FALL 2024

THE CMTA REPORT

Charcot-Marie-Tooth Association

cmtausa.org

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CAMP FOOTPRINT EAST—AUGUST 2024

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THE POWER OF COMMUNITY

LIVING WITH CMT

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CMTA
Charcot-Marie-Tooth Association

Dear CMT Community,

A LETTER FROM SUE, OUR CEO

As we reflect on the progress we've made and the challenges that lie ahead, I'm reminded of how our collective strength continues to bring help for today and hope for tomorrow to everyone affected by CMT. Together, we are building a community that supports, empowers, and inspires each of us—whether through research breakthroughs or the vital connections made when we come together.

This issue highlights the incredible spirit of resilience and progress within our CMTA family. Whether through groundbreaking research, the life-changing experiences at Camp Footprint, or the remarkable support at our CMTA Patient and Research Summit, we are reminded that we are stronger together. Every story is a testament to what can be achieved when people unite with purpose and passion.

The power of connection and community was on full display at the Summit. With more than 450 attendees, both in-person and virtual, and countless moments of shared learning, the Summit provided updates on cutting-edge research that benefits everybody living with CMT and offered a space for members of our community to come together and build lasting relationships. The Summit reflected our goal to provide help for today through practical tools and resources to manage CMT while offering hope for tomorrow by accelerating research that benefits all community members.

Camp Footprint continues to be a transformative experience for young people with CMT. This summer, campers embraced leadership roles, formed deep friendships, and found strength in being their true selves, surrounded by others who understand their journey. It's an amazing example of how community programs can foster confidence while nurturing the next generation of CMT leaders—bringing hope for tomorrow with every connection made.

At CMTA, we remain focused on accelerating research, empowering patients, and fostering the next generation —whether young campers making lifelong connections, young adults stepping into community leadership through our COMPASS program, or pioneering scientists driving treatments for CMT. Our progress in developing new therapies, from ongoing work in gene therapy to clinical trial readiness, brings us closer to a world where every individual living with CMT can access life-changing treatments.

As we look ahead, I'm filled with gratitude for the continued support of each and every one of you. Your dedication—whether through volunteering, participating in research, or raising awareness—drives us forward. The road to a cure may be long, but with your help, it is becoming shorter, and together, we will see a future where hope becomes reality.

With gratitude,

Suzanne L Bruhn

Sue Bruhn, PhD
CMTA CEO

A LIFE-CHANGING SUMMER AT CAMP FOOTPRINT 2024: BUILDING COMMUNITY AND FOSTERING LEADERS

Camp Footprint reached new heights in 2024, offering a transformative experience for 152 campers across two coasts—71 in the West (Oregon) and 81 in the East (Pennsylvania). Supported by 135 dedicated counselors and program staff across both Camps, Camp Footprint continued to serve as a life-changing experience for campers and camp staff alike. For many, it was their first time meeting others with CMT, as 30 new campers joined the Camp Footprint family this summer.

A Space for Life-Changing Connection and Impact

Celebrating its ninth year as the only sleep-away camp in the US exclusively for kids with CMT, Camp Footprint offers more than just a week of fun—it's an inspirational experience where campers can be their authentic selves, often for the first time. CMTA National Youth Programs Manager and Camp Footprint Director Jonah Berger captured the impact perfectly: "I watch firsthand every year how being around those who understand CMT has an unbelievable impact on the campers and staff that can only be defined as life-changing. The inclusive environment allows campers to shed the weight of feeling different, replacing it with a deep sense of community."

This year's Olympic-themed events fueled friendly competition and teamwork while fostering unity. The camp's lasting impact extends far beyond the week itself, with many campers continuing the friendships and connections they forged long after the campfires have faded.

Fostering the Next Generation of CMTA Leaders

At Camp Footprint, leadership isn't just encouraged—it's lived. This year, 34 counselors (13 in the West and 21 in the East) returned to camp not as campers but as leaders, having once stood in those very shoes. The progression from camper to counselor embodies the program's profound and lasting influence. As former camper Merry Wayman reflected, whose first camp experience was in 2016 when she was just 11 years old, "Helping campers grow and gain the same confidence I did has been one of the most fulfilling aspects of my journey with Camp Footprint." Standing shoulder to shoulder with her fellow counselors, Merry's eyes sparkled with the recognition of the impact she now makes on others.

Sam Docker's journey followed a similar arc. He said, "Choosing to become a counselor for Camp Footprint was one of the best decisions of my life." Sam's voice carried the weight of his experiences as he stood before a new group of campers, guiding them through the same moments of realization and acceptance that once shaped his own time at camp.

Meredith Wayman (left) with Meghan McClung

Sam Docker

Adam Palermo

Merry Wayman, Sam Docker and Adam Palermo were three of 34 former campers who returned to Camp Footprint this year as counselors.

The ripple effect of leadership at Camp Footprint reaches far beyond the campgrounds. Laurel Richardson, who once laughed and learned among the campers, now directs CMTA's Community Outreach. And, Katherine Forsey, PhD, CMTA's Chief Research Officer, started her journey with Camp Footprint as a counselor, her passion for the camp experience igniting a career in advocacy and CMTA leadership.

Camp Footprint nurtures leadership, with many counselors and program staff starting as campers—a powerful cycle of mentorship and empowerment. The camp provides more than just a week of connection; it cultivates future CMTA leaders committed to supporting the CMT community and CMTA's mission. Year after year, the bonds formed here continue to drive progress, ensuring the next generation of leaders is ready to carry the mission forward.

First-Timers: Fresh Faces and New Energy

Camp Footprint also welcomed 24 first-time camp staff members (15 in the West and 9 in the East), who brought fresh energy and enthusiasm. This year was the first time CMTA CEO Sue Bruhn and CMTA Director of Marketing Chris Cosentino attended camp, having recently joined the organization. Their experiences offered new perspectives and further appreciation for the program's impact.

Reflecting on his first camp, Chris shared, "For the first time in their lives, the campers didn't have to explain their situation or feel isolated or different—everyone understands what they're going through." Sue reflected on her experience, noting, "Witnessing firsthand the energy, confidence, and camaraderie that Camp Footprint fosters was truly inspiring. These kids are not just campers but future leaders shaping the CMT community."

Strengthening Bonds: The Power of Partnership

This year, Camp Footprint welcomed a special addition to its volunteer counselor team at Camp Footprint East. Dan Brennan, Senior Vice President at CMTA-STAR Alliance Partner NMD Pharma, volunteered as a camp counselor for the first time. His decision to engage directly with the campers illustrates the deep commitment shared by CMTA-STAR Alliance Partners. Dan's participation highlights Camp Footprint's unique impact, extending beyond the campgrounds to all sectors of the CMTA community.

Dan's experience reinforced the power of personal connections and shared experiences of Camp Footprint. His willingness to step into the role of counselor, guiding and inspiring the next generation of campers and leaders, speaks volumes about the strength of the CMTA-STAR Alliance Partnership. These partnerships not only accelerate CMT research but also foster an environment where youth living with CMT are empowered to thrive and grow into future leaders.

NMD Pharma Senior Vice President Dan Brennan (Center, Yellow Hat) volunteered as a camp counselor at Camp Footprint East.

Community in Action: Bringing Adaptive Archery to Camp Footprint

One of the standout activities at Camp Footprint is adaptive archery, ensuring that every camper can fully experience the thrill and sport of archery, regardless of their level of hand strength or dexterity. Adaptive archery has been a part of Camp Footprint since its early days, made possible by the generosity and expertise of community members like Scott Meshew, a former product representative from Ten Points Crossbow Technologies, and Bass Pro Shops, who donated the specialized equipment.

continued on page 4

CEO Sue Bruhn with a first-time camper

CAMP FOOTPRINT 2024

continued from page 3

Adaptive archery at Camp Footprint ensures that every camper can participate in this fun activity.

Thanks to a grant from Bass Pro Shops, Camp Footprint received Wicked Ridge M-370 crossbows with AccuDraw, BOG tripods, and other essential gear, allowing even campers with severe CMT to participate. The community's dedication—from the donations of Big Shot Targets to the efforts of camp parents who helped deliver the equipment—reflects the spirit of Camp Footprint: ensuring every camper gets to do every activity and that no camper is left out.

Building Bridges: Applied Therapeutics and Their Commitment to the CMT Community

As a CMTA-STAR Alliance Partner Applied Therapeutics has long supported CMTA's mission to drive progress for those living with CMT. That support extends beyond research and sponsorship, with Senior Vice President Dottie Caplan and Peter Loupas visiting Camp Footprint East for two days. During their time at camp, they engaged directly with campers, listening to their stories and ensuring that each camper knew how important they are to the broader efforts to find treatments for CMT.

The visit by Applied Therapeutics highlights the meaningful relationships the CMTA-STAR program nurtures—not just in the lab but on a personal level. By spending time with the campers, Dottie and Peter reinforced that every person in the CMT community plays a crucial role in driving progress and that the work is about more than just science—it's about people. Their time at camp was a powerful reminder of the shared commitment between CMTA-STAR Alliance Partners and the CMT community to create a brighter future for all those affected by CMT.

CMTA Board of Directors: Connecting and Celebrating with Campers

Camp Footprint East welcomed CMTA's Board of Directors for a morning of fun and connection. Their visit wasn't just ceremonial—board members jumped into the fun, spending meaningful time with the campers and participating in various activities. From arts and crafts to chair dancing, water balloon fights, and the famed powder battle, they experienced the joy and camaraderie that make Camp Footprint so special.

Board Members took the time to listen to the campers' stories, engage in playful moments, and witness the powerful connections that formed during the week. Their involvement highlighted the CMTA Board's dedication to understanding the personal experiences of those living with CMT. By joining in these activities, the Board reaffirmed their commitment to ensuring programs like Camp Footprint continue to empower youth with CMT to build confidence, foster lifelong friendships, and shape the future of CMT community leadership.

Looking Forward: Celebrating Nine Years of Camp Footprint

As Camp Footprint concludes its ninth year, the focus shifts toward its milestone tenth anniversary in 2025. Registration for next year opens on January 5th, and the CMT community eagerly anticipates another year of magic, connection, and growth. CMTA CEO Sue Bruhn captured the impact of the camp experience, sharing, "I could not be more proud of what this program delivers to the community and for these kids who I watched grow in confidence and make lifelong friends throughout the week—they are absolutely the future leaders of the CMT community."

The foam cannon at Camp Footprint East was an enormous hit!

A Special Thank You To Our Sponsors

Camp Footprint's success is due to the tireless efforts of its staff, volunteers, and the unwavering support of our community. We also extend our heartfelt thanks to our sponsors for making this program possible. Their generosity allows us to continue offering this life-changing experience to campers year after year.

APPLIED THERAPEUTICS

CMTA Launches #LetsBeatCMT Initiative During CMT Awareness Month

CMTA turned up the global volume on CMT awareness by launching the successful #LetsBeatCMT campaign during CMT Awareness Month in September. The social media initiative acquired unprecedented engagement, featuring daily videos, family stories, photos, and infographics discussing CMT's impact on individuals and their families.

#LetsBeatCMT allowed community members to share their personal experiences on how they adapt to life with CMT and why getting involved in CMTA programs is vital to improving the lives of everyone impacted by CMT. The initiative brought the global CMT community together and received support from well-known personalities such as Adam Zucker (CBS Sports) and Emmy Award-winning writer/producer Danny Zuker (*Modern Family*).

Follow the campaign on social media and CMTA's YouTube Channel: youtube.com/@CMTAssociation

KNOW THAT YOUR DONATIONS ARE BEING USED WISELY. Charity Navigator awarded us its highest 4-star rating and a Perfect 100 score based on our exceeding industry standards and outperforming other organizations that do similar work. It's a distinction enjoyed by less than 1 percent of the nonprofits rated by Charity Navigator.

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HELP FOR TODAY AND HOPE FOR TOMORROW

The 2024 CMTA Patient and Research Summit in Colorado was a remarkable gathering of more than 450 attendees—both in person and virtually—making it one of the largest CMTA Summits to date. Held from September 6-8 in Denver, the event welcomed participants from across the US, six other countries, and virtual attendees from 10 countries, with over 60% attending for the first time.

CMTA CEO Sue Bruhn, PhD, captured the essence of the weekend: "The CMTA Patient and Research Summit embodied our core focus to provide **Help for Today and Hope for Tomorrow**. Beyond the practical solutions for managing everyday life with CMT, it created a unique space for attendees to connect, share, and build lasting relationships with fellow community members, exhibitors, and speakers."

Top (left to right): **CMTA CEO Sue Bruhn, PhD and CMTA Scientific Advisory Board member Stephan Züchner, MD, PhD.** *Bottom (left to right):* **Applied Therapeutics Chief Medical Officer Riccardo Perfetti, MD and Neuromuscular Pulmonologist Ashraf Elsayegh, MD highlighted the power of patient-focused drug development and how research and care are accelerated when patients are engaged.**

A SPACE TO CONNECT AND BELONG

From the moment attendees arrived on Friday and participated in a "dine-around" across Denver's vibrant restaurant scene, the sense of community was undeniable. For many, this was their first experience meeting others with CMT face-to-face—a powerful reminder that they are not alone in their journey. One attendee captured this sentiment perfectly: "I came away with an improved understanding of and hope for current research initiatives, ways to live with CMT, and a profoundly increased feeling of connection to the CMTA Community."

Saturday's sessions were packed with educational presentations from CMT specialists, clinicians, and fellow community members. Topics ranged from the latest in symptom management to community perspectives on navigating life with CMT. Sunday's focus shifted to research, with world-renowned CMT scientists sharing groundbreaking advancements in potential CMT treatments and ongoing projects aimed at finding a cure.

HELP FOR TODAY

The Summit provided attendees with many practical tools and strategies for managing life with CMT. Expert-led sessions on physical and occupational therapy emphasized daily activities that can significantly improve quality of life. In-depth discussions on bracing options and surgical interventions offered guidance on how to approach mobility challenges and when to consider corrective foot surgery for CMT.

In addition, respiratory care and emotional well-being sessions addressed the broader aspects of living with CMT, offering solutions for managing neuromuscular breathing difficulties and mental health challenges. These useful, day-to-day strategies highlighted CMTA's commitment to providing help for today, equipping attendees with resources they can use today to improve their lives.

KEYNOTE SPOTLIGHT: VITTORIO RICCI

Sunday's keynote speaker, 26-year-old Vittorio Ricci, provided an inspiring example of the power of community and advocacy. Diagnosed with the CMT-SORD in 2021 after years of uncertainty, Vittorio shared his journey—from his initial diagnosis at age 14 to receiving genetic confirmation to his involvement in a Phase III clinical trial for govorestat, a potential first-ever treatment for CMT.

Vittorio spoke passionately about how CMTA has connected him with others facing similar challenges and empowered him to actively advocate for the CMT community. He has been working closely with Applied Therapeutics on FDA outreach, advocating for accelerated approval of the company's experimental drug for this unique type of CMT, govorestat. His story underscored the importance of family, community, and collective efforts in driving progress toward treatments for CMT.

HOPE FOR TOMORROW

On Sunday, attendees learned about the significant achievements in CMT research through the CMTA's Strategy to Accelerate Research (STAR) program. With more than 50 active research projects, including 35 sponsored initiatives, STAR has invested $30 million to accelerate research in treatments for all forms of CMT. This year alone, 9 new projects were approved, targeting both demyelinating and axonal forms of CMT. The collective impact of this research is moving us closer to treatments that will benefit the entire CMT community. One of the standout achievements shared was the rapid progress of CMT-SORD research.

Discovered through CMTA's ongoing genetic discovery initiative, CMT-SORD advanced from gene discovery to a Phase III clinical trial in just two years, thanks to CMTA's commitment to ensure the infrastructure was in place to start trials as soon as the science allowed. CMTA-STAR Alliance Partner Applied Therapeutics, which is conducting the trial, reported encouraging 12-month data earlier this year, fostering hope for the entire CMT community.

Breakout sessions provided updates on research for demyelinating CMT, axonal CMT, and undiagnosed forms of CMT (unknown genetic cause), highlighting the expansive reach of CMTA-STAR's funded research. These sessions reinforced CMTA's commitment to accelerating treatments that will bring hope to the entire CMT community. Attendees left confident, knowing that every project supported by the CMTA brings us closer to effective treatments for all CMT, not just for the few.

PERSONAL STORIES OF IMPACT

For many, the Summit wasn't just an event; it was an emotional turning point. Clarissa, diagnosed with CMT-SORD at 18, described her experience in Denver as nothing short of transformative.

Reflecting on the summit, she said, "It is an otherworldly experience to be in a room full of people with CMT. There is an unspoken bond that transcends blood… Strangers instantly turn into friends."

Her words capture the unique sense of belonging attendees felt during the Summit. This year's gathering provided a space where people could connect, share their experiences, and walk away with newfound friendships, all while gaining valuable knowledge about the future of CMT research and managing their disease.

LOOKING AHEAD

The weekend wasn't just about reflecting on progress but was about looking towards the future. With more than half of the attendees being first-timers, there was an undeniable momentum in the air—a growing movement united by the goal of finding treatments and, ultimately, a cure for CMT. As one attendee said, "The Summit, time and time again, demonstrated the power of a community and an advocacy organization to make meaningful impacts."

As we look ahead to next year's Summit, scheduled for September 5-7, 2025, in Indianapolis, Indiana, we remain committed to providing Help for Today and Hope for Tomorrow. Building on this year's success, we will continue to bring even more members of the CMT community together for another unforgettable weekend.

A Special Thank You to Our Sponsors and Exhibitors

CMTA would like to extend our heartfelt gratitude to the sponsors and exhibitors of the 2024 Patient & Research Summit. Your generous support and participation made this event possible and helped bring the CMT community together for a weekend of learning, connection, and hope.

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Your commitment to accelerating CMT research, supporting the community, and fostering innovation is invaluable. Together, we are making meaningful strides towards a world without CMT. Thank you for being an integral part of our mission.

HOPE IN MOTION: CMTA'S PATIENT SUPPORT FUND'S LIFE-CHANGING IMPACT

Financial assistance for CMT patients seeking evaluations and surgeries with renowned foot and ankle specialist Dr. Glenn Pfeffer at Cedars-Sinai Medical Center in Los Angeles, California.

In 2021, the CMTA Patient Support Fund was launched with a generous gift from an anonymous donor, setting the foundation for something truly special. The fund's purpose is to provide financial assistance to CMT patients seeking evaluations and surgeries with renowned foot and ankle specialist Dr. Glenn Pfeffer at Cedars-Sinai Medical Center in Los Angeles. Cedars-Sinai, recognized as a CMTA Center of Excellence, is home to an expert surgical team that has changed the lives of many living with CMT.

This initial act of kindness sparked a ripple effect, inspiring brothers Spencer and Taylor Bergthold to take up the cause. Witnessing the profound impact the fund could have, they were moved to contribute, ensuring more CMT patients would have the opportunity to receive life-changing treatment. The financial burden of traveling to Cedars-Sinai for consultations, second opinions, and surgeries can be overwhelming, especially when patients have already faced years of medical challenges. The fund helps ease these costs, covering travel and lodging for patients and their families, with up to $5,000 in support per patient.

As Spencer shared, “We saw how much hope this fund was giving to patients and their families, and we wanted to make it our mission to both contribute via fundraising through our networks while using it as an opportunity to spread general awareness for CMT. It's incredible what a difference this fund can make in someone's life.”

Thanks to this growing support, the fund continues to help more CMT patients access the care they need. Together, we are building a stronger, more connected community, driven by the belief that no one should be held back from life-changing treatment because of financial constraints.

For more information or to support the CMTA Patient Support Fund, please visit www.cmtausa.org/cmtapatientsupportfund/

CMTA GRATEFULLY ACKNOWLEDGES GIFTS...

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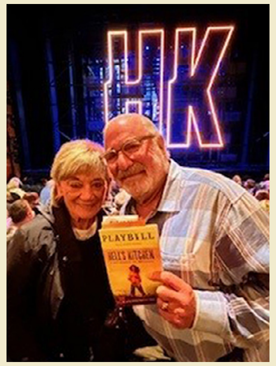
THANK YOU, GARY AND HELENE LENET,

FOR BRINGING THIS WONDERFUL EVENT TO LIFE AND TO ALL WHO JOINED US ON BROADWAY

On Saturday, September 28th, we gathered in NYC for a wonderful event to raise funds for CMTA. We want to extend our heartfelt thanks to Gary and Helene Lenet for their leadership in this initiative, bringing together over 50 supporters and raising an incredible $45,000 for our mission.



As Gary shared during the evening, “We draw inspiration from the Broadway show *Hell's Kitchen*, which tells Alicia Keys' remarkable journey—rising from her roots with the support of her friends, community, and a devoted music teacher. Just like this, with our friends and community, we remain committed to standing with you as we fight for a future where CMTA is a key part of the cure.”

Gary invites you to stand with us. Your support is essential to CMTA's continued success. Thank you to everyone who attended and donated—together, we are shaping a future for you and for generations we may never meet.

EXPLORING A MINDSET FOR LIVING WITH CMT:

STRATEGIES FOR OURSELVES AND OUR CHILDREN

BY SARAH KESTY

Almost thirty years later, I can still feel the hot pain filling my right shoe, the stale Northern California summer air, and a friend on either side of me as I limped around the field for my fourth and final lap—a mile. I finished the mile run test for sixth grade. One of my teachers said my time out loud, over twenty minutes, and the other instructed the two classes of students that they could finally get up, out of the heat, and go inside. Their last, slowest student was done. My cheeks burned with embarrassment as I heard my peers snark: "Finally!" "What is wrong with her?" "She's the slowest, laziest person in class."

Moments like these stick with a person. For a long time, they even shaped my identity. I didn't say CMT out loud until I was nearly thirty. Instead, I kept it inside like a shameful secret, avoided anything that may have exposed my differentness, and tried my hardest never to use my handicapped placard, save for after surgery.

I won't lie to you, CMT family. There are days when I still feel isolated, in deep pain, and flirting with a twinge of hopelessness. CMT is hard. But I've found several ways to manage the physical and emotional pain, and we can utilize these strategies for ourselves and our children.

First, we can change the ways we respond when our kids have big feelings. Often, in an attempt to protect ourselves and our kids from pain, we may downplay the painful experiences, quick to jump into a solution, distraction, or a way to ignore the emotional, social, or even physical pain of CMT. When I started to allow myself to feel the feels, all of them, it was transformative. Instead of getting louder, increasing in intensity in hopes that they'd finally be heard, my feelings processed through me and relaxed. It was as if all they ever wanted was to be seen, heard, and acknowledged, and when I stopped running from them, they lowered the volume.

How do we do this with our kids? Witnessing your child's pain is heartbreaking, and it's natural to seek the "shut off valve" right away. Saying things like "It will be fine" or "It doesn't matter that much" reflects your adult perspective and a positive intention to decrease their pain. However, responses like these often accidentally send a message that our kids' feelings aren't important and that we don't want to hear them. Instead, you can test out a three-part reaction: listen and allow, repeat and validate, and ask.

Listen and allow:

Allow your child to do most of the talking or even crying. Make space for them to get their feelings out, without jumping in with too much talking. You can nod and make affirmative statements to show you're listening, but in this phase, you are witnessing and honoring their experience, not fixing anything.

Repeat and validate:

As your child shows signs of calming, you can show them you heard them by sharing things like, "I hear you saying that...," "It sounds like...," or "It seems like you're feeling..." In this way, you show your child they are heard and understood. You are reflecting what they've shared and validating that you're connecting with them. Often, your child will seem to feel better after being heard or may elaborate after hearing their thoughts clarified by you.

Ask:

When the emotional storm is settling, ask your child what would help them in that moment. What may provide comfort or enjoyment? What do they need from you? If they don't know, you can offer a few ideas but don't push them into any one choice. Many children seek comfort, rest, or distraction as the neurotransmitters related to intense emotions dissipate. If choosing a calming activity is very tough in the moment, consider making an ideas list at a time when your child is feeling great. You can access it during tough moments in the future.

Other quick ideas:

Neutralize your language

Words hold a lot of meaning, and many are especially painful. Mindfully choosing neutral ways to describe CMT and our experiences can help us express ourselves without adding to the pain. When talking with your children, avoid the loaded words like "special" and opt for terms that describe but don't judge (too much). Some examples include, "I have a wonky foot" or "sometimes balance is tricky." We're not downplaying the experience, but we're also not creating extra pain by using language that is loaded with emotion.

Find role models and inspiration

Humans learn through stories. Hearing and relating to how others experience their challenges can provide models and hope. Consider learning about and celebrating public figures with disabilities. You may even want to hang quotes or photos as reminders of the tenacity of the human spirit, especially when times get tough.

Practice self-advocating

Talking about our challenges can be hard, especially for our kids. The risk of rejection when we share about our CMT may mean we avoid asking for what we need; in fact, the part of the brain that processes social or isolation pain is the very same part that processes physical pain. Being prepared with neutral descriptions and rehearsed language can help us be ready to self-advocate. Our kids can practice how to express their needs to teachers, and we can even help them learn quick and less emotional ways to reply to peers' questions about CMT, braces, or their abilities.

Celebrate small wins

Although I wish positive changes happened all at once and overnight, the reality is they will unfold in messy, non-linear ways. Keeping an eye out for small changes can help us feel like our efforts are worth it. Did you or your child process through a big emotion? Were you able to speak up about what you need? Did you find ways to use your pain to help others? Allow your brain to explore what's going right, and you'll likely find a good list!

CMT family, this can be a tough road. But using strategies and mindful communication can help us and our children develop healthy mindsets to live with CMT.

Sarah Kesty is an education and disability consultant, speaker, and author who helps CMT community members make the best of their children's school experiences. An experienced advocate who has CMT, Sarah helps families navigate school support systems with confidence and clarity.

CONNECTION WITHOUT BOUNDS: THE POWER OF COMPASS

BY HALEY WHITE

CMT AND CONNECTION— two things that can't be spelled without the letter "C" and two things that can't exist without each other. I recently watched a drama titled "Twenty Five Twenty One," which follows a group of friends as they experience the highs and lows of life, exploring how relationships evolve as they grow older. It left me wondering if we really do leave behind everything from our childhood as we move into adulthood. Do we lose those bonds, or can we continue to grow our friendships and share our ups and downs? For CMTA's COMPASS group, it's definitely the latter.

COMPASS is CMTA's support group for young adults living with CMT. Unfortunately, we may not always highlight how we connect, not only in the monthly meetings but in our everyday lives as well. To show that we don't just sit behind computer screens every month, a few COMPASS friends and I have come together to share how COMPASS has helped our friendships grow beyond physical and technological borders.

COMPASS outing at the 2024 Patient and Research Summit

Let's Start With Some Thoughts From My Camp Pals About Camp Footprint

NATHAN BURNS: "Volunteering for and experiencing Camp Footprint made my experience as a COMPASS member much more personal and intimate. Sure, meeting and connecting with fellow CMT community members via Zoom is engaging, but physically meeting, breaking bread, and laughing with extraordinary people, all while enjoying the sights and activities that camp provides, created memories that I will carry with me for the rest of my life."

DYLAN VALLAT'S JOURNAL: "This honestly feels like a long-lost home, from how welcoming everyone is to the universal aura of understanding that permeates the air. As someone who grew up knowing nothing about CMT, I now understand the beauty of having this deep shared experience and community that unconditionally accepts you and allows you to be yourself without any feelings of judgment."

Outside of Camp Footprint

If camp isn't your thing, never fear! Members have been to concerts together, traveled to visit each other, attended the CMTA Patient and Research Summit, and regularly chat on social media. Some even volunteer as branch leaders. Here's what they had to say:

JOSH FLETCHER: "Going to the Diplo concert with Kathy Chau and her friend group was an unforgettable experience with great company. Navigating the crowd was also an experience in and of itself, but I was lucky to have Manorath, Kathy's boyfriend, by my side. I can't emphasize how important it is to have friends who understand and don't make you feel less."

PAIGE ADAIR: "The CMTA Summit is a magical event, allowing many individuals to meet other young adults with CMT—sometimes for the first time ever."

CHEYENNE ALFINO ***(Los Angeles Branch Leader)***: "I was planning on visiting the Bay Area in March 2024, and I thought maybe I could see some of my online COMPASS friends in person. So, I reached out to Paul Sinclair, Dylan Vallat, and Yohan Bouchard to see if they'd be willing to go out to lunch while I was there. They all ended up coming!"

Overall, COMPASS can't be summed up in just monthly meetings, although those are a very important starting point for getting connected. It's a place to find others who are like you and understand what you're going through. We don't just discuss the challenges of having CMT; we also celebrate the joys of being alive. There's not a day that goes by when I don't reach out to a fellow COMPASS member.

In the drama I mentioned earlier, the main characters grow older and walk different paths, leaving us with a famous quote about their time together: "That summer was ours to keep." COMPASS is our summer. Enjoy it while you can.

WHAT IS COMPASS?

COMPASS, CMTA's young adult group, is not just a community—it's a movement. Over the past year, our members have come together in monthly meetings, delving into discussions, sharing stories, and forging bonds beyond diagnosis. These meetings aren't just about finding support, they're about finding strength in solidarity.

But COMPASS isn't just about meetings—it's about creating unforgettable experiences. Picture this: a happy hour evening at CMTA's Patient and Research Summit in Denver, CO, this September; laughter fills the air as you connect with peers who understand your journey. Moments like these remind us of the power of community and the power to uplift, connect, and empower.

So what are you waiting for? Connect with COMPASS today and be part of something extraordinary.

Follow us on Instagram at @cmtacompass.

To join COMPASS, scan this QR code or visit our landing page at cmtausa.org/compass

Let's empower each other and build a brighter future for young adults with CMT. Your journey starts here!

COMPASS
NAVIGATING CMT
AS A YOUNG ADULT

INNERVATORS HONOR ROLL

ACCORDING TO THE DICTIONARY, an innervator is a nerve stimulator. CMTA INNERVATORS, however, are action-oriented game-changers that sustain CMTA with monthly gifts throughout the year. Life-changing initiatives like Camp Footprint, treatment-focused research, and invaluable education initiatives depend on steady, reliable support from committed and reliable donors. Add your name to the INNERVATORS Honor Roll by visiting cmtausa.org/cmta-innervators and joining today!

Tracy Adamson
Richard Arsenault
Aaron Baker
David Balbi
Kim Bamford
Kelly Banner
Richard Barger
James Barker
Mackenzie Barnhizer
Christine Bateman
John Baun
Chevelle Bazo
Donald Bean
Jonah Berger
Cheryl Bidgood
Aaron Bokmeyer
Robert Bollenbacher
Marilyn Booth
William Boreham
H. Brand
Laurie Brandvold
Deborah Breuer
Cor Broekhuijse
Tiffany Brokaw
Edna Broman
Mary Ann Brothers
Karen Brown
Ningning Brown
Raelene Brown
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Adriana Burchard
Bruce Burns
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Santo Caivano
Patricia Camp
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Diane Covington
Erin Crawford
David Crowe
Donna Curcio
John Czerwein
Kelly Demonte
Linda Depadilla
Laura Dillon
Marilynn Dodge
Jacky Donahue
Laura Douglas
Denisa Dragu
Edward Dudash
Bruce Egnew
Kevin Emch
David Erickson
Mia Everett
Laura Favret
Mitchell Fedde
Rick Fender
John Ferraro
Tera Fey
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Karen Fleming
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Efthimios Foundakos
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Ariana Gowin
Peter Grassi
Rebeka Green
Rob Greenstine
Peter Greeves
Stacy Groenink
Leanne Guido
Kathleen Hagedoorn
David and Nancy Haines
Mary Harris
Patsy Harris
Pamela Hawkins
Brian Hearn
Steven Helmke
William Helmke
Kathy Herzog
Christopher Hilbert
Kenneth Hill
Austin Hinners
Richard Homol
Joseph Hornick
Stacy Hoyle
Elaine Hudson
Nicole Hudson
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Lars Larsen
Iman Latifpour
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Robert Louden
Abbey Loy
Miguel Lyons
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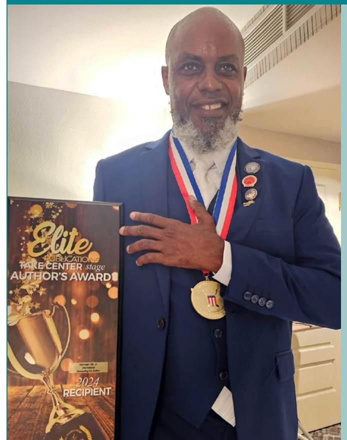


*"I have been pretty simple in my approach to things, so a direct or blunt way of saying it is, 'I Did It Because I Wanted To.' Being a donor is a nice and even noble gesture, but I have always done things because I want to. If I didn't, I would say no. It is a simple formula that has given me an almost stress-free life. I believe in CMTA and am humbled by the amazing people I have met."***—KENNETH HILL JR.**

UNDER THE MICROSCOPE

EXERCISE IS MEDICINE:
BRINGING CAMP FOOTPRINT UNDER THE MICROSCOPE

BY KATHERINE FORSEY, PhD
CMTA Chief Research Officer

In "Under the Microscope," CMTA Chief Research Officer, Katherine Forsey, PhD, takes a closer look at topics related to CMTA's Strategy To Accelerate Research (STAR). Dr. Forsey oversees STAR and CMTA's STAR Advisory Board, comprising over 30 world-leading experts in CMT who provide scientific input, evaluate ongoing or proposed CMTA-funded research projects, and guide CMTA's research strategy. Through STAR, CMTA currently has more than 50 active research projects, including sponsored research grants with academic labs and preclinical testing studies with biotech/pharma Alliance Partners.

CMT affects the peripheral nerves that connect the brain and spinal cord to muscles. People with CMT often experience muscle weakness in the hands, feet, arms, and legs, along with balance and coordination difficulties. These challenges stem from slower nerve signal transmission and loss of sensation, particularly in the hands and feet. Exercise plays a crucial role in the lives of those with CMT. In supportive environments like Camp Footprint—the only summer camp specifically designed for young people aged 10-18 with CMT—participants engage in a wide range of physical activities supported by a dedicated small army of adult volunteer counselors, many of whom also have CMT.

I Just Can't Help Myself...

CMTA's Camp Footprint is not intended to be used for physical benchmarking. Instead, it is set up to provide a diverse range of fun and challenging activities, with support and adaptations for the full range of physical abilities. 2024 marked my third year as a counselor at Camp Footprint East in Pennsylvania. While camp director Jonah and the team throw surprises into the mix every year, there is a core set of the same activities each year. These include chair dancing, climbing or bouldering, paddle boarding, archery, swimming, yoga, and not forgetting the giant slip and slide!

Exercise in action with Dr. Forsey and campers at Camp Footprint East

I'm a research biologist by training. I'm hard-wired to track and monitor my own performance. Camp Footprint provides a perfect annual opportunity to see how any progression in my CMT is affecting me. I started a new strength and resistance program last November and wanted to see how much of a difference it has made to my capabilities. I set myself a goal of getting to the top of the more challenging rock-climbing wall (there are walls with different difficulty levels) and returning to the paddle board I first met at camp the previous year. I surprised myself with how much easier paddle boarding was. Developing my core has helped my balance—I did not fall into the water once!

The rock-climbing wall was a killer, but I made it to the top with the cheers of the Camp Footprint Tribe behind me! While I wasn't entirely surprised—there's plenty of evidence showing that this type of exercise improves how people with CMT feel and function—there was still a part of me that needed to experience it firsthand to believe it!

We know CMT is a progressive disease; symptoms can worsen over time, making everyday activities increasingly challenging. This is why exercise is crucial for everyone with CMT. It is currently the only "treatment" proven to help improve balance, build strength, and delay symptom progression.

Why Exercise is Crucial for People with CMT

1. Maintaining Muscle Strength: One of the main challenges of CMT is muscle weakness. Exercise helps maintain muscle strength, which is needed for balance and mobility. For people with CMT, targeted exercises can help prevent muscle atrophy (wasting) and keep the muscles as strong as possible for as long as possible. Any muscle, as long as it is not fully denervated (disconnected from the nerves due to CMT nerve damage), can be built up and improve its strength. Not all our muscles denervate at the same time; surrounding muscles can compensate for those that don't work so well, so it's important to follow a diverse training program to work all the muscles.

2. Improving Balance and Coordination: People with CMT often struggle with balance due to muscle weakness and loss of sensation in the feet and legs. Regular exercise, particularly activities focusing on balance and coordination, such as yoga, Pilates, or simply static or walking lunges, can help improve these skills. Better balance reduces the risk of falls and injuries, which can be beneficial for all people with CMT. Check out the BALTiC study in the resources box.

3. Enhancing Mobility and Flexibility: Exercise that focuses on stretching and mobility, like gentle stretching routines or low-impact aerobic exercises, help keep joints flexible and muscles loose. For children and teens with CMT who are rapidly growing, being able to move freely without stiffness can significantly impact their ability to participate in various activities, both at Camp Footprint and in everyday life. Yoga is a regular feature at Camp Footprint, and stretching of the fingers and toes should always be included because of CMT's increased risk of contractures (the stiffening or shortening of muscles, limiting movement).

4. Boosting Mental Health and Confidence: Living with CMT can sometimes feel isolating, especially for younger individuals. Engaging in physical activity releases endorphins—chemicals in the brain that help reduce pain and improve mood. Exercise can also enhance self-esteem and confidence, particularly in a supportive and understanding environment like Camp Footprint. Campers and Counselors push themselves each year to try new things and achieve new goals; the levels of support and celebration for individual achievements are so great that we all lose our voices within the first few days from cheering!

CMTA's Camp Footprint: A Unique Environment for Exercise and Growth

CMTA's Camp Footprint provides a unique environment where campers and counselors can engage in physical activities tailored to their abilities and needs. Surrounded by peers who understand their experiences, we can try new sports and activities with people who understand. We inspire each other and show what a CMT body can do.

Camp Footprint's focus isn't just on exercise for physical benefit but also on fostering a sense of belonging and community. When campers engage in physical activities together, they're not just exercising their bodies—they're building friendships, learning from each other, and boosting their confidence. This positive peer reinforcement can greatly motivate campers to stay active and healthy beyond camp.

Finding the Right Balance

While exercise is vital, it's important to find the right balance. The balance between showing yourself compassion while not perpetuating self-limiting beliefs is something I am personally exploring. We want to train hard and push ourselves while avoiding injury. Over-work fatigue has recently been debunked in CMT, so we can trust our bodies, physical therapists, or personal trainers and push to find what works for us. Improving our symptoms through exercise and increasing strength and balance is possible. Camp Footprint supports campers in finding the right types and amounts of exercise that work best for them, ensuring they stay safe while reaping the benefits.

Conclusion

CMTA's Camp Footprint offers a safe, supportive environment where young campers and counselors alike can explore exercise, connect with others, and learn about their bodies. It empowers everyone with CMT to live their best, most active lives. If you can't make it to Camp Footprint, we have a host of exercise resources on our website you can try at home. Tracking your progress over time, however you choose to benchmark yourself, is great for motivation too.

RESOURCES

The BALTiC study explored the feasibility of a home-based balance training program for people with CMT. It combined multi-sensory balance and strength training focused on trunk muscles with falls management education. Success was measured using physical assessments, patient feedback, and interviews.

Reference the BALTiC study: ***https://ctv.veeva.com/study/baltic-study-a-feasibility-analysis-of-home-based-balance-training-in-people-with-charcot-marie-too***

CMTA EXERCISE PAGES

From CMTA Board Member Steven O'Donnell: ***cmtausa.org/tin***

cmtausa.org/pilates

cmtausa.org/letsmove

CMTA Charcot-Marie-Tooth Association | STAR Strategy To Accelerate Research

RESEARCH UPDATES

At the core of CMTA's mission, CMTA-STAR (Strategy to Accelerate Research) accelerates pioneering research to develop treatments and ultimately find a cure for CMT. With nearly $30 million invested since its inception in 2008, CMTA-STAR fosters collaboration across leading researchers, industry experts, and the CMT community, resulting in remarkable progress. In this edition of The CMTA Report, we highlight current initiatives that span gene therapy advancements, novel therapeutic approaches, and biomarker discovery—critical steps toward transforming CMT care, and we share some live research opportunities for you to participate in. Together, we are making meaningful progress towards improving the lives of those affected by this disease and moving closer to a world without CMT.

CMTA's CRISPR Research Initiative Advances for CMT1A and CMT1B

With more than $500,000 in CMTA funding, researchers led by John Svaren, PhD, at the University of Wisconsin are advancing CRISPR gene-editing strategies to target the genetic mutations responsible for CMT1A and CMT1B. This project involves collaboration with CMTA Scientific Advisory Board members Maurizio D'Antonio, PhD, at the San Raffaele Scientific Institute, Italy, and Bruce Conklin, MD, at Gladstone Institutes, San Francisco.

The research team has identified over 140 benign mutations in the PMP22 and MPZ genes, a key step in developing CRISPR tools that can specifically target and remove the mutated copies of these genes while leaving healthy copies intact. The next phase focuses on testing these CRISPR tools in human stem cells, a step towards creating a gene-targeted treatment for CMT1A and CMT1B.

IMPACT: Potential new genetic therapy to treat several types of CMT.

BECOME A PARTNER IN CMT RESEARCH: HELP US COMPLETE OUR CMT2F STUDY

We believe patients are key partners in accelerating research. With only one more participant needed to complete this groundbreaking study, your participation is vital. If you or someone you know lives with CMT2F, contact this study's University of Iowa coordinator at CMTRes@healthcare.uiowa.edu to become the final participant.

CMT2F Natural History Study Nears Full Recruitment as Biomarker Analysis Begins

With $302,071 in funding from CMTA, an international research team led by Michael Shy, MD, at the University of Iowa is nearing full recruitment for a natural history study on CMT2F. Out of 25 planned participants, 24 have been recruited across multiple study sites.

The study assesses changes in biomarkers such as intramuscular fat fraction and Schwann cell gene expression over time to understand CMT2F's progression better. Correlating these biomarkers with clinical outcome measures will provide new insights into how CMT2F progresses and inform future treatment development.

IMPACT: Understanding CMT2F progression to accelerate the testing of new treatments.

Exploring New Therapeutic Pathways for CMT1B: UPR Activation

Researchers at Ospedale San Raffaele, Italy, led by Maurizio D'Antonio, PhD, have made promising strides in developing a treatment for CMT1B by harnessing the Unfolded Protein Response (UPR). Supported by $33,000 from CMTA, this project seeks to activate the body's natural defenses to reduce the harmful effects of misfolded MPZ proteins.

Early results show that UPR pathways can be effectively activated in CMT1B models, offering a potential therapeutic pathway. Further research will determine whether these findings translate to clinical outcomes for patients with CMT1B.

IMPACT: Potential treatment for CMT1B and other types of CMT where activating the UPR can help.

Update: Progress in Developing a CMT1A Organoid Model

CMTA has invested over $200,000 in a project led by Professor Vincent Timmerman, PhD, at the University of Antwerp in Belgium to develop a human-derived organoid model for CMT1A. The research team has made significant progress in optimizing Schwann cell and myelin production, allowing real-time visualization of the myelination process.

This model will accelerate the testing of potential treatments for CMT1A and may be expanded for use in other forms of CMT. The next phase will focus on refining the organoid model for therapy testing, with ongoing efforts to optimize the protocols and expand the methods to other forms of CMT.

IMPACT: An in-the-dish model to quickly evaluate potential treatments to repair parts of the nervous system damaged by CMT.

JOIN PATIENTS AS PARTNERS IN RESEARCH TODAY!

NOT YET REGISTERED with Patients as Partners in Research? Visit **cmtausa.org/pap** today! By registering, you'll be first in line for any CMT research opportunities that match your profile and interests, and you'll stay informed on the latest developments in CMT research. Registration is free, and we welcome everyone in the CMT community to participate.

Gene Therapy for CMT1A, 1B, and X1: Progress in Nanoparticles

In a jointly-funded project between CMTA and the Muscular Dystrophy Association (MDA), Alexia Kagiava, PhD, and her team at the Cyprus Institute of Neurology and Genetics in Cyprus are pioneering the use of nanoparticles to deliver gene therapies directly to Schwann cells to treat CMTX1 (aka CMTX1, CMTX), the second most common type of CMT. This research focuses on using novel nanoparticles designed to carry therapeutic genes to Schwann cells, which are crucial for producing and maintaining the protective myelin sheath around nerves.

Dr. Kagiava and colleagues successfully produced and characterized the nanoparticles during the project's first year. These PLGA-PVA nanoparticles were designed to be combined with specific targeting molecules to ensure they reach Schwann cells. Further optimizations will reduce their size for more efficient targeting. Initial in vivo testing of these nanoparticles in animal models has already begun, laying the groundwork for targeted gene delivery.

Dr. Kagiava and colleagues will focus their next steps on refining the nanoparticles' size and testing their specificity to Schwann cells. The ultimate goal is to create a safe and targeted delivery system that can improve treatment outcomes for CMTX1 and potentially CMT1A, CMT1B, and all other types of CMT involving Schwann cells.

IMPACT: New delivery system for genetic therapy to treat several types of CMT.

Community Participation Accelerates Research Success

With CMTA support of $98,890, researchers at Hasselt University, led by Esther Wolfs, PhD, have made significant progress in creating a new model for CMT1A using dental pulp stem cells (hDPSC). Thanks to the overwhelming response from the CMT community—20 donors representing 8 different subtypes via the Patients as Partners in Research program, with some donating more than one wisdom tooth—the team gained critical materials to push this innovative project forward.

By inducing PMP22 overexpression in these cells, the researchers successfully replicated the genetic mechanisms of CMT1A. This model is now helping to reveal how Schwann cells, which produce myelin, are affected by the disease, offering new insights into treatment development. With donations representing other subtypes, work is underway to develop cell line models for these.

This success highlights the power of community involvement and marks a significant step forward in pursuing therapies for CMT1A, underscoring CMTA's commitment to accelerating research through collaboration.

IMPACT: New preclinical models of CMT1A, CMT1E, HNPP, CMTX1 (aka CMT1X, CMTX), CMT2A, CMT2C, CMT2T, and CMT4A.

CMT2S Research Opportunity: CMTA-STAR Alliance Partner Vanda Pharmaceuticals Leads New Investigational Study

CMTA-STAR Alliance Partner Vanda Pharmaceuticals has received FDA approval for an Investigational New Drug (IND) to explore VCA-894A, a potential treatment for CMT2S—a severe form of CMT caused by mutations in the IGHMBP2 gene. The study seeks individuals with confirmed CMT2S and specific mutations in IGHMBP2 to participate in an upcoming planned clinical trial. This research represents a significant step forward in developing targeted therapies for CMT2S, offering new hope to those affected by this rare and debilitating condition.

IMPACT: A potential treatment for CMT2S.

CMTA-STAR Alliance Partner Actio Biosciences Receives FDA Orphan Drug Designation and Rare Pediatric Disease Designation for CMT2C Treatment

CMTA-STAR Alliance Partner Actio Biosciences has received FDA orphan drug and rare pediatric disease designations for ABS-0871, a TRPV4 inhibitor for treating CMT2C. This achievement was made possible through collaboration with CMTA's Patients as Partners in Research program, which connected Actio with the CMT2C community. The company is planning an upcoming clinical trial.

This designation represents a significant step forward in developing treatments for CMT2C, bringing hope to those affected by this severe form of CMT. We have worked closely with Actio Biosciences to support their commitment to patient-focused drug development through our Patients as Partners in Research platform.

IMPACT: A potential treatment for CMT2C.

CMTA'S COMMITMENT TO PATIENT-CENTERED RESEARCH

These initiatives and partnerships underscore CMTA's position as the global leader in accelerating research and empowering patients. By uniting the patient community with clinicians and industry experts through CMTA-STAR initiatives and programs, CMTA accelerates the development of new treatments, improves the quality of life for people with CMT, and remains committed to finding a cure for this rare and debilitating disease.

To learn more about each of these projects and research opportunities, visit cmtausa.org

BRANCH NOTES

WESTERN CANADA *(FORMERLY EDMONTON, AB, CANADA)*

On Sunday, August 18th, the Western Canada Branch, formerly the Edmonton, AB Branch, welcomed special guest John Nixon, a member of the CMTA Advisory Board, fitness coach, bodybuilder, and well-known CMT advocate. John shared his journey with CMT and demonstrated adaptive exercises designed to help people with CMT stay active. The Branch was enthusiastic about John's visit and the chance to learn from his experience.

ATLANTA, GA

The Atlanta Branch gathered on July 30th for an engaging meeting featuring guest speaker Rocio Garcia Santibanez, MD, who shared insights from the Neurology Department at Emory University. Following his presentation, there was a lively Q&A session. Laurel Richardson, CMTA's Director of Community Outreach, and Jeana Sweeney, Chief Engagement and Gifts Officer, provided a CMTA update. The Atlanta Branch members left feeling informed and energized, eagerly awaiting their next meeting.

CHICAGO, IL

On July 16th, the Chicago Branch met virtually for their monthly meeting. The group exchanged tips on traveling with CMT, shared hobbies, and made plans for an in-person lunch at a local restaurant. Everyone is excited to meet in person soon.

SOUTHEASTERN KY

The Southeastern Kentucky Branch held a virtual meeting on Saturday, August 17th, with Dr. Nakul Katyal, CMTA Center of Excellence director at the University of Kentucky. Dr. Katyal gave an overview of his multidisciplinary clinic and work with CMT patients. After his presentation, Branch members had the opportunity to ask questions. The meeting wrapped up with Chloe Shaffer, Branch leader, sharing CMTA updates.

GUADALAJARA, MEXICO

On Saturday, August 24th, the Guadalajara Branch gathered in person for dinner at a local restaurant. Members shared their experiences with CMT, discussed local resources, and enjoyed connecting with others in the CMT community. The group is looking forward to their next gathering.


Atlanta Branch

NEW MEXICO

The New Mexico Branch held a virtual session on August 31st, focused on chair exercises and stretches led by fitness instructor and CMT community member Julie Barnett. Julie emphasized the importance of staying active and shared adaptable routines that can be done at home. Branch members appreciated learning new ways to move their bodies and eagerly await their next meeting on November 9th.

Guadalajara Branch

MINNEAPOLIS, MN

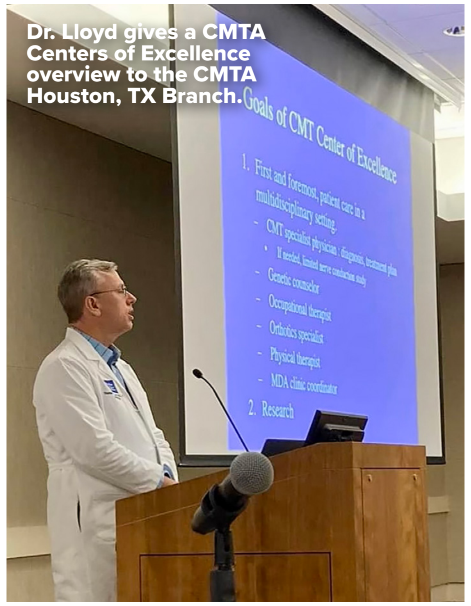
The Minneapolis Branch hosted a hybrid meeting on July 27th, with 16 members attending in person. Neurological Physical Therapist Sandy Swanson, PT, joined the meeting to share her experiences working with CMT patients and offered practical tips on staying active. The group appreciated connecting and learning strategies to manage their CMT.

CENTRAL TN

On August 26th, the Central Tennessee Branch met virtually to discuss what to do after receiving a CMT diagnosis. Branch leader Brittney Grabiel shared valuable information on available resources, treatment options, and practical strategies for managing life with CMT. The group is looking forward to their next virtual gathering.

HOUSTON, TX

On September 29th, the Houston Branch came together in person to welcome guest speaker Thomas Lloyd, MD, the new director of the upcoming addition to CMTA's Center of Excellence network at Baylor College of Medicine. He provided an overview of the comprehensive care available at his clinic for individuals living with CMT and answered questions from the group. The Branch was delighted to have Dr. Lloyd join them and looks forward to future meetings.



Dr. Lloyd gives a CMTA Centers of Excellence overview to the CMTA Houston, TX Branch.


Minneapolis Branch

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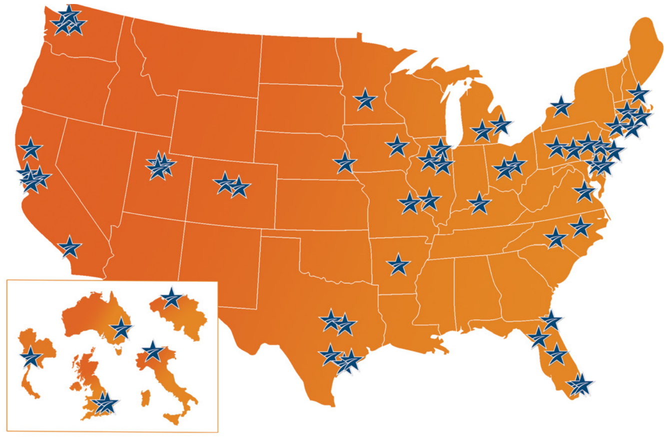
INTERESTED IN STARTING A BRANCH IN YOUR AREA?
Contact CMTA Director of Community Outreach Laurel Richardson at **laurel@cmtausa.org**

CMTA CENTERS OF EXCELLENCE

**CMTA's mission is to support the development of new treatments for
to improve the quality of life for people with CMT, and, ultimately, to
a cure. One of the many ways we implement this mission is by spons
patient-focused, multi-disciplinary Centers of Excellence CMT clinics.
World-renowned CMT care specialists and researchers staff each CM
Center of Excellence, ensuring those living with CMT receive only the
comprehensive care for themselves and their loved ones.**

**CMTA Centers of Excellence affiliated with the Inherited Neuropathy
Consortium (INC), marked below with an asterisk, goes further by col
and recording genetic, biological, and other data from individuals wit
CMT as part of CMTA-funded research. For more information, visit
cmtausa.org/coe.**



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The SAB provides scientific input for ongoing and proposed projects, the TEB evaluates the translational quality of ongoing and proposed projects, and the CEB provides expert guidance and support to CMTA's STAR Alliance Partners regarding clinical trial planning and delivery.

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INDICIA

WHAT IS **CMT?**

Named after the three doctors who first described it in 1886: Charcot (shar-coh), Marie, and Tooth, Charcot-Marie-Tooth disease (CMT) is an inheritable peripheral neuropathy that includes many motor and/or sensory neuropathies, axonopathies, myelinopathies, and neuronopathies.

Due to the effects on the nerves, people with CMT suffer lifelong progressive muscle weakness and atrophy of the arms and legs, and/or progressive sensory loss; and CMT can affect other parts of the body. There is no treatment or cure for this debilitating and often overlooked disease.

CMT leads to problems with balance, walking, and hand use. CMT can cause foot drop, chronic nerve pain, chronic muscle and joint pain, abnormal reflexes, fatigue, tremors, sleep apnea, hearing loss, breathing difficulties, and much more.

Early signs of CMT can be toe-walking, especially in children; frequent trips and falls, frequent ankle sprains, and difficulty with handwriting, tying shoes, or buttoning a shirt.

Visit CMTA's What is CMT webpage today: cmtausa.org/cmt

The Charcot-Marie-Tooth Association is a community-led, community-driven 501(c)(3) nonprofit organization with a mission to support the development of new treatments for CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure. As the leading global philanthropic funder of CMT research, CMTA unites the community with clinicians and industry experts to accelerate the advancement of treatments, with investments of nearly $30 million since 2008.

CMTA CAMP FOOTPRINT
ONE STEP AT A TIME

SPONSOR A CAMPER & CHANGE A LIFE!

CMTA's Camp Footprint gives kids with CMT, ages 10-18, an empowering week that transforms how they see themselves and their future. Your donation helps make this life-changing experience, full of friendships and adventures, **FREE** for campers.

Give today and make a lasting impact at **cmtausa.org/supportcampfootprint**.