WINTER 2023

THE CMTA REPORT

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UNITY IN COMMUNITY

MEET FOUR UNITERS

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THE CMTA REPORT | WINTER 2023

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

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cmtausa.org

Dear Friends,

When like-minded individuals with unwavering determination unite, they can change anything. In this issue of *The CMTA Report*, you'll read about just a few of those like-minded people—and what they are doing to change lives. We hope their stories inspire you to join the Charcot-Marie-Tooth Association (CMTA) in changing the world.

The CMTA's journey started in 1983 when a group of patients and doctors dared to dream of a CMT-free world. They were pioneers, the first in a wave of hope, innovation and dedication that has grown unstoppable over the years.

Stuart Feen joined the CMTA 35 years ago. He recalls that we were working out of a basement office, and he helped buy our first fax machine. Today, he says he continues to support the CMTA because, "Their hard work is yielding results, benefiting future generations. They are a shining example of what can be achieved when people unite for a meaningful cause."

Feen is just one of the CMTA's legion of supporters, whose collective impact has grown exponentially since that long-ago fax machine. With the support of our community, we've advanced CMT research, education and support.

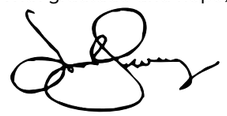
In 1991, researchers broke barriers by identifying the gene that causes CMT1A. In 2001, we established patient registries, and in 2018, we began funding biomarker research, providing crucial resources for researchers and pharmaceutical and biotech companies to access clinical data, track disease progression and identify potential clinical trial participants. In 2018, we engaged patients and families in our Patients as Partners in Research program to ensure their valuable perspective was included.

Fueled solely by our dedicated community, we've invested $23.8 million in our Strategy to Accelerate Research (STAR) program since 2008, making us the world's largest funder of CMT research (as well as the top provider of patient services).

Today, with the latest advancements in gene therapy and platforms capable of screening potential CMT therapeutics, we are standing on the brink of disease-altering treatments that can change our world. Thanks to the collective efforts of our community, we are on the verge of human clinical trials for treatments like gene editing and personalized medicine that were once unimaginable. The next few years are going to be groundbreaking.

At the CMTA, we envision a future where individuals with all types of CMT cast aside their braces, abandon their wheelchairs and dismiss any fears about the road ahead. Achieving this vision requires the collective effort of everyone touched by CMT in any way. As you make your urgently needed year-end gift, remember that every action, no matter how small, has the potential to create a ripple effect that can change the course of CMT's future.

With gratitude and hope,



Jeana Sweeney, *Chief Engagement and Gift Officer*

CMTA Appoints Biotech Industry Veteran Suzanne Bruhn, PhD, as New CEO

The Charcot-Marie-Tooth Association announced Nov. 6 that Suzanne (Sue) Bruhn, PhD, an accomplished biotech executive with extensive experience in the development and commercialization of treatments for rare diseases, will take the helm of the patient-led nonprofit as it moves to the next phase of its search for a cure for CMT.

Dr. Bruhn brings to the CMTA more than 25 years of biopharmaceutical experience and a track record in developing and commercializing therapies for the treatment of serious diseases with significant unmet need.

CMTA Board Chair Gilles Bouchard said, "We are delighted to have such an accomplished biotech leader as our new CEO. Sue has spent her career in rare disease drug development, having brought multiple products to market, raised significant capital and has a deep commitment to the patient community. I also want to thank board member Jon Pastor for doing such a fantastic job as interim CEO."

Dr. Bruhn said, "I am incredibly excited to join the CMTA, the largest philanthropic funder of CMT research in the world, and the provider of the most CMT patient services in the world. I have spent my career on patient-focused drug development and believe deeply in the power that patient communities can bring. I am committed to the vision of the CMTA: A world without CMT."

Bruhn comes to the CMTA with a long and successful career in drug development, having been the CEO of three biotech companies, all focused on rare diseases. She held multiple leadership roles at Shire Human Genetic Therapies (formerly Transkaryotic Therapies), where she saw multiple rare disease products advance from research through clinical development and launch onto the commercial market. She has significant experience in raising capital, business development and strategy, with a deep network in the biopharmaceutical space, coupled with a strong commitment to patients and the patient community.

She holds a bachelor of science with distinction in chemistry from Iowa State University of Science and Technology, a PhD in chemistry from the Massachusetts Institute of Technology and was a postdoctoral research fellow in the Department of Genetics at Harvard Medical School.

Bruhn is married with two adult sons. She and her husband live in New Hampshire.

FORTY YEARS AGO, THE CMTA MADE A COMMITMENT:

to provide unwavering support to our community by offering connection, information and resources. In 2008, recognizing the importance of research to our mission, we took a significant step forward by establishing CMTA-STAR. Today we are the largest philanthropic funder of CMT research in the world. Our broad range of patient services, which has never lapsed, distinguishes us from other nonprofits operating in the CMT space. Our community outreach efforts invigorate and inform our research efforts, creating a synergy between immediate support and longer-term research. All of our community services are aimed at creating a sense of belonging and purpose that enhance patient well-being for the 3 million people worldwide living with CMT.

Since 1983, CMTA Branches have connected 280,000 patients, serving as lifelines for those affected by CMT. Branches provide emotional support, share essential information and build community. They offer educational resources, advocate for CMT awareness and connect patients and caregivers.

Since 1984, we've delivered 81,258 copies of *The CMTA Report* to patients and families, providing education on research, fostering connections and encouraging advocacy. These reports offer resources, expert insights and inspirational stories, empowering individuals on their CMT journey with knowledge and hope.

Since 2005, 15,400 patients have attended CMTA patient conferences online and in person, benefitting from research, education, community connections and inspiration for a brighter future. These conferences empower patients to make informed healthcare decisions.

Since 2011, CMTA Centers of Excellence have provided 35,172 patients with specialized care, accurate diagnoses, personalized treatment and research access. The centers improve lives through comprehensive care and research opportunities.

Since 2016, the CMTA has provided 756 kids with the opportunity to experience Camp Footprint for free. At camp, children meet and befriend other kids with CMT, many for the first time. Camp Footprint empowers kids with knowledge and enhances mobility and confidence while providing emotional support, independence and resilience.

Since 2018, 6,161 people have joined the Patients as Partners in Research initiative, getting actively involved in understanding their unique CMT types and challenges. This collaboration accelerates treatment development and provides tailored information to patients.

Since 2021, The CMT 4 Me podcast has been downloaded 15,600 times, explaining CMT and reducing isolation through shared stories and encouraging listeners. The podcast has been rated in the top 5 percent of over 3 million podcasts.

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Charcot-Marie-Tooth Association
1983–2023

CMTA'S NEW VENTURE PHILANTHROPY ARM INVESTS IN ARMATUS BIO'S CMT1A GENE THERAPY

The CMTA announced Nov. 14 that it has invested in Armatus Bio's unique gene therapy clinical candidate to target CMT type 1A, the most common form of the disease. The investment in Armatus' Seed Series Extension syndicate is the first by the CMTA's new venture philanthropy arm, which will make selected early-stage investments in biotech companies developing unique and promising therapies for all types of CMT.

The Armatus treatment—ARM-101—is an adeno-associated virus (AAV)-based gene therapy that encodes a small interfering RNA (siRNA) to lower the production of PMP22 protein in Schwann cells. Armatus has already demonstrated the approach's efficacy in CMT1A mouse models and is currently conducting studies that will enable the company to submit an investigational new drug (IND) application to the Food and Drug Administration in 2025. Positive results will result in a Phase 1 clinical trial to evaluate the safety, tolerability and possible clinical benefit of ARM-101 in patients with CMT1A.

Armatus Bio, based in Columbus, Ohio, is an emerging biotechnology company collaborating with renowned gene therapy experts in Ohio to develop a pipeline of novel therapeutic candidates designed to overcome the limitations of today's approaches and propel the next generation of genetic medicines.

Armatus CEO Rachel Salzman, DVM, said, "Armatus is extremely grateful to the CMTA for its support, and we look forward to their continued advice and counsel as we advance ARM-101. Our ARM-101 development studies are particularly important for the CMT community because the data generated are designed to answer critical questions about how we can effectively deliver genetic medicines to the right parts of the body to meaningfully address this disease."

ARMATUSBIO

Salzman continued, "As we accelerate development of ARM-101 and gain further evidence that our vectorized RNAi can normalize PMP22 in Schwann cells as a means of enabling human trials, we believe this therapy has the potential to provide benefit to the thousands of people living with CMT1A in the United States and around the world."

CMTA Board member Thomas Dubensky, PhD, said, "The CMTA is very excited to facilitate the advancement of novel therapies to be ultimately evaluated in patients living with all types of CMT." He explained that "the venture philanthropy arm will work in tandem with STAR (Strategy to Accelerate Research), the largest private funder of CMT research in the world."

CMTA AWARDS $225,483 FOR STUDY USING ASOs TO TREAT CMT2E

The CMTA Board of Directors announced Sept. 28 that it has approved a $225,483 award to Dr. Mario Saporta at the University of Miami for a study on the use of antisense oligonucleotides (ASOs) to treat CMT2E.

CMT2E is caused by single mutations in one copy of the neurofilament light chain gene (NfL). Saporta's approach uses antisense oligonucleotides to target the mutant NfL copy, leaving the normal gene copy intact to perform its function.

ASOs are short man-made pieces of genetic material designed to bind to a specific target messenger, RNA (mRNA). They can be used to alter how specific genes in the body are expressed, or turned from DNA into a functional protein.

The Food and Drug Administration has approved ASO-based treatments for several neuromuscular conditions, including spinal muscular atrophy (SMA) and familial amyloid neuropathy. The study uses the same chemistry as the SMA treatment (Nusinersen) to accelerate potential use in patients. Nusinersen has been used since 2016 and demonstrates a very favorable safety profile.

The study will provide further understanding on how neurofilament levels impact axonal health, which may have implications for other forms of CMT. If it is feasible and effective, this approach should support the development of treatments for several forms of CMT type 2, using patient-derived cells and customized genetic treatments to treat patients with ultra-rare forms of CMT.

Dr. Saporta said, "We are very excited to continue this long-standing collaboration with the CMTA. This project has been supported by the CMTA-STAR initiative since day one and foundational work to characterize the human cellular model we are now using to validate our treatment strategy was a product of previous grants received from the CMTA. We look forward to seeing this treatment approach advance into animal models and then patients."

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 manages STAR and the STAR Advisory Board, a group of 30 of the world's leading CMT clinicians and scientists charged with shaping and delivering the CMTA's research strategies. The CMTA currently has more than 50 active research projects, including sponsored research grants with academic labs and pre-clinical testing studies with biotech/pharma Alliance partners.*

Nanoparticles

The tiny particles known as nanoparticles are revolutionizing the field of gene therapy by transporting therapeutic genes or gene-editing tools to specific cells within the body. This targeted delivery is essential to ensure that the genetic material reaches its intended destination and effectively treats the disease, a key challenge in the development of CMT treatments.

The miniscule particles typically measure less than 100 nanometers in size. To put that into perspective, a human hair is about 80,000 nanometers wide. They are composed of various materials, including metals, polymers and lipids.

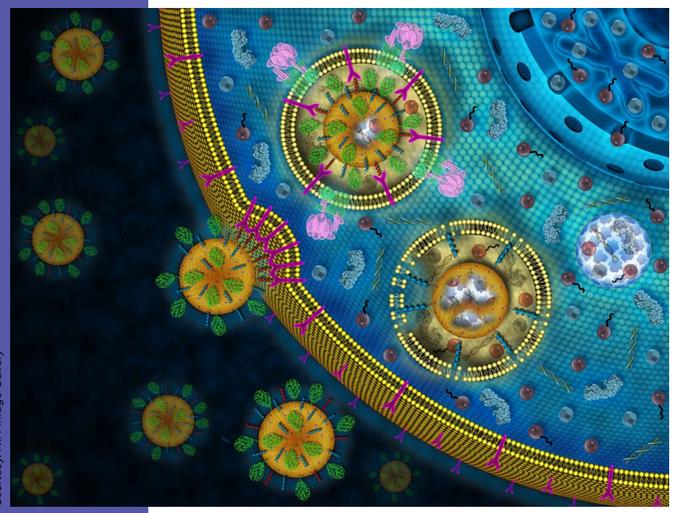
Nanoparticles can be engineered to carry therapeutic genes or molecules directly to the affected nerve cells in CMT patients. This precision minimizes side effects, maximizes treatment efficacy and can reduce the dose of treatment needed. They also provide a protective shield for the fragile genetic material, which can be easily degraded in the body. That shield ensures that the therapeutic cargo remains intact until it reaches the target cells.

Nanoparticles can release their cargo gradually over time, providing a sustained therapeutic effect, which can be particularly beneficial for chronic conditions like CMT. They can also help evade the body's immune system, reducing the risk of rejection and inflammation when delivering foreign genetic material.

Researchers are using nanoparticles to advance CMT research in a number of ways, including:

- **Gene Replacement:** Nanoparticles can deliver healthy copies of the mutated genes in CMT patients, potentially restoring normal nerve function.
- **Gene Editing:** Advanced gene-editing techniques, like CRISPR-Cas9, can be facilitated by nanoparticles to precisely modify the defective genes causing CMT.
- **Drug Delivery:** Nanoparticles can also deliver therapeutic drugs directly to affected nerve cells, offering symptomatic relief and potentially slowing the progression of the disease.
- **Non-Invasive Monitoring:** Some nanoparticles can serve as imaging agents, allowing researchers to track the distribution of therapeutic materials in real time, providing valuable insights into treatment effectiveness.

Nanoparticles offer new hope for individuals battling genetic disorders like CMT. Their unique properties make them ideal delivery vehicles for therapeutic genes and drugs, and they are helping researchers develop innovative treatments not previously possible.



Courtesy: NIH Image Gallery

Illustrated at left: **Porous silica nanoparticles loaded with multicomponent cargos, covered with a lipid bilayer act via a targeted delivery mechanism to release their contents directly to the target cells.**

MDA AND CMTA ANNOUNCE GRANT FOR NON-VIRAL GENE THERAPY RESEARCH FOR CMT1X

On Sept. 12 the CMTA and the Muscular Dystrophy Association (MDA) announced a collaborative research grant totaling $299,992 to test gene delivery to Schwann cells using nanoparticles to treat CMT1X.

The three-year study, entitled "Nanoparticle-based Gene Delivery to Schwann Cells for Treating CMT Disease," will be led by Dr. Alexia Kagiava of the Cyprus Institute of Neurology and Genetics in Nicosia, Cyprus.

Positive results from this study will provide a novel strategy for gene delivery to the peripheral nervous system that is anticipated to be more targeted and safer for clinical translation than adeno-associated virus (AAV) gene delivery strategies. The novel Schwann-cell targeted nanoparticle delivery is also anticipated to apply to other forms of CMT and other demyelinating neuropathies caused by gene defects in Schwann cells.

CMT1X is a common inherited neuropathy, characterized by progressive muscle atrophy, weakness and sensory loss in the limbs. It is caused by mutations affecting connexin32 (Cx32), a protein responsible for the formation of gap junction channels in the myelin sheath and plays an important role in nerve function and integrity. Although researchers have developed an effective gene therapy approach for treating CMT1X by intrathecal injection of the gene encoding Cx32 to mice using AAV delivery, potential long-term toxicity and lack of cell specificity may limit clinical translation.

To develop a safer and potentially more targeted approach, this study aims to design a novel aptamer-conjugated nanoparticle carrying the gene expressing Cx32 that would enable gene entry specifically to Schwann cells in the CMT1X mouse model. This targeted nanoparticle approach is anticipated to result in a more targeted biodistribution and provide a safer and more translatable gene therapy for CMT1X, as well as other demyelinating neuropathies caused by gene defects in Schwann cells.

"This project applies the latest techniques in nanoparticle technology to tackle a major challenge in the development of CMT treatments, getting them to the part of the body where they are needed," said Katherine Forsey, PhD, chief research officer, CMTA. "The goal of the CMTA's Strategy to Accelerate Research (STAR) is to develop treatments for CMT, and this exciting new project builds on our long-standing collaborative relationship with the MDA as we work together to achieve that goal."

NOVARTIS ISSUES OCTOBER UPDATE ON ACQUISITION OF DTx-1252 FOR CMT1A

Dear Charcot-Marie-Tooth Disease (CMT) Community,

In July 2023, Novartis announced the acquisition of DTx Pharma, a San Diego-based, preclinical stage biotechnology company focused on leveraging its proprietary FALCON platform to develop siRNA therapies for neuroscience indications.

DTx's lead investigational program, DTx-1252, targets the cause of CMT1A, the overexpression of the protein PMP22. This overexpression causes the myelin sheath that supports and insulates nerves in the peripheral nervous system to function abnormally. DTx-1252 decreases the expression of this protein in Schwann cells.

Novartis is in the process of onboarding information from DTx and developing next steps. We look forward to continuing DTx's therapeutic programs and bringing new hope to patients with neuromuscular and other neurological disorders for which there have historically been few treatment options, including CMT1A.

Novartis is committed and excited to work with our partners in the CMT community to make a difference in the diagnosis, treatment, and care of those affected by CMT. Novartis deeply appreciates the collaboration and support of the CMT community. Our CMT advocacy partners are strong allies who we look forward to working with to deepen our understanding of this disease as we advance promising science with transformative potential for CMT1A.

We look forward to collaborating closely with the CMT community and commit to providing you with updates on a regular basis as we have more information available to share. We thank you for your engagement and will continue to keep you informed of our progress.

Sincerely,

The Novartis CMT1A Development Team

THE CMT NAME GAME

CMT is named for the three doctors who first described it in 1886: Jean-Martin Charcot (1825-1893), Pierre Marie (1853-1940), and Howard Henry Tooth (1856-1925). Today, CMT is an umbrella term covering many different inherited sensory and/or motor neuropathies.

The inherited neuropathies that come under this umbrella are sorted by types and subtypes. There are 13 of them—CMT1, CMT2, CMT4, CMTX, dominant intermediate CMT (CMTDI), recessive intermediate CMT (CMTRI), distal hereditary motor neuropathy (dHMN), distal spinal muscular atrophy (dSMA), giant axonal neuropathy (GAN), hereditary motor and sensory neuropathy (HMSN), hereditary sensory and autonomic neuropathy (HSAN), hereditary sensory neuropathy (HSN) and spinal muscular atrophy with lower extremity predominance (SMA-LEP).

There is an additional group for "unclassified" subtypes, which don't fit in any of the 13 classifications. They are referred to as "[Gene Name]-CMT," as in "BAG3-CMT" or "SORD-CMT."

The CMT Classifications

Each classification has certain criteria for determining how the subtypes are grouped and how a new subtype is classified. This is referred to as the naming convention or the nomenclature. Each has a specific meaning. A nerve conduction study is necessary to determine whether a nerve injury is primarily demyelinating, axonal, or both, and is essential in the assessment of peripheral nerve injury. Demyelinating neuropathy characteristically shows a reduction in conduction velocity while axonal neuropathy shows a reduction in amplitude:

CMT1 subtypes are demyelinating and are autosomal dominant in inheritance.

CMT2 subtypes are axonal and are either autosomal dominant or autosomal recessive in inheritance.

CMT4 subtypes are demyelinating and are autosomal recessive in inheritance.

CMTX subtypes are X-linked in inheritance.

CMTDI subtypes are intermediate and are autosomal dominant in inheritance.

CMTRI subtypes are intermediate and are autosomal recessive in inheritance.

dHMN subtypes primarily affect the most distal points and motor neurons. They have little to no sensory nerve involvement, are axonal and are either autosomal dominant or autosomal recessive in inheritance.

dSMA subtypes are motor neuropathies affecting primarily the most distal points and motor neurons. They have little to no sensory nerve involvement. They are synonymous with dHMN. dSMA subtypes are either axonal or intermediate CMTs and they are either autosomal recessive or X-linked recessive in inheritance.

GAN subtypes affect both the central nervous system and the peripheral nervous system. They are axonal CMTs. There are two subtypes: GAN-1 is autosomal recessive in inheritance, and GAN-2 is autosomal dominant in inheritance.

HMSN subtypes affect both motor and sensory nerves. The acronym has historically been used to represent CMT as a whole, and some people prefer this acronym over CMT. Currently, six subtypes are known only by their HMSN name. Each is an axonal CMT, and all are either autosomal dominant or autosomal recessive in inheritance.

HSAN subtypes affect primarily the sensory nerves and the autonomic nerves. They have little to no motor nerve involvement and are axonal. Each is either autosomal dominant or autosomal recessive in inheritance.

HSN subtypes affect primarily the sensory nerves, with little to no motor nerve involvement. They are axonal and are either autosomal dominant or autosomal recessive in inheritance.

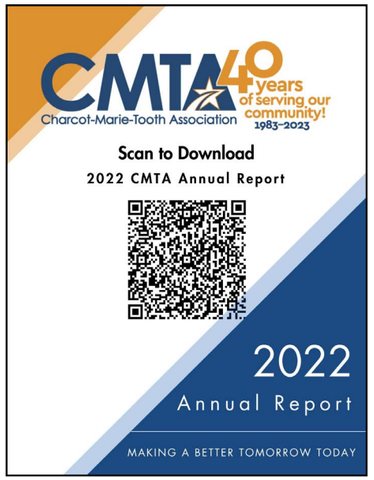
SMA-LEP subtypes primarily affect the lower extremities and motor neurons. They have little to no sensory nerve involvement and are axonal. Each is autosomal dominant in inheritance.

The **"Unclassified"** subtypes are a group known only by their CMT-associated gene name. These subtypes are either demyelinating or axonal, and are either autosomal dominant, autosomal recessive or X-linked dominant in inheritance, plus one axonal CMT subtype that is inherited via mitochondrial DNA.

Additional Names

HNPP is the acronym for hereditary neuropathy with liability for pressure palsies. Despite its name, this is a CMT subtype. Because it is a demyelinating CMT that is autosomal dominant in inheritance, it is classified as CMT1.

SORD-Deficiency, aka SORD-Deficiency CMT, SORD-CMT, or just SORD, is a CMT subtype caused by autosomal recessive mutations in the SORD gene. The scientist(s) who discover a new gene for CMT have the honor of naming their discovery. This name becomes known as the subtype name. Sometimes, the scientist(s) choose a conventional CMT name and other times they do not. SORD-CMT is an example of a non-conventional, non-traditional name. Despite its name, SORD is a CMT subtype, and because this subtype is known by its gene name, it is grouped with the "unclassified" subtypes.



CMTA AND UNIVERSITY OF PENNSYLVANIA GRANTED PATENT FOR CMT2A RAT MODEL

The U.S. Patent and Trademark Office granted the CMTA and the University of Pennsylvania a patent on a CMT2A rat model Oct. 31. CMT2A is estimated to cause up to 7 percent of all CMT and is the most common type 2 form.

The patent covers genetically authentic CMT2A animal models harboring either the R364W or H361Y mutation, both of which cause severe, early-onset axonal neuropathy, as well as myelopathy and optic atrophy phenotypes in humans.

The mutant rats develop a length-dependent axonal neuropathy in the peripheral nerves and in the fasciculus gracilis, both of which appear after 7 weeks of age, making this model a valuable tool for examining the pathogenesis and treatment of CMT2A.

While prior attempts at generating a CMT2A mouse model failed to produce a progressive axonal neuropathy, the mutation in the R364W rat model has a more severe effect. It is also possible that longer axons in rats compared to mice better reveal the deleterious effects of the R364W mutation.

The patent lists as inventors CMTA consultant Mark Scheideler, Human First Therapeutics; Guojun Zhao, PhD, Washington University; John Svaren, PhD, University of Wisconsin; David C. Chan, CalTech; Dr. Steven S. Scherer, University of Pennsylvania; and Taleen Hanania, PsychoGenics.

Mark Scheideler, PhD, chair of the CMTA's Therapy Expert Board, noted: "These represent the first animal models of an authentic, progressive axonopathy in CMT2A, and will be a valuable asset for the research community as it searches for strategies to treat the disease. Importantly, these models are a key contribution to the CMTA's preclinical testing platform that has been made available for the testing of possible CMT therapies, and which includes additional models representing several CMT disorders."

The CMTA has established a unique capability to develop new therapies directly with companies and to expertly test those potential therapy candidates. This allows a company interested in positioning a therapy for CMT to access the infrastructure needed—like authentic rat models—to evaluate the therapy without committing significant time and money up front.

TALKING THE TALK:
EXPLAINING CMT TO STRANGERS

BY KAREN BROWN

I have a love-hate relationship with Drs. Charcot, Marie and Tooth. I was diagnosed with Type 1A at age 25 and will forever be grateful to them for enabling me to understand what was happening in my body.

But I wish they'd left their names out of it because "Charcot-Marie-Tooth disease" leaves me fielding strangers' questions about sharks and teeth. When I say no, not that, people get confused, and I'm tempted to rescue the interaction by comparing CMT to something else they've heard of just so I can end the painful exchange.

But we need help curing CMT, and that means we need people to know what it is and care about curing it. For that to happen, we need to get comfortable naming what we have. It matters for us to talk about CMT and support STAR research. We are the reason other people give their money, their time and their brilliant minds to our cause. More will do the same if they learn about CMT (and we can avoid the tricky bit of what CMT stands for until the next time we chat).

I rarely know why any particular person decides to ask uncomfortable questions about my disability. It's tempting to generalize that strangers are simply nosy, but I believe most people ask when they care, and I know from experience that sometimes they will later act helpfully on the information they receive.

Maybe our inquisitive stranger is an engineer who will one day design a new AFO, or the friend of someone with hands like ours but without a diagnosis. Maybe they're holding a winning lottery ticket and feeling incredibly generous. We don't know why they are asking, but they are giving us an opportunity to welcome them to our cause, so let's all do that. It's in our collective best interest to give people accurate information that enables them to help if they want. Not ALL the information, but enough accurate information to answer the question. The more we talk about CMT, the more financial, intellectual and volunteer resources our community can access.

In this season of giving, I want to give my Tribe some of the words I've come up with over the years to explain Charcot-Marie-Tooth Disease without stress. Living with CMT is hard enough; talking about it doesn't have to be.

Particularly for a first interaction, I've learned less is more. I use this A+B+C equation to help me talk easily about CMT:

I have CMT. It's....

A

+

hereditary and...
a nerve disease...
degenerative and...
a neuromuscular disease...
a rare disease that...

B

+

makes me drop things.
that makes me trip on my own feet/the ground/nothing.
affects my balance; I have to be careful not to fall.
that causes me to have less energy / need more time.
makes it hard for me to open packages.
causes my hands to shake.
makes some things more challenging for me.
made surgery necessary.
makes it necessary for me to budget my energy.

C

I choose what to say depending on my mood and why I think they are asking: "I have CMT. It's a nerve disease that makes my hands shake." Column C is some of what I personally deal with, but your column C might be different. Once I had my A+B+C in muscle memory so I no longer had to think about how to answer, I stopped feeling stressed when a stranger approached me.

Now it feels easier to say more if I want to, like what CMT stands for (tip: I learned that if I start with "It's named for the doctors who first defined it," I get fewer questions about my teeth), how my braces help me or that they may have heard that country singer Alan Jackson announced he has it, too—whatever I feel led to say in the moment. And if I don't want to elaborate, I can walk away knowing I may have helped our community with my answer. The beauty of this approach is it educates the askers a little bit about CMT, addresses their immediate questions and is as easy as I need it to be.

This holiday season, I've decided to use my words in a more formal way by adding a short note to my holiday cards asking folks to donate to CMTA-STAR research at cmtausa.org/curecmt. I don't know if or how many gifts will come in, but the top reason people give is because someone asked, so I'm asking. Even if they don't do anything with it this year, they will see "CMT" when they read it, and maybe one day they will be in a position to attend a walk, volunteer or make a financial gift. I don't know what it will look like, but I'm still planting a seed and having faith that it will grow. I can say from experience that it's a delightful surprise when someone I wasn't expecting to help actually does. I hope you all get to experience that at least once.

Let's give all we can to our cause, including our words.

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

INNERVATORS HONOR ROLL

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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Richard Arsenault
Aaron Baker
David Balbi
Kelly Banner
James Barker
Chevelle Bazo
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Cheryl Bidgood
Aaron Bokmeyer
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***RICK CLEMENTE** of Valencia, Penn., became an Innervator to honor his late wife, Cecilia. "The influence of Cecilia's CMTA family helped her to reclaim a sense of normalcy and joy," he said, adding, "The members of the Pittsburgh branch of the CMTA had a profoundly positive impact on our lives."*

TWO PATIENT PERSPECTIVES

CONNECT AND INFORM *By Catherine Whittemore*

I had the pleasure of attending the recent CMTA Patient & Research Summit in Boston Nov. 4. I went specifically to hear about genetic testing—about 10 years ago my family looked into testing and found it cost-prohibitive. At the conference, though, genetic counselor Trisha Multhaupt-Buell, MS, LCGC, from Massachusetts General Hospital made it sound like genetic testing would be feasible and potentially useful. I also met many others with CMT in their families who found testing useful.

The conference not only provided answers from experts, it provided connection. I was surrounded by an entire community of concerned people facing the same challenges my family does. My daughter Tulip, 14, has attended Camp Footprint for the last five years, and I was pleased to see her connecting with friends young and older who clearly know and love her. There really is unity in community, as keynote speaker Victoria Brezovich told the group.

Orthotist and CMTA Advisory Board member Ken Cornell gave a presentation on gait. I hadn't known half of what he said, and I left feeling like I needed to up my game for orthotics. My daughter has a goal of hiking with a peer group. The next trip includes "rock scrambling," which I have doubts about. But with different AFOs, maybe she could.

I was not prepared for the onslaught of information, but I am so glad that I attended in person so I could also connect face to face.

Catherine is a registered nurse in Saco, Maine. Her daughter, husband and father-in-law all have CMT. While she works in long-term care, she had never heard of CMT until she met her husband.

FAST FRIENDS FROM THE START *By Kathy Chau*

I'm a student at the University of Utah studying biology with an emphasis in genetics and genomics with a disabilities studies minor. I also have CMT2A. The CMTA Patient & Research Summit covered all my interests. I felt honored to be in the presence of the top researchers and scientists spearheading the research for a cure for CMT. I felt the love and community of these people whose drive is to help all of us with this progressive disease.

You'll meet wonderful people at any event or organization that the CMTA leads. I sat down next to a gentleman who was wearing the same braces as me. He was positively giddy and told his wife to take a look at mine. From then on, we were friends relating to each other about our deepest struggles. I even gave him a tip to prevent the squeaking of our braces. I was also privileged to have my significant other join me for the conference. It was his first time meeting others with CMT, and it changed his perspective.

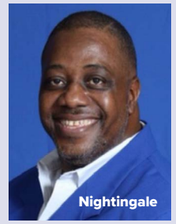
That evening, we attended a COMPASS meeting with Board Chair Gilles Bouchard and new CMTA CEO Sue Bruhn. COMPASS is a program for young adult professionals with CMT and this was the first time for some of us to meet in person. We shared our ideas of how to navigate COMPASS and the future of CMTA. It was a breath of fresh air to have the chair and CEO sit in our meeting and listen with compassion.

During the happy hour that followed, I got to know these people, who are now my friends for life, whether they like it or not. We stayed up until three in the morning having meaningful and deep conversations that I couldn't have with the loved ones in my life. I feel immensely grateful to have experienced the Patient & Research Summit. I am excited to see what the coming years will bring.

CMTA PRIORITIZES STRATEGIES FOR DIVERSITY, EQUITY, INCLUSION AND ACCESSIBILITY

The CMTA board and staff are dedicated to providing equity and inclusion for all members of the CMT community. In 2021, they launched a DEIA (diversity, equity, inclusion and accessibility) program aimed at ensuring that historically marginalized communities have equal access to community engagement, education, patient support and research opportunities.

According to staffing firm Insight Global, "Diversity refers to a wide and varying range of groups within a community or population—think ethnicity, religion, abilities, sexual orientation, and other dimensions of diversity. Inclusion is the active engagement of all members of that community or population. Equity is the fair and just treatment of those members regardless of how they identify." And accessibility, a recent addition to the theory, refers to the opportunity for a person with a disability to acquire the same information and materials, engage in the same interactions and enjoy the same services.



Reaching toward those goals, the CMTA launched a pilot program in Jacksonville, Fla., in 2022. The aim was to provide people of color (POC) in Jacksonville (JAX) with education about CMT, to share resources with them and to invite them to be part of the CMTA community. Led by project manager Tim Nightingale (also leader of the Jacksonville Branch), the CMTA invested in a multi-layer marketing plan to reach the target audience. It included radio ads (traditional and streaming) on the largest R&B station in the region. A 30-second commercial ran on broadcast radio 94 times and garnered 62,000 impressions on the station's digital platform.

A radio interview with Nightingale ran in the Community News segment, and the CMTA ran Google and Facebook ads at the same time as the radio campaign. The team also conducted grassroots church outreach to 15 traditionally Black churches. During the three-month campaign, the JAX CMTA Branch page was the seventh most visited page on the CMTA's website.

Looking back, Nightingale praised the project's success at reaching people and driving traffic to the website. On the other hand, he noted, 90 percent of the increased traffic came from Google ads and not from the radio or church outreach.

The CMTA made a number of additional outreach efforts in 2022, including community members of color in the materials and on the website and providing educational materials in Spanish.

Based on the lessons of 2022, the DEIA committee decided to adjust its focus and go directly to people who might bring CMT community members of color into the CMTA. They began calling on Black and Latinx neurologists and podiatrists in the largest markets in the country with the goal of educating them about the CMTA and creating awareness for its programs. The committee also hoped that people of color with CMT would feel more comfortable talking to a doctor of color about their disease. Nightingale personally called 57 clinics, nine of which requested patient folders.

For the rest of 2023, the committee will focus on branch outreach—identifying community members of color who want to lead a branch in their areas and asking three to five branch leaders to ask Disability Offices in their market to share CMT educational materials and patient folders with their CMT clients. Anyone interested in leading a group or helping to start a group, please reach out to Laurel Richardson at laurel@cmtausa.org.

More educational materials will be translated into Spanish by year's end, and the CMTA will be offering the newly translated "PT/OT Guide" in a hard copy and digitally. In addition, the CMTA offers live captioning at monthly educational programming events and at the annual Patient & Research Summit.

The Mexico branch has been added to the Spanish-speaking section of the website, and two new Latinx community members will be leading the new Miami branch.

In 2024, the committee plans to start branches in two new cities with high populations of Black and Latinx Americans and seek out people of color in the community to lead branches or fundraising events. They will also continue to ensure diverse community members and their families are represented in marketing materials and continue to build trust and relationships with diverse community members and their families via Camp Footprint.

THE UNITERS

Alicio (far left) and fellow climbers

As the saying goes, "Individually we are all one drop, together we are an ocean." But it takes a uniter to bring those drops together. At the CMTA, we are fortunate to have hundreds—if not thousands—of uniters working tirelessly to unite others in an effort to create awareness about CMT. They bring people together for walks, rides, branch meetings and fundraising. Their fundraising powers the CMTA's research, and together we all move forward. At a time when it's tough to get people to unite around anything, our uniters push us forward and lift us up.

UNITED ON KILIMANJARO

People have walked 4 CMT, golfed 4 CMT, biked 4 CMT and danced 4 CMT but Alicio Pina is one of the very rare few who have climbed Mount Kilimanjaro for CMT. He did it because his son Chris has CMT.

Chris was a hiker until he reached his teens. Now 36, he was diagnosed with CMT in his late 20s. Since then, he has worked diligently to build up his muscles through exercise and physical therapy. He wears foot braces to avoid unnecessary falls, but other than that he lives a normal life.

Climbing the highest mountain in Africa was on Alicio's personal bucket list: He wanted to do it before he turned 60 in January. After a friend hiked the Camino de Santiago as a fundraiser for a local children's hospital, Alicio decided to make his climb a fundraiser for the CMTA.

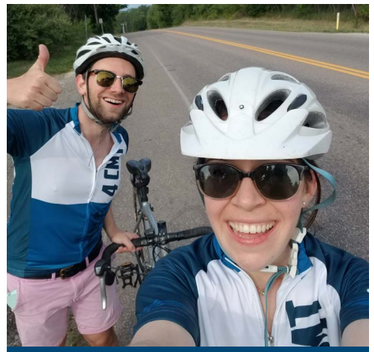
Fueled by a deeper purpose and meaning—raising funds and awareness for CMT and CMTA-STAR—he began training. He did extra training for two months before the hike, which took place Sept. 25 to Oct. 3, including leg-strengthening exercises and special classes in an enclosure that simulated working out at the decreased oxygen levels found at 12,000 feet.

He also hiked Mont Blanc in the Alps, Pico Duarte in the Dominican Republic and numerous parks and beaches near his Miami home.

Alicio and his wife Nirma first got involved with the CMTA after learning that she was a CMT carrier: Chris's younger brother has a mild case of CMT, while their daughter tested negative. They took part in several Walks 4 CMT and decided to get more involved because "We believe it's important and necessary to join efforts and work together. We also saw how much good the CMTA does."

A fundraiser doesn't have to be a gala or a walk, Alicio said. "We should all think outside the box in ways to raise research funds for the CMTA."

Friends, family and business associates all united behind Alicio and his out-of-the box fundraiser. Together they raised an astonishing $50,000 for CMT research and the gratitude of the entire CMT community.



Mary Cate Zipprich and her husband Aaron hosted the 2023 Cycle 4 CMT in Boston.

UNITING AGAINST CMT4C

Mary Cate Zipprich is another uniter. Through her 4C Facebook group and Patient as Partners in Research community, she has motivated and inspired other 4C patients to unite as a task force and work together to raise funds for the CMTA's Strategy to Accelerate Research (STAR).

Mary Cate's CMT journey is unique. She had symptoms—weird feet, severe spinal deformity requiring surgery and clumsiness—from a young age. But it wasn't until she was in college that she read an article about CMT in *The New York Times* and a lightbulb went off. She diagnosed herself and when she went home to New York City over break, a neurologist confirmed the diagnosis. She ultimately received genetic confirmation of her recessive demyelinating type. She is the only one in her family to have CMT.

After college in Boston, Mary Cate moved to Somerville, Mass. She worked for a time at Mass General, where she began seeing a neurologist at the CMTA Center of Excellence. Today, she works as a healthcare IT consultant for a hospital in Texas.

Her work means she knows firsthand how important "patient access" is—seeking an appointment to get a diagnosis, or a PT referral or trying to get genetic testing covered by insurance aren't abstract to her. She looks for ways to get patients through the new patient process and in the door to see the right specialist from the start. "Having a lot of experience as a patient has really helped keep me motivated in my job and striving for excellence in all of my projects because I know that there is so much stress and even financial burden on patients when that process does not go smoothly and efficiently."

Mary Cate's day job also informs her volunteer work for the CMTA. She's a planner and likes to research all her options and then make a thoughtful decision based on that research. "Having CMT really challenges that sense of control. We still know so little about CMT, especially the rarer types like 4C, and what the pathways are in the body, what the long-term outcomes are and what factors play into the progression of the disease."

Those unanswered questions drove Mary Cate to try to understand CMT better, to connect with other 4C patients and the researchers working on the disease and to become a better patient advocate. She spends more and more time volunteering because she feels "like we are on the cusp of something important," and she recognizes that committed volunteers are needed for the work to proceed. As she noted, "In order to cure a disease, researchers have to know what it is, be able to build on each other's work and discoveries and identify patients that they can partner with when the time is right for clinical trials." Mary Cate participates in the longitudinal natural history study for several types of CMT, including 4C.

In addition to her 4C groups, Mary Cate and her husband Aaron fundraise for the CMTA. They started off with just the two of them going to the Cycle 4 CMT in Vermont, then began recruiting family and friends to go with them. When they found out there wasn't going to be a Cycle 4 CMT in Vermont in 2023, they decided to host their own ride in Boston. CMTA Walks Coordinator Mary Louie connected them with another couple in the Boston area and they partnered up for the event.

The couple has also raised funds for the CMTA using some of their big life events: When they married in 2022, they set up QR codes so guests could make donations to the CMTA in lieu of wedding presents.

While Mary Cate isn't a big Facebook user, she says the CMTA Facebook groups have been a lifeline. They were an incredible source of knowledge when she was planning a trip to California for foot surgery with Dr. Glenn Pfeffer, and many casual Facebook connections have turned into meaningful relationships that continue outside the CMTA group.

The private CMT4C support group that she helps moderate has also been a great source of friendship and solace on her tougher days, and she has met up with several internet CMT friends

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UNITING AGAINST CMT4C

continued from page 15

in real life. The group, which just reached 200 members, runs quarterly Zoom meetings so 4C patients from around the world have a chance to chat face to face. “I know so many of us don’t know any other CMTers so I am grateful to the CMTA for providing this virtual space and I hope others are able to find meaningful support and friendships that can extend beyond the group in the way that I have.”

Mary Cate’s advice for other CMT patients is simple: Find support. Go to a CMTA meet-up, post on the Facebook group and find a care team that understands CMT. Being able to reach out to someone who understands CMT makes such a difference after a hard day. Also, she points out, being proactive feels really good. While she can’t control the progression of her disease, she can control how much she does to bring awareness to CMT, how involved she gets in research and how knowledgeable she is about the latest studies. “Knowing that I have done my part to fundraise and advocate brings me that sense of control and has been extremely fulfilling,” she said.

UNITING ON TIKTOK

Kyle Will, who has CMT2, is an online uniter. He shares his personal fitness journey with some 50,000 TikTok subscribers (kylewilltv) and livestreams with his audience every night, dispensing healthy lifestyle tips and information about CMT and inspiring everyone within earshot.

Kyle was born in Australia, where he was diagnosed at the age of 5. He’s the only one in his family with CMT. He hid his disease until he was 32, covering his braces with long pants. He was so overweight that he found it difficult to walk for five minutes. He says there was no particular catalyst for his transformation—one day he just woke up feeling terrible and said, “I can’t do this anymore.”

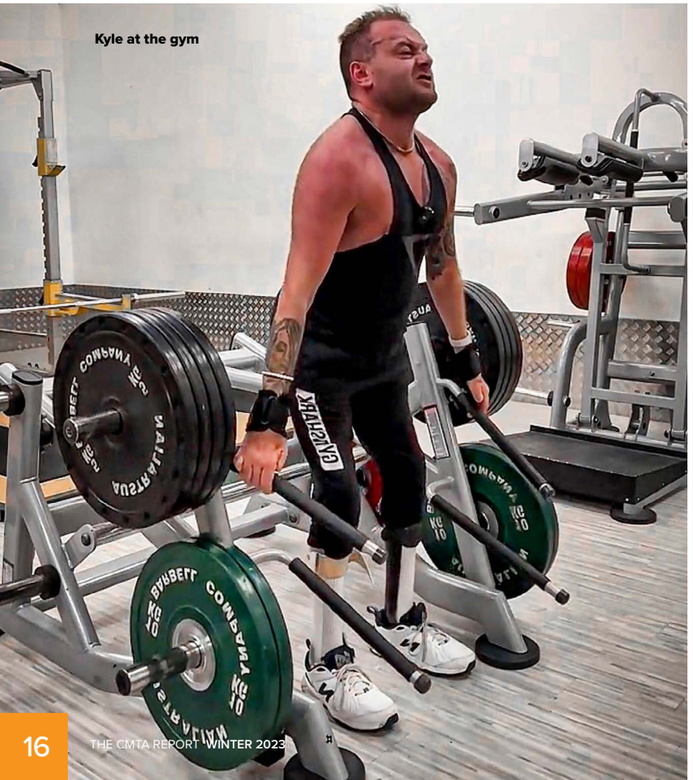
He resolved to start living a healthier life, closed his ad agency and moved to Darwin, the tropical capital of the Northern Territory. His biggest challenge wasn’t physical, but mental—coming to terms with his CMT. He stopped telling people that his limp was caused by an accident, which he thought somehow made it cooler, and switched out the long pants for shorts.

Kyle’s workout regimen and healthy eating brought the 5'6" influencer’s weight down from 101 kilograms (222 pounds) to a very fit 69 kilograms (152 pounds). There was another positive side effect—once he became healthy, he was much less ashamed of his disease. “Once you find your purpose, nothing is a struggle,” he says today.

Kyle is looking forward to being a counselor at Camp Footprint in 2024, where he will share his message of hope and inspiration with still another audience.

KYLE’S TOP TIPS FOR PEOPLE WITH CMT:

- **Don’t hold back, push yourself.**
- **You are way more capable than you think.**
- **You are you, not your disease.**
- **Exercise and a good diet are essential.**



Kyle at the gym

UNITED BEHIND CADEN

Like many other brave parents in the CMTA community, Kara Kornberger decided to turn anxiety into action when her then-3-year-old son was diagnosed with CMT2A. The anxiety came first; “Caden’s diagnosis was very unexpected and hard to swallow. I had a very hard time talking about it with anyone. Being told that your son has a progressive disease is very scary.”

The action followed. Kara started Caden’s Crew to Walk 4 CMT in 2022. Sixty close friends and family joined the walk, raising $11,300 for CMT research. “Starting this journey made it a little easier to talk about,” Kara said. “Raising money and joining together to walk for CMT made me feel like we were making an impact. The love that we felt was inspiring.”

In 2023, Caden’s Crew grew to 100 friends and family members and raised $13,577. As an added benefit, Kara found that “Spreading awareness with our friends and family has made life easier. We have an amazing team of support at school, at work, in sports and with family.”

Kara is no longer reluctant to talk about Caden’s CMT. Starting a walk gave her hope, she said. “In addition to the money raised, each person that we make aware of the disease is one more person that knows about it. The more awareness, the more calls for a treatment or better yet, a cure. It has given me hope that one day Caden will be able to live his dream of playing on a high school sports team.”

The family’s CMT journey began when Caden was just 2½. Within a five-month period, he broke both legs and his foot and sprained his ankle. He was in a boot/cast for the better part of five months and his muscles atrophied. Prior to the injuries, Caden hit all his milestones early and the family saw no signs of CMT. Afterward, Kara noticed that he was struggling to keep his balance.

Kara knew something was really wrong the day she dropped Caden off for preschool and couldn’t get him to stand up. He started physical therapy with Michele LaManna of Kidz on the Move (who has become a vital part of Caden’s team), and she recommended that the family seek further testing. After a nerve conduction test and electromyography, the doctors made the diagnosis. They found that he had severe nerve damage in his legs and mild damage in his hands. Genetic testing confirmed that Caden had a spontaneous case of CMT, the first in the family to have it.

Caden, now 6, attends public school, where he has a plan to help accommodate his needs and teachers who help him. While he struggles with stamina and keeping up with his peers physically, he loves sports and is always throwing a ball, shooting hoops or hitting a baseball. He is the youngest player on a coach pitch baseball team, does Taekwondo at the brown belt level and plays basketball and flag football. But basketball is his favorite, and he spends hours shooting hoops. If he is not at practice or a game, he is asking his parents or his 8-year-old brother to play with him. His peers and coaches are amazed at his determination and attitude.

Kara thinks everyone should live life like Caden—starting each day with a smile and laughing a lot along the way. Figure out fun ways to exercise and keep moving, she advised, noting that “Caden never stops.” She also recommended finding a good team of people, both medically and personally. Above all, she said, “Set your goals high and don’t sell yourself short.”

Caden was diagnosed with a spontaneous case of CMT2A when he was 3. Friends and family have joined Caden’s Crew to raise funds for CMT research.

Prepping High-Schoolers With CMT For the Transition to College

Transitioning to college is exciting and terrifying, hope-filled and overwhelming. For students with CMT, the transition can involve additional challenges. Annie Tulkin founded Accessible College after she discovered that many of the disabled students she was working with as the associate director of the Academic Resource Center at Georgetown University had not received the support needed to prepare for the transition.

According to Annie, the transition starts with picking a college. She recommends that students choose a school based on their desired college experience, looking at factors like location, size, staff-to-student ratio and special programs. After identifying their top colleges, they should research what kind of support the schools provide. All colleges seem to call their disability support office something different, but they can often be found by searching for the words “disability” or “accessibility” on the school’s website.

Any school that accepts federal funding (a majority of colleges) must provide “reasonable accommodations” in accordance with the Americans with Disabilities Act (ADA), which serves to “level the playing field” by accommodating for disability-related needs.

Accommodations are tailored to the individual and based on need. For students with CMT who experience fatigue or pain, accommodations may include alternative ways to move about campus and/or complete class work that requires the use of hands. It isn’t necessary to go to the disability support office with a “wish list,” though having a sense of what’s needed for a particular condition is good. The office will interview and possibly assess the student in order to work together to develop a plan with appropriate accommodations.

Typically, a 504 plan or Individualized Education Program (IEP) from high school doesn’t transfer to the college setting. The disability office may look at a high school 504 plan or IEP,

Any school that accepts federal funding must provide “reasonable accommodations” for disability-related needs.

but most colleges require primary documentation from healthcare providers and will create their own unique document after talking with the student. The big shift from high school to college is the increased emphasis on student responsibility.

Additionally, colleges do not provide services that may have been included in an IEP such as an aide/paraeducator or occupational therapy, because college is optional and high school is not. Self-advocacy and self-awareness are very important in college. College professors won’t chase students down for missing work, while high school teachers may have held students’ hands a bit more.

To deal with the fact that disabilities and chronic health concerns manifest inconsistently, accommodations should be written for the toughest days, leaving students in charge of when to use them. Some college plans will include language to express that the disability’s impact varies to ensure professors and staff understand.

Annie suggests that high school students get comfortable talking about CMT, using the word “disability” and self-advocating. This can involve small steps at first: Being able to discuss CMT with a teacher or asking for help in more private places can help build comfort and confidence. Rehearsing these things with trusted adults can make them less emotional or overwhelming.

She cautions that while the word “disability” can be emotionally charged for many, it will show up on some forms at college because the process for requesting accommodations in the college setting is based on the ADA definition of a disability (“...a person with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activity”). Helping your brain feel okay about the word can ease future conversations.

For more information on the CMT college experience, read “A Guide to Surviving College for CMTers” at https://bit.ly/3rUxHtN. For more information about Accessible College, visit https://accessiblecollege.com.

THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS...

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Darrell Adolphus
Shane and Nicole Gorman
Jennifer Jones

Christine Bikos
Henrietta Cook

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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 CMT1B.

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

Dear Elizabeth,

One of my family members has to have surgery because of CMT, and I am wondering how to provide support.

Elizabeth Replies:

It's never easy to witness someone's suffering, and surgery can be particularly daunting for both the patient and their family. In our household, we've gone through more than eight surgeries to address foot and hand issues related to CMT over the years. With each surgical experience, we've gained valuable insights and have come to understand that we're doing the best we can in any given moment. It's crucial to approach this journey with consideration and empathy, both for the patient and yourself as a caregiver or supportive family member. Here are some ideas to keep in mind.

Open Communication: Promote open and honest communication. Let the patient know that you're there to listen, and that they can freely share their feelings and concerns. Sometimes, all someone needs is a listening ear, and you don't have to fix everything.

Empathy: Display empathy and understanding regarding their fears and concerns. Offer reassurance and validate their emotions. Being empathetic can go a long way in providing comfort.

Education: Help the patient grasp the surgical procedure, what to anticipate before, during, and after surgery and any potential complications. Knowledge can alleviate anxiety. Compile a list of questions for the surgeons. For example, when my son had his initial surgery at age 7, we had a list, and the orthopedic surgeon addressed each question, which helped my son's fears.

Provide Distraction: Engage in activities or conversations that serve as distractions. We fondly remember watching "Shark Week" on TV after one surgery and enjoying a "Star Wars" movie marathon after another.

Seek Help from Others and Say Yes When People Offer It: Don't hesitate to seek assistance with practical matters from people around you. This includes organizing transportation to and from the hospital, preparing the home for their return and arranging meals. Small gestures like a plate of brownies or a container of soup can make a significant difference.

Create a Comfortable Recovery Environment: Before surgery, spend time preparing a comfortable recovery space that is well-organized and put all the necessary items within easy reach. For instance, extra pillows can be a lifesaver when a foot needs to be elevated for pain relief.

Support Mental Health: Maintaining mental well-being plays a crucial role in the healing process. Keep in touch regularly during their recovery to provide companionship and support. Simple gestures like texting a funny story or a friendly "How are you today?" can lift spirits.

Encourage Positive Thinking: Help the patient focus on positive aspects and potential outcomes, while also acknowledging their concerns. Seek out and share stories of individuals who've undergone similar surgeries and had successful recoveries. These stories can provide hope and inspiration.

Normalize Emotions: Let them know that it's perfectly normal to experience a range of emotions throughout the process. Feelings may cycle from fear, exhaustion, frustration, sadness to moments of joy, and that's okay.

Adapt Your Support: Every individual has unique needs and preferences. Ask the patient what you can do to support them. Your presence and care can have a profound positive impact on their mental well-being during this challenging time.

Your presence and support can make a significant difference in the journey to recovery, and your empathy and understanding are invaluable during this challenging time. I wish you all the best and remember your CMT community can support and help you too. Try attending a virtual branch meeting to hear other people's stories and to build connections and support. For a complete list of branches, visit bit.ly/3QivdyP.

A Neurologist Said I'd Be in a Wheelchair By 40, But Surgery Got Me Back on My Feet

BY VICTORIA CARRAI

I am incredibly grateful for those who have shared their CMT surgery journeys, and I hope my story will provide encouragement for someone else. I recently had reconstruction surgery on my right foot with Dr. Tyler Gonzalez in South Carolina, and I'm glad I did.

CMT1A is in my family and though I started showing mild signs of it in my childhood, I was resistant to learning more about it. Stubbornly judging from what my family members with CMT looked like, I figured CMT was just a "disease" that I wouldn't have to deal with until far later in life and it didn't seem "that bad."

That changed with my first serious ankle sprain while wearing platform heels in my senior year of high school. It finally started sinking in while I was in college when I continued spraining my ankles more times than I can remember. In 2018 I joined a gym, but I took a bad fall off a treadmill and became very embarrassed doing any sort of physical activity in front of others.

In 2019, I attended my first-ever branch meeting in Wilmington, N.C. I'm so grateful that I did because Dr. Gonzalez spoke there about surgery options. He graciously took the time following the presentation to examine my feet. He also showed me exactly which athletic braces would help protect my ankles from reinjury.

While my progression was almost unnoticeable day to day, I remember waking up one day after many months of being mostly sedentary and weeping over how much ability I'd lost. I realized I'd never be able to wear flip-flops again because my toes just couldn't hold onto the shoes anymore. I work in parks and recreation and find pride in doing things with my hands or mowing the lawn, but I realized it was time to start asking others for help. I also realized that I needed to do something to slow the progression.

In 2022 I saw a neurologist for the first time. Her opinion from my nerve conduction test was that I'd "be in a wheelchair by age 40." That hit me hard and lit a fire within me to prove her wrong. I began wearing personalized shoe inserts—which have been everyday game changers. I joined Orange Theory Fitness and started gaining muscle and feeling much healthier.

I also started really digging into learning about CMT. I followed Dr. [Glenn] Pfeffer's Instagram account @charcotmarietoothsurgery and listened to his interview on the CMT 4 ME podcast about not living with crooked feet. These, along with reading about others' first-hand experiences on the CMTA Facebook group, really gave me hope and I started wrapping my head around the possibility of having CMT foot surgery myself.

Logistically and financially, however, I had trouble rationalizing having surgery in Los Angeles with Dr. Pfeffer when I lived on the opposite end of the country. I recalled from the CMTA branch meeting presentation that Dr. Gonzalez had studied under Dr. Pfeffer—and his office was only 3.5 hours away.

When I finally went to see Dr. Gonzalez, he was just amazing. We discussed options, and he assured me that he wouldn't suggest surgery for anyone who didn't truly need it. He took the extra time with me (which he does with all CMT patients) to have a detailed visit. We reviewed my X-rays, he asked about my lifestyle and current issues and he voice-recorded himself explaining his surgical plan. My reconstruction surgery focused on stabilizing my ankle, flattening my arch, and straightening my heel and toes. We were ultimately able to work out a plan for outpatient surgery.

On the morning of the surgery, I was nervous, but everything went smoothly. I had no issues with the anesthesia and the nerve block was well worth it. The surgery lasted about four hours and my husband received regular updates to his phone in the waiting room.

Thanks to the nerve block, I was able to travel home and sleep in my own

Victoria recuperates from surgery.

bed that evening without experiencing any pain. My surgery included right foot reconstruction with Achilles tendon lengthening, medializing wire type calcaneal osteotomy through a minimally invasive approach, longus transfer, posterior tendon transfer to the lateral cuneiform, plantar fascia release, medial soft tissue release, dorsiflexion osteotomy of the first ray and correction of the second, third and fourth hammertoes.

My post-op experience was a wave of ups and downs. I experienced some pain, but it was manageable. One thing I didn't fully anticipate was how difficult using crutches would be and I wish I had spent time practicing using them with an ankle weight before the surgery. Being new to using crutches, having a bulky heavy cast on, and feeling slightly dizzy from medication during the first few days made them very difficult for me, but I felt much more confident once I was able to use the knee scooter. Also, I don't think anyone tells you just how good and refreshing that first post-surgery shower will feel once you're up to it—I felt like a whole new person.

While recovery was a long process, I'm still incredibly glad that I made the decision to have surgery. Once I'm fully recovered, I plan to ease back into exercising and exploring the outdoors again. As my favorite parks and recreation professor would say, "Move everything that still moves, every day."

Victoria, 29, is a parks and recreation worker from Wilmington, N.C.

FUNDING CMT RESEARCH WORLDWIDE:

CMTA'S STAR LEADS THE WAY

The CMTA's Strategy to Accelerate Research (STAR) is the largest philanthropic funder of CMT research worldwide. Our commitment to advancing research is unwavering.

Just as the CMTA is the driving force behind CMT research, the patient community is the driving force behind the CMTA. Community members and their friends and families are the reason we thrive and will ultimately change the future of CMT.

With the support of our community, the CMTA has invested $23.8 million in 60 research projects covering more than 90 percent of all CMT subtypes since STAR was founded in 2008. We have also developed critical research tools that have attracted more than 40 partners to our STAR Alliance.

The pace of research can feel frustratingly slow, and we haven't yet reached our ultimate goal of a cure for CMT. But we've achieved a number of key milestones on the road to a world without CMT, and we are determined to continue driving progress with your support.

MAJOR MILESTONES

Critical Infrastructure

In 2001, Dr. Michael Shy and the CMTA established the North American CMT Database to give researchers ready access to families categorized by their types and subtypes.

In 2011, the CMTA established Centers of Excellence to help ensure that CMT patients receive the best possible evaluation and care and that their information is collected for possible recruitment into clinical trials. This network has now grown to 52 centers in five countries.

With CMTA support, the global Inherited Neuropathy Consortium (INC) has expanded to 20 sites and recruited over 7,000 patients to the clinical registry and natural history studies, which will support clinical trials.

In 1991 we identified the gene that causes 1A. Today 129 genes and 163 subtypes have been identified. CMTA support has directly contributed to 25 of these discoveries.

Critical Research Resources and Learnings

New rodent models of CMT have emerged as crucial testing resources for potential therapies covering CMT1A, CMT2A, CMT1X, CMT2E and CMT1B. The CMTA directly funded the creation of several best-in-class animal models, reducing the barriers faced by researchers and pharmaceutical companies.

Working with the New York Stem Cell Foundation, we established the first CMT biorepository in 2014. The stem cell lines and patient samples in the repository are an essential resource for academic and commercial researchers.

We're pursuing multiple strategies to develop therapies for various CMT types. For instance, in CMT1A, we're investigating genetic therapies (ASO, RNAi, AAV gene therapy, and CRISPR-Cas9 genome editing) as well as drug-based approaches. Our collaborations with various companies encompass diverse methods, and we aim to identify the most effective CMT1A treatment through parallel clinical trials. Similar parallel approaches are being pursued for other major CMT types.

Gene Therapies

Gene therapy has been shown to be an effective strategy in preclinical models of CMT1A, CMT1X, CMT4C and CMT4J. Company partnerships have been established to advance these therapies from the lab bench to the next stage of pre-clinical and regulatory testing in readiness for first-in-human clinical trials.

Delivery of gene therapy reagents to motor neurons has culminated in an approved therapy for spinal muscular atrophy. Similar approaches for CMT4J and giant axonal neuropathy (GAN) have been successful in preclinical studies, and other efforts in CMT2A, CMT4A and CMT2E are underway.

Delivery of gene therapy reagents to Schwann cells for demyelinating CMT remains a challenge, but AAV gene therapy studies have been successful in some preclinical models, with other advances reported for delivery of RNAi in demyelinating CMT. The CMTA recently funded a study that will investigate nanoparticles as a non-AAV delivery vehicle for gene therapy.

Gene editing using CRISPR-Cas9 is in clinical trials for ATTR-associated neuropathy. This technology may be applied to several types of CMT if effective delivery strategies for Schwann cells and motor neurons are found.

Drug Therapies

Several studies have highlighted the efficacy of lowering PMP22 gene expression in preclinical models of CMT1A, including the use of antisense oligonucleotides and RNA interference.

HIGHLIGHTS AND LEARNINGS OF ALLIANCE PARTNERS

The CMTA's research is done in teams drawn from academic labs and clinical centers sponsored by the CMTA (the STAR Alliance). One of the Alliance's first initiatives was to develop a toolbox of cell and animal models for Alliance partners to use in their research. The toolbox has been crucial in recruiting partners and in 2022 drew 12 Alliance partners to invest more than $2 million in 28 studies.

Most companies do not have the time and knowledge (or the funding) to put a CMT testing infrastructure in place. Without the infrastructure provided by the CMTA, they probably wouldn't explore CMT therapy opportunities.

Company projects are often adapted from treatments for other neurodegenerative diseases, increasing the possibility they'll be effective against CMT. Company approaches to CMT cover the span of therapy modalities: Small molecule, biologic and genetic therapy approaches are all represented. The Alliance approach is intentionally "therapy agnostic," which allows us to partner across the spectrum.

We regularly get requests for relatively rapid and valid tests in a dish that would show whether a potential therapy should advance to animal testing. The CMTA is investing in the development of additional in vitro models to add to the toolbox, removing yet more barriers for companies that want to test a therapy's effectiveness against CMT.

Many companies want to see effectiveness across a number of CMT types and commission studies in multiple models. The CMTA's broad capability makes this approach possible.

Companies deciding whether to enter the field of CMT look at several criteria: (1) Is the mechanism of their therapy's action in the disease understood? (2) Can a clinical trial be successfully done? (3) Can the therapy be used safely and effectively over time? This is especially important in non-lethal but chronic diseases such as CMT. The CMTA's STAR efforts are helping to meet these criteria, from basic science and discovery to clinical trial readiness.

Most Alliance partners are well-financed and/or publicly traded companies, but the toolbox can also be used by early-stage companies, university projects and foundations that need know-how, early-stage investment or access to resources.

Company discussions and collaborations have shown that muscle therapies used in conjunction with CMT therapies to slow disease progression are a viable commercial option, and a broadly applicable approach for many CMTs.

Axon degeneration clearly plays a major role in the progression of CMT, and some candidate drug targets have emerged for testing.

A novel type of CMT caused by SORD mutations led to rapid clinical trials using a drug developed for diabetic neuropathy.

In a recent major advance, researchers have clarified the disease mechanisms in CMT2D, identifying treatment targets that will enable new types of therapy.

The Food and Drug Administration is designating an increasing number of potential CMT treatments (and drug-repurposing efforts) as orphan drugs, an important step on the path to CMT treatments.

Clinical Trials

One hurdle to clinical trials is CMT's relatively slow disease progression, which necessitates very long (and expensive) trials. CMTA-supported research on biomarkers—calf muscle MRI and blood and skin samples have provided several candidate predictors of therapeutic benefit to patients. Effective biomarkers can shorten the length of clinical trials and reduce the number of patients needed, lowering barriers to industry investment. Other important measures for evaluating functional outcomes (CMT-FOM), pediatric and infant assessments have been developed to support clinical trials. A vital prerequisite for clinical trials is the development of natural history studies for each type of CMT, and these have been completed and published or are currently in progress for most major types of CMT.

A new clinical trial for one type of CMT (HSAN1) will provide a major test of calf muscle MRI as a clinical trial outcome measure and will open the door for its use in clinical trials in other forms of CMT.

Our efforts in CMT research are designed to have a wide-reaching impact across various CMT types:

The development of biomarkers for clinical trials holds promise for improving the assessment and treatment of most CMT variations.

Our gene therapy strategy targeting CMT1X is poised to indirectly benefit other types that affect Schwann cells, such as CMT1A, CMT4C, and CMT1B.

A crucial element in combating CMT progression lies in preventing the loss of nerve-muscle connections, or axons, which could prove to be a common strategy with benefits extending to many different CMT types. Through these multifaceted approaches, we aim to advance treatments and therapies that can positively impact the lives of all individuals affected by CMT, regardless of type.

DONATE ONLINE AT: cmtausa.org/curecmt **or use the form on page 19.**

BRANCH NOTES


Long Island Branch

DENVER, CO
The Denver branch held its first in-person meeting since COVID on Sept. 16 with 11 people in attendance. Members enjoyed catching up, sharing their experiences at the University of Colorado CMT Center of Excellence, and sharing life hacks for the upcoming snowy season.


Jacksonville Branch

JACKSONVILLE, FL
The Jacksonville, Fl branch gathered in person on Sept. 16 to welcome guest speaker Gleydiane De Oliverira, PT. Gleydiane shared practical tips on managing CMT and improving balance. The branch concluded its meeting by discussing possible fundraising efforts for 2024.

CHICAGO, IL
The Chicago branch met virtually on Oct. 24 with 20 members in attendance. They introduced themselves, shared their CMT journeys, talked about local resources, and heard CMTA updates from branch leaders. The Chicago branch is enjoying monthly meetings and the community they bring.

SOUTHEASTERN KENTUCKY
The Southeastern Kentucky branch met in person on Oct. 7 for the first time. The new members introduced themselves, shared their CMT journeys, shared information about local medical professionals that they have had positive experiences with and planned future meetings.

MINNEAPOLIS, MN
Twelve members attended the Minneapolis branch's in-person and virtual meeting Oct. 28. Branch member Brianna Engebretsen spoke on how to live a healthier life with CMT, covering nutrition, movement and attitude. The Minneapolis branch will continue to meet regularly throughout the year.

NEW MEXICO
Seven members of the New Mexico branch welcomed guest speaker Erin Weierbach to a virtual meeting Oct. 28. Erin, a community program specialist for the CMTA, talked about advocating for ourselves with family and friends who may or may not understand CMT, how we view ourselves as "CMTers" and other related issues. The New Mexico branch will meet again in February.

LONG ISLAND, NY
The Long Island Branch held its inaugural in-person meeting on Aug. 26 at the Hauppauge Public Library. Led by Alessandro Cacciani, 16 members of the new branch introduced themselves and shared their CMT journeys. Laurel Richardson, CMTA director of community outreach, updated members on CMTA research and community programs. The branch plans to meet quarterly throughout the year.

PORTLAND, OR
The Portland, OR Branch met in-person on Aug. 5 to discuss wellness advice and lessons on living with CMT. They shared practical activities for those living with CMT and enjoyed learning from each other's experiences and socializing.

CENTRAL VIRGINIA
The Central Virginia branch held an inaugural meeting on Sept. 27. Twelve members introduced themselves and shared their CMT journeys, local resources and fundraising opportunities. Branch leader Karen Dyer-Smith provided CMTA updates.

MANITOWOC, WI
The Manitowoc, WI branch welcomed guest speaker David Misener B.Sc. (H.K.), CPO, MBA to a virtual meeting June 28. The CMTA Advisory Board member spoke about orthotics and prosthetics, sharing valuable information on bracing and how it benefits CMT patients.

IRA Charitable Rollover
The easy way to donate and make a difference!

- You can make a gift directly from your IRA.
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- Recently more and more CMTA donors have made gifts from their IRAs.
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- Our simple form can help you make a gift.

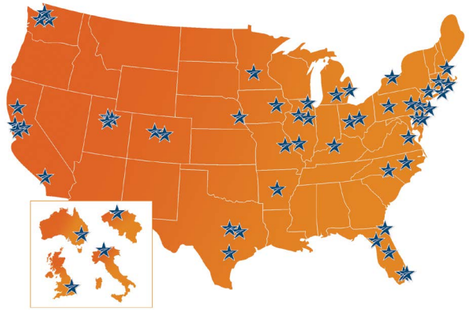
Email Jeana Sweeney at jeana@cmtausa.org.

CMTA
Charcot-Marie-Tooth Association

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

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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

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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
Appts: 801-585-7575

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Primary Children's Hospital
Clinical Director: Russell Butterfield, MD, PhD
Appts: 801-213-7756

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Shriner's Hospital
Clinical Director: Russell Butterfield, MD, PhD
Appts: 801-536-3564

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Clinical Director: Michael Weiss, MD
Appts: Gail Schessler, 206-598-7688

SEATTLE (ADULT)
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Appts: Kara Smith, BSN, 206-987-6678

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

(PEDIATRIC TO AGE 21)
Children's National Hospital
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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.

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