, apart from the cases of vincristine and, probably, paclitaxel. This message is definitely reassuring, although it does not mean that surveillance on possible drug-induced side-effects should be reduced. As in all medical practices, the risk-to-benefit ratio should always be considered in drug prescription: however, there should not be excessive (and unmotivated) concern in treating CMT patients, provided the correct treatment is proposed.”

A manuscript based on the report has been accepted for publication in the Journal of the Peripheral Nervous System. It is available to view online ahead of print publication at http://doi.org/10.1111/jns.12566.

PUT THIS IN YOUR WALLET!



CMTA
Charcot-Marie-Tooth Association

Scan for full report

Medication that is toxic to people living with CMT:
Vincristine (anti-cancer drug) • Paclitaxel (anti-cancer drug)

Cut out this handy neurotoxin medication card and keep it in your wallet at all times.

CMTA
Charcot-Marie-Tooth Association

CMTA AND ACTIO BIOSCIENCES HOST CMT2C PATIENT FOCUS GROUP

BY STEPHANIE CARMODY AND KATHERINE FORSEY, PhD

The CMTA and Alliance partner Actio Biosciences hosted a virtual patient focus group in June for 10 individuals with CMT2C, seeking their input on the patient journey, unmet needs and future treatment goals.

CMT2C is a TRPV4-related hereditary neuropathy, like the related diseases Scapuloperoneal spinal muscular atrophy (SPSMA) and congenital distal spinal muscular atrophy (CDSMA). It can cause vocal cord paralysis, respiratory muscle weakness, hearing loss and limb weakness among other symptoms. Severity and age of onset vary widely. Only about 1 percent of genetically diagnosed CMT cases are type 2C.

Actio Biosciences, founded in October 2021 and headquartered in San Diego, Calif., is in the preclinical stages of developing a small-molecule inhibitor of TRPV4 that can be administered orally. The tablets will target TRPV4’s gain of function, which releases an excess of calcium into cells and causes damage to nerves. The potential treatment would apply to all of the TRPV4 hereditary neuropathies. The CMTA is providing Actio patient advocacy support, facilitating engagement of the CMT2C patient community to enable patient-centric planning and design for future studies and trials.

Stephanie Carmody, who lives with CMT2C, said the aim of the focus group was for the CMTA and Actio to actively engage with key experts from the CMT2C patient community and gather insights. The meeting provided a platform for patients to directly share the impact CMT2C has on their daily lives and their treatment priorities, she explained.

Actio Biosciences CEO Dr. David Goldstein said the focus group meeting “provided an invaluable opportunity to learn about the challenges faced by individuals living with CMT2C and reinforced the urgent need for treatment options.” He continued, “The Actio team was humbled by the openness and candor displayed by each participant in the focus group, and we are immensely grateful for the support and guidance we have been provided.”

Rod Pollard, another patient with CMT2C, told the Actio team, “I just want you to know that from everything I see it looks like you are moving forward with what may be a very effective treatment for this condition. Even though it is not a large patient population, it could mean everything to us. I want to thank you for the research you are doing and what might come of this.”

“Listening to your voices, we are even more committed now and we are genuinely on a journey together that we intend to see through to the introduction of an effective treatment,” Goldstein said in concluding the meeting.

Johns Hopkins University has made great progress in its preclinical work on CMT2C in the past few years, as investigators work to translate new research understandings into an easy-to-administer treatment. The university will open a natural history study between October and December that will help researchers understand the natural course of CMT2C and inform the design of a treatment study.

For more information about participating in the Hopkins natural history study on 2C, email study contact Maya Hoke at mhoke4@jhmi.edu. To learn about future focus group opportunities, receive research updates, and stay informed on natural history studies open for recruitment, create a profile on the CMTA’s Patients as Partners in Research https://bit.ly/CMTAPatientsPartners and opt-in to receive research news.

Stephanie Carmody is a speech-language pathologist who owns her own healthcare company and serves as the CMTA’s CMT2C patient liaison. Katherine Forsey is the CMTA’s chief research officer.

THERE'S STILL TIME TO BE PART OF AWARENESS MONTH 2023!

LET THE WORLD KNOW THAT YOU ARE "NAVIGATING CMT" IN SEPTEMBER with an Awareness Month toolkit that includes a distinctive social media profile picture frame, compelling sample social media text and graphics and insightful email content. Amplify your support by adding the official CMT Awareness Month profile picture frame to your social media profiles. In connection with Twibbon website, users can seamlessly overlay a frame onto their existing profile pictures. By actively engaging in these online initiatives, supporters not only exhibit solidarity with the CMT community but also foster crucial conversations about the challenges posed by this neurological disease. As "Navigating CMT" takes center stage this September, the CMTA's multifaceted approach empowers individuals to share their stories, learn from one another and collectively work towards enhancing the quality of life for those living with CMT.

For more information about CMT Awareness Month 2023 and how to participate, visit the official CMTA website: https://www.cmtausa.org/get-involved/cmt-awareness-month-2023/

FIRST-EVER CMT CLINICAL SUMMIT EDUCATES HEALTHCARE PROFESSIONALS

A common complaint from members of the CMT community is that their doctors don't know enough about CMT to help them manage the disease to reduce its impact on their lives. To address this knowledge gap, the CMTA partnered with global leading CMT disease experts on April 21 for its first CMT Clinical Summit for healthcare professionals. The summit offered eight in-depth sessions covering a wide range of topics related to CMT, including neurology, genetics, clinical trials/studies, surgical intervention, PT/OT, breathing-related issues and social work.

Laurel Richardson, the CMTA's director of community outreach, explained that the goal of the summit was to expand the CMTA's commitment to improving care for all people living with CMT—and to educate their healthcare professionals about the disease. "We are elated to make this type of education a reality," she said, noting that of 113 healthcare professionals who registered, 79 percent were new to the CMTA.

Registrants joined from five countries—the United States, the United Kingdom, France, Italy and Japan—and 28 of them signed up for continuing medical education (CME) credits. They came from a variety of professions, including neurology, physical and occupational therapy, nursing, genetic counseling, orthopedic surgery and physiatry. Their reasons for attending the summit also varied and included the desire to learn more about clinical trials, to learn about how different professional disciplines are treating people with CMT and to ensure up-to-date knowledge on treating adults with CMT.

The program included a keynote presentation followed by four sessions, each of which had two choices running in parallel professional tracks so that participants could mix and match them depending on their interests. The three sessions with the most attendance included neurology with Steven Scherer, MD, PhD; clinical trials and patient recruitment with David Hermann, MD; and surgical interventions with Glenn Pfeffer, MD.

Of the registrants who filled out the post-session evaluation link, 55 percent said that after attending the "CMT Surgical Interventions" session, they would refer cases for surgical evaluation of foot deformity to orthopedic surgeons sooner than they had previously. One hundred percent of respondents found value in patient advisory groups hosting medical education conferences for healthcare professionals.

In another positive outcome from the summit, the CMTA is now in contact with leaders of four new clinical centers that could potentially become CMTA Centers of Excellence.

UNDER THE MICROSOPE

BY KATHERINE FORSEY, PhD
Chief Research Officer

*In "Under the Microscope," **CMTA Chief Research Officer Katherine Forsey, PhD,** takes a closer look at issues related to the CMTA's Strategy to Accelerate Research. Katherine is a research biologist by training and holds a doctorate in biology from the University of York in the area of expression, activity and localization of metabolic enzymes during preimplantation embryo development. She and members of her family have CMT1A. She lives in Yorkshire, England with her husband and two children.*

Induced Pluripotent Stem Cells (iPSCs)

Induced pluripotent stem cells (iPSCs) are adult stem cells that can be "reprogrammed" back into an embryonic state and then used to create the specific cell types that scientists need for research. Derived from skin or blood cells, they offer a renewable source of pluripotent stem cells with tremendous potential for understanding and combating CMT.

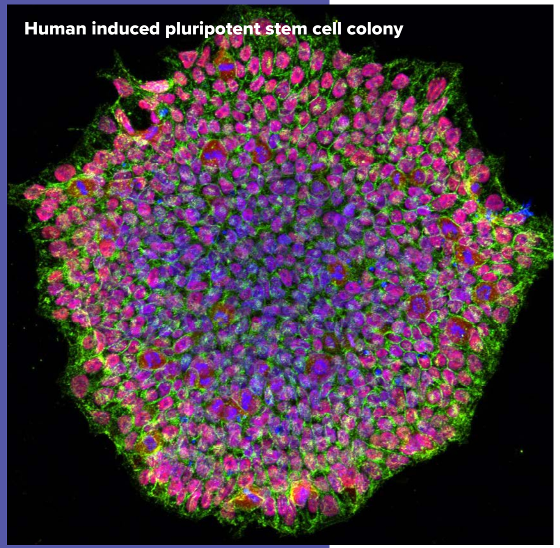
Using iPSCs derived from patients with CMT, scientists can create motor neurons and Schwann cells—the cells primarily affected by the disease. By observing how these cells behave and interact in a lab setting, researchers gain insights into disease progression and discover potential drug targets for therapeutic interventions. iPSCs also open new avenues for personalized medicine: By generating iPSCs from individual patients, researchers can create CMT sub-type specific disease models. This approach allows for tailored drug testing, as medications can be screened using the patient's own cells to identify the safest and most effective treatment.

Stem cells are unique because of their ability to transform into different cell types within the body. They have two defining characteristics: self-renewal and differentiation. Self-renewal enables them to divide and create identical copies of themselves, while differentiation allows them to transform into specialized cell types like nerve cells, muscle cells or blood cells.

Stem cells are classified into two main categories: embryonic stem cells (ESCs) and adult stem cells. ESCs are derived from embryos and possess the highest differentiation potential. However, their use has been a subject of ethical concerns, leading researchers to explore other sources. Adult stem cells, also known as somatic or tissue-specific stem cells, exist in various tissues of the body and play essential roles in repair and regeneration. While adult stem cells have limited differentiation potential compared to ESCs, they offer less controversial, more practical approach to regenerative medicine. The stem cells in use for CMT research can be derived from blood samples or skin biopsies donated by CMT community members and carry the same genetic mutations responsible for causing CMT.

In 2006, Shinya Yamanaka, MD, PhD, and his team at the University of Kyoto created a technique to reprogram adult cells back into a state reminiscent of embryonic stem cells, leading to the birth of iPSCs, which possess the characteristics of both embryonic and adult stem cells. By introducing a specific set of genes into adult cells, scientists can turn back the cellular clock and "de-differentiate" them into iPSCs. These iPSCs are then capable of differentiating into any cell type in the body, just like embryonic stem cells. Not only does this discovery offer a nearly unlimited supply of pluripotent stem cells for research, but it also bypasses ethical controversies associated with using embryos. Yamanaka won the 2012 Nobel Prize in Physiology or Medicine for his work on iPSCs. He is now part of the Gladstone Institutes, San Francisco.

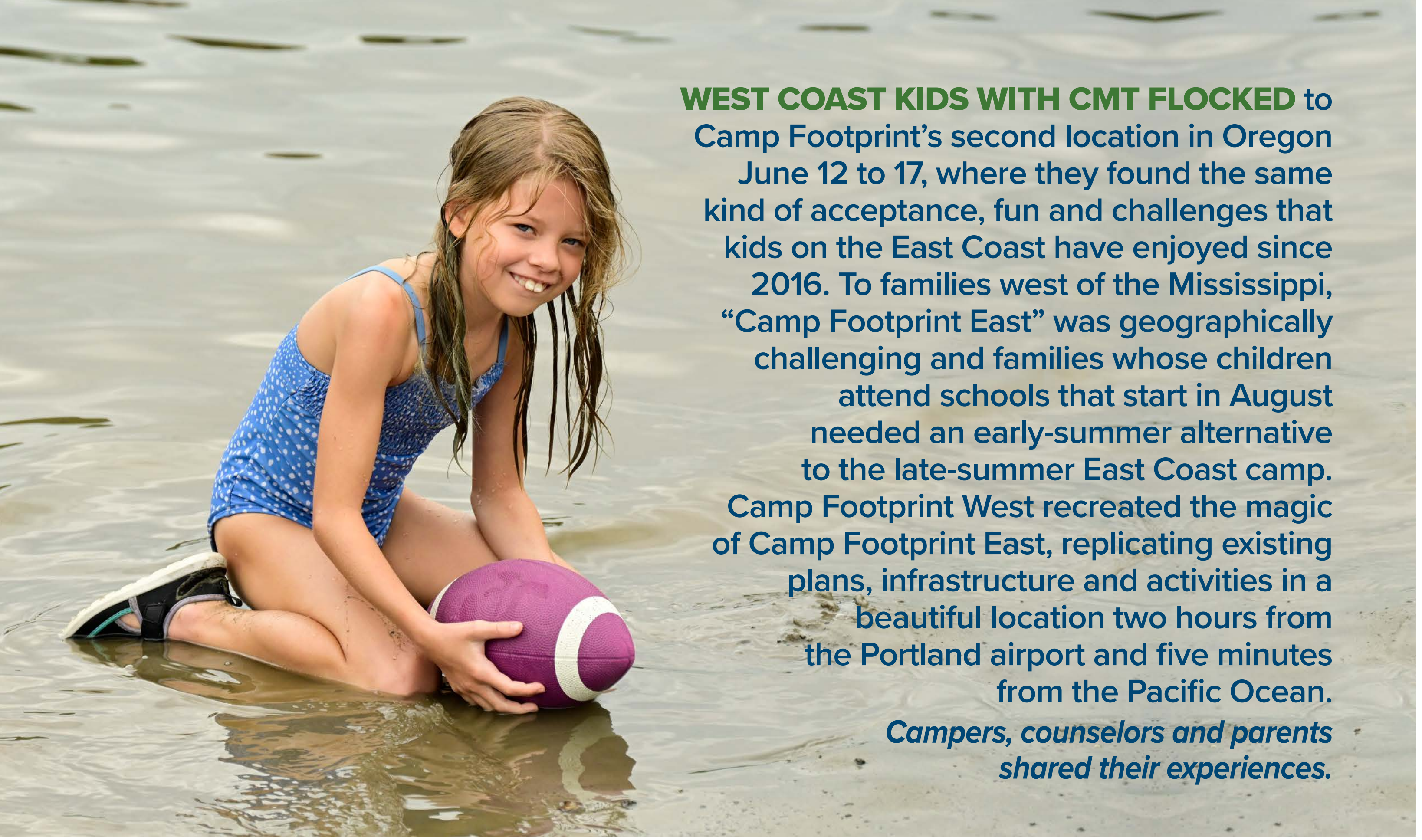
Since 2014, the CMTA has collaborated with the New York Stem Cell Foundation (NYSCF) to create the largest global repository of CMT stem cell lines across a wide range of CMT sub-types. These are available for academic and commercial investigators. Over the next 12 months, the CMTA plans to add 12 new stem cell lines (at a cost of $25,000 per line) to include more CMT mutations and ensure full gender representation in the lines.



Human induced pluripotent stem cell colony

Courtesy: NIH Image Gallery

CAMP FOOTPRINT **TIMES 2**



WEST COAST KIDS WITH CMT FLOCKED to Camp Footprint's second location in Oregon June 12 to 17, where they found the same kind of acceptance, fun and challenges that kids on the East Coast have enjoyed since 2016. To families west of the Mississippi, "Camp Footprint East" was geographically challenging and families whose children attend schools that start in August needed an early-summer alternative to the late-summer East Coast camp. Camp Footprint West recreated the magic of Camp Footprint East, replicating existing plans, infrastructure and activities in a beautiful location two hours from the Portland airport and five minutes from the Pacific Ocean.

Campers, counselors and parents shared their experiences.

VIEW FROM A CAMP FOOTPRINT WEST CAMPER: ASHLYNN LUISI

When I was diagnosed with CMT I felt like my whole world was on fire. I didn't have friends who understood and despite my family's best efforts I still felt isolated with my disease. This feeling of isolation lasted years and I felt alone in my battles. Camp Footprint West changed all that. I was ecstatic to experience the warmth of being surrounded by people who understand. People who don't get irritated because you walk too slowly or need to sit down for a minute. People who will complain about their feet hurting and gladly listen to you do the same. People who have war stories of surgeries, muscle spasms and diagnoses. People who want to help and people you want to help. People who just get it. I was instantly amazed by this world of people who understood how I felt.

I was thrilled to be able to participate in exhilarating activities that I could actually do at my pace. There was rope climbing, archery, canoeing, tubing, swimming, yoga and a powder battle. All things I thought I would never get to experience to the fullest extent, yet the amazing people of Camp Footprint made this possible not only for me but for hundreds of kids across the country.

I can go on and on about how amazing and accessible each activity was. But what truly made Camp Footprint so life-changing was the perspective it gave me. Some of my best friends on the planet have CMT. My sister, who was recently diagnosed with CMT—and I are now closer than ever. Even though we have different symptoms, we both have CMT. But it doesn't define us. People with CMT will never see your disability or any physical difference because we are all alike.

Before Camp Footprint, I thought CMT burned my world down. I now truly believe that CMT opened a new world of possibilities for me. My newfound perspectives, the people I've met and the world of possibilities I now have are all due to CMT. So thank you CMT for giving me my world. I wouldn't change it for a thing.

Ashlynn, now 19, is a college sophomore in California.

VIEW FROM A CAMP FOOTPRINT WEST COUNSELOR: KENDALL TROUT

This year's first-time Camp Footprint West in Otis, Oregon, delivered the same great experience as its eastern counterpart. The campsite itself was almost perfect for our needs—just the right size, clean and well-maintained and in a beautiful location.

The camp counselors and support staff are also the best. Absolutely everyone had the right attitude to make this one of our best camps ever. I don't know how Camp Director Jonah Berger finds and assembles these warm, fun and hard-working individuals who make our camp run so well. I was particularly moved by listening to one member of the support team at the climbing wall, where he displayed such compassion and hope as he coached the campers on conquering this difficult task. His ease and grace showed through with each of our campers.

The off-site activity at the Adventure Park was also very well-staffed and managed. As anxious as I was about being 20 feet in the air with just a few hooks and cables holding me up, I always felt safe and watched by the support staff. The spotters projected a confidence that made this activity possible for almost all of our campers.

Having CMT is just one part of these kids' lives. There's puberty, social media, depression, poverty and learning disabilities that many of our kids deal with daily. For first-time campers, the experience has to be a shock to their systems. For one thing, some of them have never even met someone else with CMT. And then, all of a sudden, they are at Camp Footprint being recognized and cheered on by their peers with CMT as well as counselors and staff with CMT! This feeling of belonging is like an awakening. The blossoming I witnessed in these kids—from the day we picked them up at the airport to the day they left—was incredible. Witnessing them inspires me to work at this camp for as long as I am allowed back.

There are tons of activities at camp but one of my favorite things is the quiet times, the in-between times. Foot time at night, walks and rides to camp functions and just helping campers with AFOs, socks and lacing up shoes allow space for some great discussions. Campers and counselors alike share heartfelt stories, CMT experiences with AFOs, surgeries, doctors, family and school. The campers are so comfortable sharing in this camp environment. I only hope that this comfort and openness follows them back home.

Kendall has been a Camp Footprint counselor since 2018. She is also the San Diego branch leader.

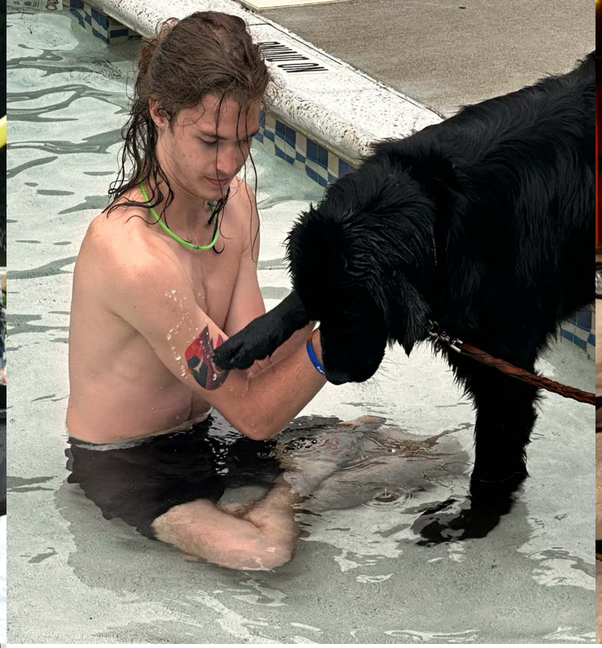
VIEW FROM A CAMP FOOTPRINT WEST PARENT

I don't know that words could possibly express the gratitude we have for this camp. Firstly, we were pleasantly surprised that we were allowed to attend given that we are from Canada.

The whole experience leading up to camp was seamless. Ample information was provided and there was always someone available to answer any questions we had. When we arrived at camp, we experienced the warmest welcome ever. Immediately people were greeting us and Brianna. Many people told her that they have CMT. I can't express what that meant to her and us. Brianna had never met anyone with CMT until this camp. As one of the nurses said, Brianna has now found her tribe. My heart is exploding with joy as I write this.

Picking her up from camp, I could see how connected she became with her counselors. When we pulled away from camp she said "Mom, this was the best week of my life. I am sorry to say but it even beat going to Disneyland." Those words were music to my ears. This is going to forever change Brianna in the most positive way ever. She has been talking about next year since we left camp. We are eternally grateful for this amazing experience and are already looking forward to next year with eagerness and anticipation.

—Sandra, mother of Brianna, 14



VIEW FROM CAMP FOOTPRINT EAST STAFFER KAREN BROWN: FRANKIE GOES TO CAMP

In 2023, Camp Footprint East hosted 78 campers and 71 staff/volunteers, which made it a little challenging to spot any one kid in the crowd. The easiest way for me to find Frankie throughout the week was to look for rapid movement in the vicinity of William, his older brother/caregiver and counselor or Mac, his favorite counselor from amongst the rest of us. It was also useful if I could spot campers Beau or Logan, who were often running around with Frankie and some combination of water balloons, super soakers and silly string.

While the typical camper arrives solo and spends the week paired with an unrelated volunteer, in Frankie's situation it was necessary and appropriate to bring William in to manage his brother's needs, and Frankie soon chose Mac from the volunteer camp staff as his second go-to counselor (and best friend forever). I caught up to Frankie and William at the end of the week, on the porch of the Peace Palace cabin where they had private sleeping quarters.

For high-energy, water-loving Frankie, spending a week in a continual rotation of swimming, boating, floating, slip-n-sliding, water ballooning, super soaker shooting, and stomping through puddles with friends like him was very exciting, like a video game where players can do things they don't ordinarily get to do.

Frankie says CMT gets in his way "a little bit" with cramping, fatigue and breathing. His older brother kept close tabs on him, watching for signs of pain or fatigue that could require rest, medication or a breathing treatment. William said that staff understood the importance of not over-exhausting the campers by using golf carts for every camper. "This allowed the campers to have full strength during activities," he observed. Allowing the campers to hang out with each other instead of just their counselors was also a big bonus, he said.

With William's help, Frankie was able to participate in everything he chose from this year's camp offerings: chair dancing, wall climbing, archery, zenitude (a new offering that includes mindfulness and gratitude), yoga, airbrush tattoos, face painting, petting zoo, pony rides, lake games, paddle boarding, kayaking, water cycling, field games, campfire with s'mores, talent show (Frankie dressed as a giant inflatable shark!), evening cabin time with peers and his favorites—swimming and slip-n-slide.

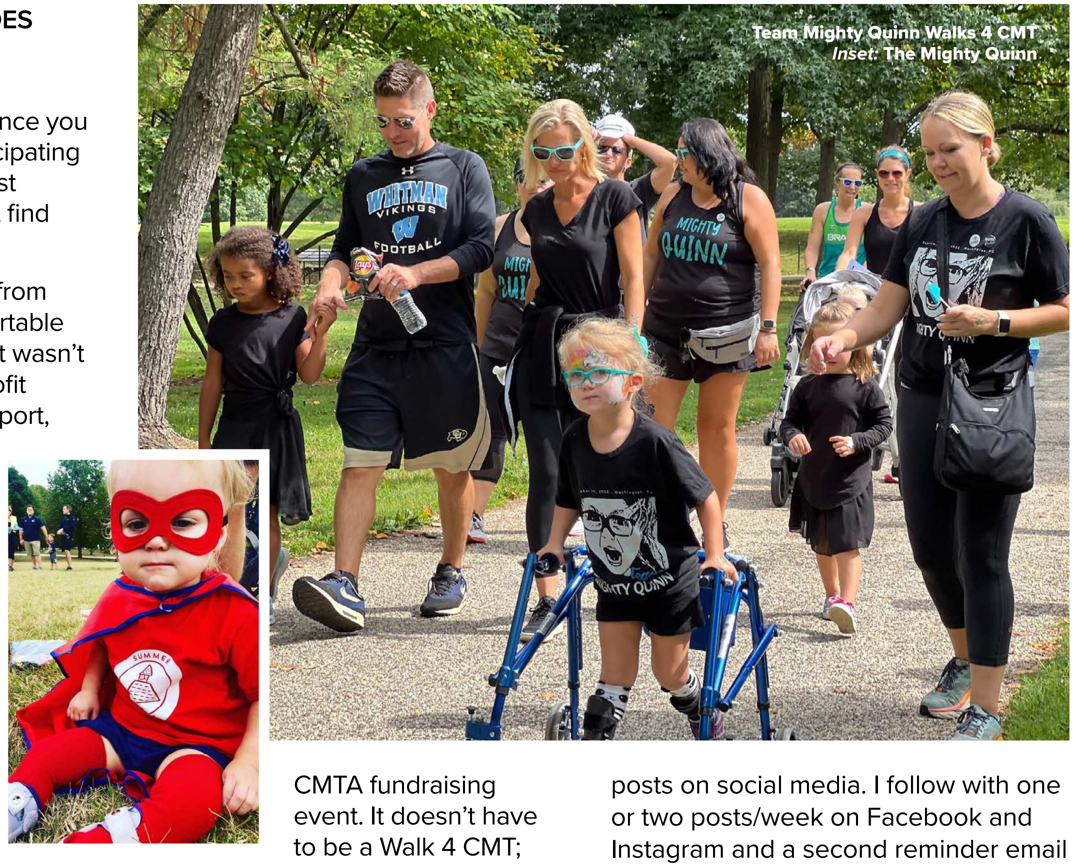
Frankie and William both want to come back next year. Frankie hopes the camp directors will modify next year's program to include more swimming (we swam six times in five days), at least two lop-eared rabbits (the petting zoo had one, and it was his favorite) and "one more day of slip-n-slide."

Karen Brown is a grant writer, camp staffer and the Southwestern Virginia branch leader for the CMTA.

Editor's note: Frankie B., 11, last appeared in the pages of The CMTA Report in a story about a sperm donor who passed CMT on to multiple families, including Frankie's. At the time, it was unclear whether his medical needs would allow him to attend Camp Footprint East: In June he began wearing a ventilator at night, during naps and for rescue during the day. While Frankie thought "it would be kinda cool" to spend a week with other kids who have CMT, it was a major decision for his family and medical team. After a previous summer camp experience proved medically dangerous for Frankie, who has CMT type Intermediate B, his care team was understandably cautious about Frankie's interest in Camp Footprint. They wanted him to have the experience of a week with "the Tribe of the Funky Feet," but they needed to be confident of the care he would receive away from home. CMTA National Youth Programs Director Jonah Berger and Camp Footprint East head nurse Renee Kulback worked with the family and their medical team to develop a customized plan for Frankie that included his 28-year-old brother William acting as his primary counselor. According to William, the CMTA's professional camp structure and advance information session gave his family the confidence they needed to proceed.

FUNdraising for a World Without CMT

BY MOLLY McLEARN FERNANDES


Team Mighty Quinn Walks 4 CMT
Inset: The Mighty Quinn

If you're like me, the thought of fundraising is off-putting. But once you get past your discomfort, participating in a fundraiser is one of the best ways for you to help the CMTA find treatments and a cure for CMT.

For most of my life, I shied away from fundraising. It made me uncomfortable to ask people for money even if it wasn't for me but for a reputable nonprofit organization that I wanted to support, usually through some sort of walk or run event. Most of the time, I opted to donate and not fundraise at all.

In 2019, my youngest daughter, Quinn, was diagnosed with CMT1B. You can probably remember the dreaded line that comes next: "There is no cure and no treatments." Sheer panic followed, then tears—lots of tears. Then I began to search for action, asking myself, "If I cannot fix this for my baby, what CAN I do?" During my search for answers and hope, I discovered the CMTA. I was impressed by its commitment to research and the support they offered the CMT community. With an instant connection to the mission of the organization, I signed up to participate in the Washington, DC, Walk 4 CMT.

Here's the thing: I could have gone with a simple donation, a sizeable one even. That would have been just fine. But I wanted to do more. I wanted to do EVERYTHING I possibly could, so I switched gears mentally and made this my "job." I wrote this article to show readers that if I can change my attitude about fundraising, they can too. The key is to organize and make it fun.

With professional event marketing experience under my belt, I put together a plan as I would for any marketing campaign. I successfully raised money for team Mighty Quinn and the DC Walk 4 CMT. And the best part? It was fun! As a result, I continue to form a team and fundraise every year. I'm sharing my process in the hope that I can inspire readers to support a nearby CMTA fundraising event. It doesn't have to be a Walk 4 CMT; it can be a Cycle 4 CMT or another already-established event. Also, if there isn't a local event, there may be an opportunity to launch one—and the CMTA can help make that possible.

Here are the steps I take when fundraising for Team Mighty Quinn for the DC Walk 4 CMT:

1. BUILD A CONTACT LIST

Who are you going to ask to donate? Friends, family, colleagues, teammates, neighbors, local business owners? If you send a print or email holiday card each year, that's a great place to start. Fill in as many contact details as possible: email, telephone and mailing address. This way, you can reach out in more than one way for better results.

2. CREATE A CALENDAR

I aim to have the first communication hit about one month prior to the walk. Last year, I did a postcard and started that process about two months out, so I had time for design, printing and mailing. The rest of my outreach is email and social media. One month out, my postcard hits mailboxes, I send a detailed email out and coordinate posts on social media. I follow with one or two posts/week on Facebook and Instagram and a second reminder email one to two weeks out from the walk.

3. DRAFT COPY

All of my communication includes a call to action to donate (with a link to click) but I vary my message to make it more interesting.

- The first message is all about giving the details (what, where, when, and why) and my primary call to action is simply JOIN US! People want to support you and they're likely to want to join you in your mission even before they know how much they want to donate.
- In subsequent posts, I share photos and videos of Quinn either working hard at physical therapy or doing everyday things like walking to the school bus stop to illustrate how CMT affects her everyday life. The corresponding message supports this and includes the call to donate.
- The last week or so, I create a sense of urgency with an "Only seven more days until the DC Walk 4 CMT" message, and a LAST CHANCE message just before the event.
- Following the event, I send a THANK YOU message and let people know they can still donate until X date.

NOTE: I draft copy, test links and choose photos/videos beforehand so that I am ready to post or send according to the calendar. Then I review everything before I send/post just in case anything has changed or needs to be altered.

4. THEME THE TEAM

Obviously, this is completely optional, but we enjoy coming up with themes for Team Mighty Quinn. The first year we did red superhero capes and masks. This past year, we did black tee shirts and turquoise sunglasses (to match Quinn's everyday glasses). This was also used for the postcard design, T-shirts and a banner.

5. THANK DONORS & TEAM

Be sure to thank your donors and everyone who joins your team. They will receive an email from the CMTA if they donate to a Walk 4 CMT and you can follow up with your own email using the tools provided or by emailing them directly. This past year, we also printed a second postcard with a team photo and recap of our success to thank donors and teammates.

TO JOIN A WALK, visit www.cmtausa.org/walk.
TO START A WALK, contact Mary Louie, the CMTA's national events manager at mary@cmtausa.org.

This specific plan may not work for everyone, but coming up with a plan will. Otherwise, it's too easy to put off. So, keep it easy, make a plan and have some fun fundraising for the CMTA.


Quinn and family!

In the words of Helen Keller, "Alone we can do so little; together we can do so much." These simple words carry a lot of weight when it comes to fundraising for a rare disease like CMT. We must work for every dollar put towards programs to help people living with CMT and research to find a cure. We must all do our part to make this happen. I take pride in the fundraising efforts I've made so far, and the fact that Quinn shares this sense of pride means everything. This is why I continuously seek opportunities to do even more. And, if I can inspire a few people to begin fundraising, that would allow us to accomplish so much more than what each of us can do on our own. I believe it will lead to a world without CMT, my greatest wish.

Molly McLearn Fernandes is an engagement event strategist for the CMTA.


CMTA 40 years of serving our community!
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WALK, SCOOT, OR PEDAL...

However you move, you can help the CMTA.
Register today for a Walk 4 CMT or Cycle 4 CMT event and help us make strides towards a cure!"

REGISTER TO WALK AT:
cmtausa.org/walk4cmt
REGISTER TO CYCLE AT:
cmtausa.org/cycle4cmt

GET OUT AND GET ACTIVE
FOR PHYSICAL AND MENTAL BENEFITS

BY KATERINA B.


Katerina dancing

Exercise is essential to help with balance and physical strength. But what about the mental health benefits of exercise, particularly for those living with physical limitations?

A few years ago, I noticed that my lack of exercise and failure to take care of my physical health was affecting my mental health. I have been a dancer (even before my diagnosis) for most of my life.

During the pandemic, when everyone stayed home, I had to start thinking creatively about how to stay active. I found it difficult when everything shifted online. I was used to going to the studio weekly, taking classes and being surrounded by a community of encouraging friends and instructors.

I dance because it's a beautiful art form that uses movement and expression to share a story or message of hope. I also dance as my body would weaken if I didn't stay active. But, when classes migrated to Zoom, I noticed a change in my physical and mental health. I spent most of my time in my room and away from in-person interactions. My pain and fatigue grew worse. I started feeling more depressed. It took a couple of months to realize how my mental health affected me physically. I knew something needed to change.


Katerina walking

I have always enjoyed being outdoors. Even in my early teens, I felt better when surrounded by nature instead of being indoors all day. So I began going on walks in my neighborhood. It started with about 10-15 minutes in the morning along with taking pictures of flowers or trees.

As the weeks went by, I started going on walks more frequently and noticed a change in my physical and mental health. Walking in my neighborhood got me out of the house and wearing my AFOs more often helped with pain levels and balance. And I wasn't feeling as depressed. Getting outside helped me to shift my focus from not feeling like doing anything to finding a positive outlet.

MY LESSON FROM THE PANDEMIC:

You can find ways to adapt no matter your physical limitations.

My lesson from the pandemic: You can find ways to adapt no matter your physical limitations. Find ways to continue exercising even if it means simply going on a short walk or stretching to your favorite music. This will help with feelings of depression and isolation. And if exercising by yourself affects your mental health, invite a family member or friend to join. Or join the CMTActive group on Facebook, where those living with CMT share how they continue to exercise. I enjoy sharing videos of chair dancing, stretches or walking outdoors. Sharing is a great way to stay positive and find encouragement and inspiration from those who know firsthand what it is like to experience pain.

Katerina is a dancer, recent college grad and an administrator for the CMTActive group.

THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS...

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Courtney Baros

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ACCORDING TO THE DICTIONARY, an innervator is a nerve stimulator. According to the CMTA, an Innervator is an action-oriented donor who gives monthly to the organization, sustaining STAR (Strategy to Accelerate Research), our premier research initiative, as well as important community initiatives like Camp Footprint, Patient/Family Conferences and educational programs. All of these programs require steady, reliable support from committed donors. Please join the Innervators today!

www.cmtausa.org/cmta-innervators

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BEFORE AND AFTER
Limb Amputation with CMT

BY DOMINICK CALSOLARO

IT'S A CLUB NO ONE WANTS TO JOIN.

Earlier this year, I had my left leg amputated below the knee (BKA) due to osteomyelitis in my left foot. I'm 68 and was diagnosed with CMT when I was 14. Genetic testing later confirmed CMT1A.

I've lived with a lot of pain in my left foot for the past few years, sometimes finding it almost impossible to walk or even stand. But I resisted having more surgeries on my left foot beyond the five I'd already had. A test result stating that an infection could be fatal was all I needed to make the decision to amputate my foot/lower leg. Since the surgery, I've had NO more pain.

Because information about the interaction between the surgery and my CMT was lacking, I'd like to share my own hard-earned lessons with those who will come after me. I wish I'd had time before the surgery to prepare my body and living space for the post-surgical world.

VALERIE HANKS, an occupational therapist in Nashville and member of the CMTA Advisory Board, agreed with Dominick about the importance of occupational therapy, saying he hit the nail dead on. "Don't be afraid to ask for OT if you need it. Your doctor may not realize you need PT *and* OT! Be proactive before surgery to get your upper body as strong as possible and definitely educate yourself about available adaptive equipment." She also agreed that energy conservation is key, and that prepping one's home for seated tasks is great advice. "Amputation is really a life-altering experience," she said.

Following the surgery and initial 10-day in-house rehab, I found that CMT directly affected my ability to prepare for living and functioning without a limb. Immediately following the surgery, my right leg was not strong enough to allow me to use a walker or crutches to get around. Worse, CMT affected my hands' ability to put on a "shrinker," which resembles a large compression sock and is needed to keep the swelling down in the residual limb and to prepare the leg for the prosthesis. Even after getting the prosthesis, the shrinker needs to be worn when the "new leg" is not being used.

Unlike other new amputees, I needed occupational therapy (OT) during my initial rehab stint to work on hand and arm strength. I continue to do daily OT exercises for my hands and arms. PT evaluation of my good leg's strength concluded that I could not safely use crutches or a walker to help me get around, even in the house. I couldn't return to my home of 36 years and moved into my sister's one-level apartment with wide hallways. I am now renting my own apartment with 36-inch-wide doorways and no stairs, thus increasing the economic burden of maintaining both my home and apartment. I spend about four hours a day on exercises to stretch and strengthen both my residual limb and good leg.

While I was waiting for my "new" leg, I continued to do PT and OT and wear the shrinker 24 hours a day. My prosthetic evaluation concluded that while my thigh muscles are pretty strong, I still needed a lighter prosthesis. My prosthetist thought I would have to use a walker for quite a while after getting my new leg to help me walk due to leg weakness and balance issues caused by CMT. In addition, hand weakness will affect my ability to put the "sleeve" on my residual limb before the prosthesis goes on. The hand weakness may also affect my ability to release the pin in order to remove the prosthesis. Thanks to CMT, I have no feeling below my knee, and I'll have to be extra vigilant in watching for skin breakdowns caused by the prosthesis.

I received my prosthetic leg at the end of April. For the first couple of weeks, I wore it a couple of hours a day until I could wear it for eight hours or longer. I got a "pin-type" prosthetic rather than the "suction" type and for the first couple of weeks, I used a walker when getting around on the "new" leg. After about four weeks, I was walking without a walker or a cane. The prosthetist was surprised that I was able to walk without aid. He thought that due to CMT, I would most likely have to use a walker for a few months, if not longer. I was very diligent in following the daily physical therapy routine I was given when I left Sunnyview Rehab Hospital in Schenectady, New York, and I think that doing the exercise program helped me to walk without a walker or cane sooner rather than later.

At the end of May, after five weeks with the prosthetic, I went back to Sunnyview for more in-patient PT and to learn the correct way to walk (I told the physical therapist that, due to CMT, I had never "walked the correct way!" —Ha ha). I was initially scheduled to be at Sunnyview for up to seven days, but I was doing well enough that I was released after two days. The post-stay PT evaluation recommended that I continuously work on balance and core strength. I didn't have good balance before I lost the lower left leg, so that is a life-long issue.

Currently, I am going twice a week to outpatient PT at Albany Medical Center's Rehab facility and following a new at-home PT exercise program designed to improve my balance and core strength. I started occupational therapy for my hands the first week of July to try to keep my hands/fingers from constricting/contracting more than they already have and to build up more strength in my upper arms. I also started driving again.

I'll most likely never move back to my house with its narrow hallways and bathroom and bedrooms upstairs because I need the wheelchair to go to the bathroom and get around the apartment when I am not wearing the prosthetic leg. Plus, if I have a skin breakdown and can't use the prosthetic leg for a few days, I will need the wheelchair to get around. And, due to my house being two floors (bathroom and bedrooms upstairs) and having narrow hallways and doorways, I would be unable to navigate the wheelchair inside the house. In addition, there is no room for a ramp to be constructed outside the house.

My best advice to anyone facing amputation of a limb is don't be afraid to reach out to a therapist. You will certainly be referred to physical therapy, but you may have to request occupational therapy if you need help in that area.

Dominick is a retired New York state employee and a former elected member of the City of Albany's Common Council. He lives in Albany, NY.

Facing the loss of a lower extremity can be frightening for anyone, but especially for someone with CMT. Here are some tips from an occupational therapist that might help you prepare if that time ever comes.

1 Look into adaptive equipment for dressing your remaining foot as you will have difficulty reaching down for a while.

2 You will likely need some sort of chair or bench to sit on in your shower. You will also need a handheld shower and a long-handled sponge to reach your foot.

3 Work on strengthening your upper body prior to surgery, particularly triceps and scapular depressors.

4 If you are a member of a gym, use the arm cycle to build your upper body's endurance and strength. If you have access to a pool, consider aerobic pool exercises to build up as much strength and endurance as possible.

5 Consider how you can implement energy conservation into the tasks you will need to complete, for example by taking breaks, prepping food and freezing it and gathering everything you need before starting a task.

6 Prepare your home so that you can complete tasks while sitting, as you may have to be in a wheelchair for a period of time if you are not able to "hop."

7 Familiarize yourself with mobility equipment that you may need after surgery like transfer boards, Hoyer lifts and leg lifters.

8 You will have a period of adjustment that can be very challenging so educate yourself about phantom limb pain, phantom limb syndrome and hypersensitivity. Knowledge is power!

SUPPORT THE CMTA IN THE FIGHT AGAINST THE PROGRESSIVE AND DEVASTATING EFFECTS OF CMT

YES! I want to support STAR Research with a donation in the amount of:

○ $3,500 ○ $1,000 ○ $500 ○ $250 ○ $100 ○ $50 ☐ Other: $__________

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Complete and mail to the CMTA, PO Box 105, Glenolden, PA 19036

While *Ask David* columnist David Tannenbaum will be missed forever, we are lucky enough to have another psychiatric professional on the CMTA Board of Advisors who also has lived experience with CMT. Elizabeth Misener, PhD, LMSW, picks up the baton with this issue.

ASK ELIZABETH

BY ELIZABETH MISENER,
CMTA Advisory Board Member

Elizabeth has been working with clients to alleviate depression and decrease anxiety for more than 18 years. Her passion is listening to her clients' stories and providing evidence-based tools to support them in their journeys with depression, anxiety, grief, suicidal thoughts, life transitions and everyday struggles. She has experience working with a range of individuals, including college students, seniors and adults facing life balance issues, as well as families dealing with disabilities. Elizabeth's 19-year-old-son Ethan and husband David, a board-certified prosthetist and orthotist who is also on the Board of Advisors, both have CMT 1B.

ASK ELIZABETH
A QUESTION AT:
info@cmtausa.org.

Dear Elizabeth,

What advice do you offer for someone with CMT who wants to build their emotional well-being?

Elizabeth Replies:

1. **Develop a support network:** Reach out to your local CMTA branch or join a virtual meeting with the CMTA. Connecting with others who understand your challenges can provide valuable emotional support and practical advice.
2. **Practice self-care:** Take care of your overall well-being by prioritizing self-care activities. This could include getting sufficient sleep, maintaining a balanced diet, and engaging in hobbies or activities that bring you joy, such as reading, painting, writing or any other thing that maybe you have not done in a few years.
3. **Talk to loved ones:** Openly communicate with your family and friends about your experiences. Sharing your feelings and challenges with trusted individuals can provide comfort and support.
4. **Gratitude Practice:** Keeping a gratitude journal or regularly expressing gratitude has been shown to enhance well-being and increase happiness. This involves either writing down or thinking of things you are thankful for, which helps shift focus towards the positive aspects of life.

Here are some ideas to get you started on how to focus on building a gratitude habit (just like brushing your teeth). You can focus on different aspects of your life and foster a deeper sense of appreciation:

- Three things I am grateful for today are (a good cup of coffee, my dog and the rain.)
- Describe a moment today that made you smile or feel happy.
- What are some small acts of kindness you received or witnessed today?
- Write about someone in your life who you are grateful for and why. Then share it and make someone else's day brighter.
- Reflect on a challenge you faced today and find something positive, or a lesson learned from it.
- List three things in nature you are thankful for and why.
- What are some accomplishments or progress you made recently that you're grateful for?
- Write about a happy memory that you cherish.
- Describe a positive interaction you had with a friend, family member or colleague today.
- What is something you have that brings you comfort and gratitude?

Feel free to adapt these prompts or create your own. The goal is to encourage a regular practice of focusing on the positive aspects of your life, fostering a grateful mindset and reaping the benefits of gratitude in your overall well-being to balance the frustrations that come with CMT.

Kayden (center) with her uncle Michael and her maternal grandparents, Gigi and Jim.

Friend, *a Poem*

When proud grandpa Jim Stetor sent us his granddaughter Kayden's award-winning poem about living with CMT, we knew that other kids with CMT would recognize themselves in it.

After years of tests Kayden, now 13, was diagnosed with a de novo case of CMT1E. As an infant, she missed several developmental motor milestones and wasn't able to walk on her own. She had a tethered cord release surgery, but it didn't fix her motor delays. Kayden was finally able to walk with AFOs and a pediatric walker at the age of 2. She loved her new-found freedom and occasionally scared her grandparents by lifting her feet up when going down a ramp.

Like other kids with CMT, Kayden gets frustrated at times, but for most part accepts her condition. She is a very good student and has friends who accept her the way she is. Most recently, she was a vocalist in her middle school play, using her walker to move around. Her grandfather says she is a typical teen, and enjoys sleeping, using makeup and getting on social media.

Friend

By Kayden

At the age of three
I was diagnosed with CMT.
A disease that made me unable to walk.
It has never prevented me from being able to talk.

Not being able to play soccer or ride a bike
Not being able to kick a spike.

Feeling left out all the time
I give up trying overtime.

Then about three years ago
Three friends made my happiness overflow.
They helped me find my rainbow.
And finally, my sadness let go
Friends are here, friends are there,
And friends are everywhere.

"I'm unique" I say out loud
And I could not ever be more proud.

I am me you are you
I can do everything you can do.

Do Shoes Make the Wo(Man)?

BY DUSTIN TURNER

Does wearing something other than a dress shoe in a space of power signal that a person is not worthy of honor or respect? A recent New York Times article titled “Do Dress Sneakers Belong in the Oval Office?” made it clear that the writer believed the members of Congressional leadership who wore dress sneakers to a meeting at the White House debased themselves and the Office of the President.

While on its face this article is about powerful able-bodied men, it is also about people all over the United States and around the world who cannot wear dress shoes due to a range of walking disorders caused by a variety of neurological and musculoskeletal disorders, including the 2.6 million people worldwide who have CMT. I am one of those people. Like others with neurological and musculoskeletal disorders, every day I put on casual shoes and orthoses so I can move through the world on more stable footing. For me and others like me, this article is just one of many messages that say we are not welcome or equal.

> What is fashion for? Is it to exclude people based on a rigid hierarchy that attaches professional acumen or moral attributes like courtesy and good manners to footwear? Or could it be to help everyone look their best?

People with physical disabilities have the same range of moral character, wit, intelligence and ambition as the rest of the human population. We have professional and social interests that place us in the same formal settings at the same frequency as everyone else. We are acutely aware when we sign up for a professional conference, book a meeting with a customer or investor, or RSVP for a wedding that we are going to stick out in those spaces.

We are also aware that first impressions matter and that many people will believe that we lack “courtesy and good manners” simply because of the footwear or other physical accommodations we require to navigate life safely. It is unfortunate that millions of people are marginalized for their inability to conform to a dress code that has no correlation to all that they have to offer this world.

What is fashion for? Is it to exclude people based on a rigid hierarchy that attaches professional acumen or moral attributes like courtesy and good manners to footwear? Or could it be to help everyone look their best? What would the world look like if we all decided that people should be judged based on the content of their character rather than their shoes? I would love to find out.

Dustin Turner is a CPA with Cullinan Oncology in Cambridge, Massachusetts.

SUPPORT THE CMTA AND HONOR A LOVED ONE WITH AN IN HONOR/IN MEMORY GIFT

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MY JOURNEY TO COPENHAGEN

BY BOB CHRISTENSEN

This past summer, I had the unique privilege of attending a full-day CMTA-STAR Advisory Board meeting, held during the Peripheral Nerve Society’s annual meeting in Copenhagen, Denmark. My takeaway from the experience: We are in good hands with this bunch, and they deserve our support.

You may ask, how was I fortunate enough to go to Copenhagen? I have CMT1X and took part in the CMT biomarkers and outcome measures study at the University of Pennsylvania in Philadelphia. My neurologist, Dr. Steven Scherer, led a branch of the study. I have been his patient for the better part of 30 years and have always appreciated his candor with me and his interest in CMT. During a visit in February, I mentioned to him my desire to visit northern Denmark, my father’s childhood home. Dr. Scherer mentioned he would be in Copenhagen for the CMTA-STAR Advisory Board meeting. We put two and two together, and I began planning my trip, obtaining the CMTA’s permission and signing nondisclosure agreements.

Bob (far left, third row from front) with members of the CMTA-STAR Advisory Board

Above: **Sunset at Stenbjerg Landingsplads National Park, Jutland, Denmark, taken by the author.**

At a dinner the night before the meeting, I was unsure how the evening would develop. I am neither a physician nor a scientist and was a little intimidated by the clinicians and investigators who were my dinner companions. Could I keep up? Would I have anything interesting to say?

Those fears were quickly put to rest. While some discussions were well over my head, most of the other attendees took the time to learn about me and to explain their work in terms I could understand. I was immediately impressed by their contagious enthusiasm about their work. Formal presentations followed the next day, but that night I listened to them talk about the importance of their work, share informal thoughts, laugh and speak of a more hopeful future.

The next day, John Svaren, PhD, chair of the CMTA-STAR Advisory Board, made opening remarks, followed by 12 presentations, each followed by a brief Q&A session. The pace was quick, the content was deep and the discussions were serious. After roughly eight hours the meeting was adjourned.

As a patient, I walked away feeling lucky—lucky to have witnessed some of the work being done across the CMT spectrum and lucky to meet those physicians, researchers and board members who are spending their careers caring for patients with CMT and pushing to find treatments. They get it, and yes, a few of them have CMT, too. They are as motivated as you and me and for that I am very grateful.

At the closing dinner, I assumed that everyone would be tired, but I was wrong. Once again, the evening was filled with good food, laughter and some great conversation, never straying far from the reason that brought us all together.

The next morning found me in my car heading to Thyholm in northern Denmark (Jutland). I visited the room where my father was born (in a church rectory) and two farms he grew up on before coming to the United States. Prior to my trip I had worked with local historians on my family history, going back five generations. I spent my final evening at the Stenbjerg Landingsplads National Park on the North Sea experiencing the latest sunset I had ever seen (10:24 p.m.). Needless to say, I’ll be back soon.

Bob Christensen is a CMTA community member from Princeton, New Jersey and organizer of this year’s Cycle4CMT in Lambertville, New Jersey.

BRANCH NOTES

SAN FRANCISCO, CA

The San Francisco Branch welcomed guest speaker Carly Siskind, a board-certified genetic counselor and a member of the CMTA Advisory Board, to its meeting June 24. Carly led a discussion about genetic testing, the various testing options, prenatal planning and much more. Members also shared their personal CMT stories and socialized.


Hartford Branch

HARTFORD, CT

The Hartford Branch hosted its first in-person branch meeting May 6. Guest speaker Allison Fell, OTR/L, shared recommendations for improving independence and function. Members also discussed useful CMT gadgets and practical advice.

WASHINGTON, DC

The Washington DC Branch met virtually in May to discuss "Life Hacks for Living with CMT." Members shared practical activities for those living with CMT. Washington DC branch leader Steve Weiss also left time for branch members to share their CMT journeys and socialize.

JACKSONVILLE, FL

The Jacksonville branch gathered in person on June 17 to welcome guest speaker Amanda Lazo, OT, who shared practical advice for those living with CMT. The branch also discussed possible fundraising efforts and quarterly meeting dates planned for the remainder of the year.

CHICAGO, IL

Eight members of the Chicago branch met virtually on June 20, sharing their CMT journeys, local resources, their Walk 4 CMT and research updates. The Chicago branch meets monthly.

MINNEAPOLIS, MN

The CMT community of Minneapolis had a meaningful weekend making connections in May. The weekend kicked off Friday evening with a Conversations & Cocktails reception that provided an opportunity for community members to come together and strengthen their connections. Dr. Michael Shy, director of the CMTA Center of Excellence at the University of Iowa, and Dr. David Walk of the University of Minnesota Health Neurology Clinic were guests of honor. Other guests included Minneapolis walk leaders Lynn Anne Groebner and Angela Christensen and longtime CMTA supporters Robert and Gail Buuck. Dr. Shy, Dr. Walk and Jeana Sweeny, the CMTA's chief engagement and gifts officer, all spoke about the importance and strength of the CMT community. The Hyland Lake Park Reserve provided a picture-perfect setting for the Minneapolis Walk 4 CMT the following day. It was a beautiful setting for community members enjoy the outdoors while talking to each other.

NEW MEXICO

Six members of the New Mexico Branch welcomed guest speaker Jeana Sweeney to their meeting May 6. She gave a highly informative update on CMTA-sponsored research. After Jeana's presentation, the group had a brief discussion about coping with various situations such as airport TSA, going to theaters, restaurants, and more. Everyone shared their experiences, asked questions and shared personal updates with the group.


Wilmington NC Branch

RESEARCH TRIANGLE AREA, NC

The Research Triangle Area Branch met in person on May 6 with 16 members in attendance, including four first-timers. Guest speaker Rebecca Bryant, P.T., D.P.T., from the UNC Center of Excellence, spoke on "Exercise and Stretching to Maximize Functioning in CMT." Rebecca demonstrated several exercises and stretches, and provided handouts. The meeting concluded with a discussion on fundraising options, a pizza lunch and socializing.

WILMINGTON, NC

The Wilmington, NC CMTA Branch held its first in person meeting since COVID on Saturday, June 3 with 11 people in attendance. They spent time welcoming several new members, hearing everyone's CMT journey, and sharing local and regional resources. A few people talked about their positive experience at the CMTA Center of Excellence at Chapel Hill with Dr. Traub. One member shared their recent CMT surgical story. It was wonderful to connect in person again!

STATE COLLEGE, PA

Board member and CMT patient advocate Elizabeth Ouellette was the guest speaker at the June 26 State College Branch meeting (virtual). She shared her story and work as a life coach. She talked about emotional wellness and managing stress. She also shared some exercises with the group that may help them manage anxiety and stress. The State College branch will continue to meet regularly throughout the year.

EDMONTON, AB, CANADA

The Edmonton, AB, Canada Branch met for its inaugural meeting June 1 with new branch leader Victoria Berezovich. The attendees then introduced themselves and shared their connection to CMT. They discussed the goals of the Edmonton branch and plans for future branch meetings. It was a successful first meeting. The Edmonton Branch is excited about the newfound community in Canada.

Angel Flight NE Offers CMT Patients Free Flights for Medical Care

Angel Flight NE, a nonprofit that coordinates free air and ground transportation for medically stable patients seeking medical care, is encouraging patients with CMT to make use of its services.

Angel Flight NE was founded by Fr. Larry Camerlin, an avid pilot and priest who dedicated his professional career to the healthcare field. Recognizing that patients with rare and ultra-rare diseases sometimes have to travel hundreds if not thousands of miles for the specialized care they need, he began flight operations in May 1996 with donated office space and 10 volunteer pilots. To date, the nonprofit has flown more than 108,000 patients more than 15 million miles to 750+ medical facilities throughout the United States.

Now located at the Lawrence Municipal Airport in North Andover, Massachusetts, Angel Flight NE works with more than 450 volunteer pilots, JetBlue, Cape Air and hundreds of earth angels /ground crew members to coordinate flights for thousands of patients annually.

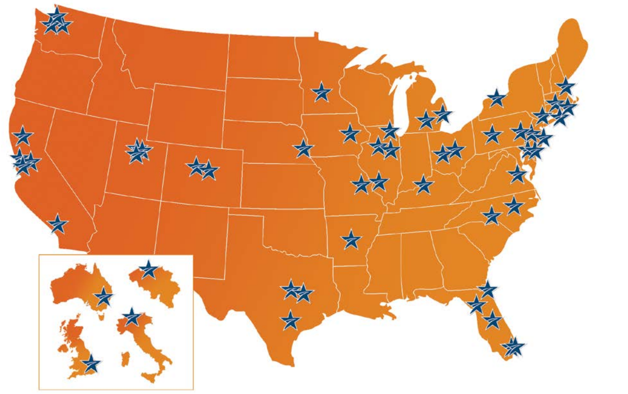
Recently, the nonprofit has received increasing flight requests and started an initiative to reach out to rare disease organizations and groups like the CMTA to let them know about its services.

For more information, visit www.angelflightne.org.

CMTA CENTERS OF EXCELLENCE

One of the CMTA's primary missions is improving the quality of life for those with CMT and one way we accomplish this mission is by sponsoring patient-centric, multi-disciplinary CMT clinics, staffed by some of the highest quality CMT clinicians and researchers in the world. Through these CMTA Centers of Excellence, children, adults and families affected by CMT can be assured of receiving comprehensive care by a team of CMT experts.

Although all the Centers of Excellence listed below include multi-disciplinary teams of CMT specialists, the CMTA's Centers of Excellence affiliated with the Inherited Neuropathy Consortium or INC (marked with an asterisk), go a step further by collecting and recording genetic, biologic and other data from people with the disease.



ARKANSAS

LITTLE ROCK (PEDIATRIC)
Arkansas Children's Hospital
Clinical Director:
Aravindhan Veerapandiyan, MD
Appts: 501-364-1850

CALIFORNIA

LOS ANGELES (ADULT & PEDIATRIC)
Cedars-Sinai Medical Center
Clinical Director: Richard A. Lewis, MD
Appts: 310-423-4268

PALO ALTO (PEDIATRIC)
Stanford Children's Health*
Clinical Directors: John Day, MD, PhD, and Ana Tesi Rocha, MD
Appts: 650-723-0993

PALO ALTO (ADULT)
Stanford Neuromuscular Program*
Clinical Director: John Day, MD, PhD
Appts: 650-723-6469

SAN FRANCISCO (ADULT)
University of California, San Francisco
Clinical Director: Mark Terrelonge, MD
Appts: 415-353-2273

SAN FRANCISCO (PEDIATRIC)
University of California, San Francisco
Clinical Director: Alex Fay, MD, PhD
Appts: 415-353-7596

COLORADO

AURORA (ADULT)
University of Colorado*
Clinical Director: Vera Fridman, MD
Appts: 720-848-2080

AURORA (PEDIATRIC)
Children's Hospital Colorado
Clinical Director: Michele Yang, MD
Appts: Alison Ballard, 720-777-3907

CONNECTICUT

FARMINGTON (PEDIATRIC)
Connecticut Children's Medical Center, Farmington*
Clinical Director: Gyula Acsadi, MD, PhD
Appts: Nanci Stolgitis, RN, 860-837-7500

NEW BRITAIN (ADULT & PEDIATRIC)
Hospital for Special Care
Clinical Director: Kevin J. Felice, DO
Appts: Sharon McDermott, 860-612-6305

NEW HAVEN (ADULT)
Yale School of Medicine
Clinical Director: Sasha Zivkovic, MD
Appts: 203-785-4085

FLORIDA

ORLANDO (PEDIATRIC)
Nemours Children's Hospital*
Clinical Director:
Omer Abdul Hamid, MD
Appts: 407-650-7715

GAINESVILLE (ADULT & PEDIATRIC)
University of Florida
Clinical Director:
James Wymer, MD, PhD
Appts: 352-294-5400

JACKSONVILLE (ADULT)
Mayo Clinic Florida
Clinical Director: Christopher Lamb, MD
Appts: 904-953-0853

FLORIDA (CONT.)

MIAMI (ADULT)
University of Miami*
Clinical Director: Mario Saporta, MD
Appts: 305-243-9173

MIAMI (PEDIATRIC)
Nicklaus Children's Hospital
Clinical Director: Migvis Monduy, MD
Appts: 786-624-2154

ILLINOIS

CHICAGO (ADULT & PEDIATRIC)
Northwestern Memorial Hospital
Clinical Director: Daniela Maria Menichella, MD, PhD
Appts: 312-695-7950

University of Illinois at Chicago
Clinical Director:
Charles K. Abrams, MD, PhD
Appts: 312-996-4780

Rush University
Clinical Director: Ryan D. Jacobson, MD
Appts: Sherri Taylor-Kennedy, 312-942-4500

O'FALLON (ADULT AND PEDIATRIC)
HSHS St. Elizabeth's Hospital
Clinical Director:
Raghav Govindarajan, MD
Appts: 618-641-5803

IOWA

IOWA CITY (ADULT & PEDIATRIC)
University of Iowa Hospitals & Clinics*
Clinical Director: Michael E. Shy, MD
Appts: 319-384-6362

KENTUCKY

LOUISVILLE (ADULT)
University of Louisville
Clinical Director:
Zeng Y. Wang, MD, PhD
Appts: Anson Ashburn, 502-588-4800

MARYLAND

BALTIMORE (ADULT & PEDIATRIC)
Johns Hopkins University*
Clinical Directors:
Charlotte Sumner, MD and
Bipasha Mukherjee-Clavin, MD, PhD
Appts: (Adult) 410-614-1196, (Pediatric) 410-955-4259

MASSACHUSETTS

BOSTON (ADULT & PEDIATRIC)
Massachusetts General Hospital*
Clinical Director:
Reza Seyedsadjadi, MD
Appts: Tamika Scott, 617-726-3642

MICHIGAN

DETROIT (ADULT)
Wayne State University School of Medicine and Detroit Medical Center*
Clinical Director: Ryan Castoro, MD
Appts: 313-745-3000

ANN ARBOR (ADULT & PEDIATRIC)
University of Michigan
Clinical Director: Gary Gallagher, MD
Appts: 734-936-9020

MINNESOTA

MAPLE GROVE (ADULT)
University of Minnesota*
Clinical Director: David Walk, MD
Appts: 763-898-1000

MISSOURI

ST. LOUIS (ADULT & PEDIATRIC)
Washington University School of Medicine
Clinical Director: Stefanie Geisler, MD
Appts: 314-362-6981

NEBRASKA

OMAHA (ADULT)
Chi Health Clinic Neurology Institute
Clinical Director: Yu-Ting Chen, MD
Appts: 402-717-0070

NEW JERSEY

HACKENSACK (ADULT & PEDIATRIC)
Hackensack University Medical Center
Clinical Director:
Florian Thomas, MD, PhD
Appts: Annerys Santos, 551-996-1324

NEW YORK

ROCHESTER (ADULT & PEDIATRIC)
University of Rochester*
Clinical Director: David Herrmann, MD
Appts: 585-275-2559

NORTH CAROLINA

CHAPEL HILL (ADULT & PEDIATRIC)
University of North Carolina*
Clinical Director: Rebecca Traub, MD
Appts: 984-974-4401

CHARLOTTE (ADULT & PEDIATRIC)
Atrium Health Neurosciences Institute
Clinical Director: Urvi Desai, MD
Appts: 704-446-1900

OHIO

COLUMBUS (ADULT & PEDIATRIC)
Nationwide Children's Hospital
Clinical Director:
Zarife Sahenk, MD, PhD
Appts: 614-722-2203

COLUMBUS (ADULT & PEDIATRIC)
Ohio State University, Wexner Medical Center*
Clinical Director:
Clinical Director: Michael Isfort, MD
Appts: 614-293-4969

PENNSYLVANIA

PHILADELPHIA (ADULT)
Hospital of the University of Pennsylvania*
Clinical Director:
Steven Scherer, MD, PhD
Scheduling for Clinic Visits:
Shana Millner, 215-662-3606
Scheduling for Research Visits:
Pooja Patel, 215-898-0180

PHILADELPHIA (PEDIATRIC)
Hospital of the University of Pennsylvania*
Clinical Director: Sabrina Yum, MD
Appts: Hannah Borger, 215-590-1719

PITTSBURGH (PEDIATRIC)
Children's Hospital of Pittsburgh
Clinical Director:
Hodas Abdel-Hamid, MD
Appts: 412-692-6106

TEXAS

AUSTIN (ADULT)
Austin Neuromuscular Center
Clinical Director: Yessar Hussain, MD
Appts: 512-920-0140

DALLAS (PEDIATRIC)
University of Texas Southwestern
Clinical Director: Kaitlin Batley, MD
Appts: 214-456-2768

BEDFORD (ADULT 16+)
Kane Hall Barry Neurology
Clinical Director:
Sharique Ansari, MD, MPH
Appts: 817-267-6290, option 4

HOUSTON (ADULT)
Houston Methodist Hospital
Clinical Director: Jun Li, MD
Appts: 713-441-3763

UTAH

SALT LAKE CITY (ADULT & PEDIATRIC)
University of Utah*
Clinical Director:
Russell Butterfield, MD, PhD
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SALT LAKE CITY (PEDIATRIC)
Primary Children's Hospital
Clinical Director:
Russell Butterfield, MD, PhD
Appts: 801-213-7756

SALT LAKE CITY (PEDIATRIC)
Shriner's Hospital
Clinical Director:
Russell Butterfield, MD, PhD
Appts: 801-536-3564

WASHINGTON

SEATTLE (ADULT)
University of Washington Medical Center*
Clinical Director: Michael Weiss, MD
Appts: Gail Schessler, 206-598-7688

SEATTLE (ADULT)
Swedish Neuroscience Institute
Clinical Director:
Christyn Edmundson, MD
Appts: 206-320-3494

SEATTLE (PEDIATRIC)
Seattle Children's Hospital
Clinical Director: Seth Perlman, MD
Appts: Kara Smith, BSN, 206-987-6678

WASHINGTON, DC

(ADULT)
Medstar Georgetown University
Clinical Director: Nicholas Streicher, MD
Appts: 202-444-1774

(PEDIATRIC TO AGE 21)
Children's National Hospital
Clinical Director:
Diana Bharucha-Goebel, MD
Appts: Kathleen Smart, 202-476-6193

INTERNATIONAL LOCATIONS:

AUSTRALIA

WESTMEAD (PEDIATRIC)
The Children's Hospital at Westmead*
Clinical Director: Manoj Menezes, MD
Research Director: Joshua Burns, PhD
Appts: (02) 98451325
daralyn.hodgson@health.nsw.gov.au

BELGIUM

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Antwerp University Hospital
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ENGLAND

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University College London Hospitals*
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ITALY

MILAN (ADULT & PEDIATRIC)
C. Besta Neurological Institute*
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*** Denotes the CMTA Centers of Excellence that are included in the National Institutes of Health Inherited Neuropathy Consortium (INC). The INC is co-sponsored by the CMTA and the Muscular Dystrophy Association. Worldwide more than 10,000 patients with CMT have been enrolled in protocols, and their data, de-identified to protect patient privacy, is housed in a common repository. As a result of this collaboration, a new CMT evaluation scale for children has been established, along with a new evaluation system for adults, and an infrastructure has been developed to perform natural history studies and clinical trials for CMT.**

CMTA BRANCHES

ALL CMTA BRANCHES CAN BE ACCESSED ONLINE AT www.cmtausa.org/branches

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Phoenix Area
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HAWAII
Honolulu Area
Monica Rocabado
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IOWA
Iowa City Area
Jeffrey Megown
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Doreen Pomykala
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INDIANA
Fort Wayne Area
Aimee Trammell
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Indianapolis Area
Leader Needed—Call:
800-606-2682

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Aron Taylor
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St. Louis Area
Payton Rule
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Amanda Rule
618-698-3039

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Durham Area
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Wilmington Area
Laurel Richardson
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Central New Jersey
Mark Willis
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Albuquerque Area
Gary Shepherd
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WHAT IS **CMT?**

More than 3 million people worldwide have CMT. It is one of the most commonly inherited nerve disorders and affects the motor and sensory nerves.

CMT is slowly progressive, causing the loss of muscle function and/or sensation in the lower legs and feet, as well as hands and arms.

People in **all ethnic groups may be affected by CMT.**

CMT is genetic, but it can also develop as a new, spontaneous mutation.

CMT can vary greatly in severity, even within the same family.

CMT causes structural deformities such as high-arched or very flat feet, hammertoes, hand contractures, scoliosis (spinal curvature) and kyphosis (rounded back).

CMT can also cause foot drop, poor balance, cold extremities, cramps, nerve, muscle and joint pain, altered reflexes, fatigue, tremor, sleep apnea, hearing loss and breathing difficulties.

CMT rarely affects life expectancy.

Some medications are neurotoxic and pose a high risk to people with CMT, notably vincristine and paclitaxel.

More than 100 different genetic causes of CMT have been identified.

Many types of CMT can be determined by genetic testing. Please consult with a genetic counselor (www.nsgc.org) or your physician for more information.

Although there are no drug treatments for CMT, a healthy diet, moderate exercise, physical and/or occupational therapy, leg braces or orthopedic surgery may help maintain mobility and function.

The CMTA-STAR research program and extensive partnerships with pharmaceutical companies are driving remarkable progress toward delivering treatments for CMT, bringing us closer to a world without CMT.

Donating to
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