

THE CMTA REPORT

www.cmtausa.org



“NO MAN STANDS SO TALL AS WHEN HE STOOPS TO HELP A CHILD.”

—ABRAHAM LINCOLN

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PONYING UP FOR THE CMTA:
BOARD MEMBER DAVID COLDIRON HOSTS A KENTUCKY DERBY PARTY

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Dear Friends,

As the great author E.M. Forster wrote in *Howards End*, “Only connect.” At the CMTA, we are emerging from the myriad difficulties of the pandemic with a newfound sense of connection.

We reached out to connect with the community right from the start. You may have been the recipient of one of the more than 10,000 “welfare” calls we made to community members to ensure they were well and safe. We also expanded the mailing list for *The CMTA Report* and published multiple articles on CMT and COVID-19 so community members could stay informed.

The pandemic forced virtually all of the CMTA’s community outreach and education activities online. Our intrepid branch leaders held meetings throughout the pandemic, inviting CMT experts to share educational talks on the many facets of CMT, from genetics and foot care to occupational therapy for CMT hands to breathing issues. Members connected over shared tips, as they always do, and you’ll read about one of them in this issue: a heater massager that a member learned about at a branch meeting.

The CMTA’s Facebook groups provided a much-needed space for connection during the uncertainties of the pandemic. The CMTA Discussion Group, a Facebook group with more than 17,000 members, provided a welcoming and helpful community to everyone with CMT. If you’ve not yet connected, we invite you to join at www.facebook.com/CMTAssociation.

At the national level, we connected people across the country with our monthly educational meetings featuring special guest speakers on everything from pain management, bracing and surgery for the CMT foot, to occupational therapy, emotional wellness and nutrition. In this issue, you’ll read about two such sessions: Managing CMT Symptoms with Nutrition and Occupational Therapy for CMT Hands.

The CMTA’s Strategy to Accelerate Research (STAR) is also continuing to forge new connections between and among our alliance partners. While we delivered a comprehensive research update in the spring, we already have more to report as you’ll read about in stories on grants totaling \$1.5 million. The new grants will fund a study into whether a common food additive can be used to treat CMT1X, biomarker studies on CMT1X and CMT2A and gene discovery.

It’s wonderful to be able to plan events again and we are hard at it. That doesn’t mean that all events—branch meetings, Patient/Family Conferences and monthly educational sessions—will all of a sudden take place in real life. Virtual meetings have proved invaluable and we will continue holding them. For a while you’ll probably be seeing a hybrid model—some events like walks in person and others like branch meetings online. Whatever the format, we sincerely hope you’ll take advantage of the CMTA’s many opportunities to connect.

Best,

CMTA Chief Executive Officer



A MESSAGE FROM THE CEO

The Power of Connection

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STEVE WITH QUINN AND HER BIG SISTERS—
ELIZA, JULIANA AND CHLOE



CELEBRATING STEVE (AND HIS 2 DECADES OF FUNDRAISING)

Steve O'Donnell is a force of nature, as relentless as a hurricane and as powerful as an 8.5 earthquake. He also has a heart of gold, a soft spot for kids with CMT and a firm belief that a cure for CMT is within reach.

Whatever Steve does, he does full out, with unmatched drive and tenacity. It's what made the CMTA's longest-serving board member a successful businessman and it's what makes him a powerful fundraiser for the CMTA, with some \$1.78 million in his column (and more coming in daily) over the last 20 years. Steve sold his steel company in 2020, but you couldn't call him retired. Instead, he's focusing his prodigious energies on what has become his life's mission—finding a cure for CMT.

It all started with a swim. For many years, Steve's yearly fundraiser was a swim across the Chesapeake Bay he called the "Swim for the Cure." Beginning in 2002, he piggybacked his CMT fundraising event onto a swim held by another nonprofit. When they objected, he pivoted to a lesser body of water—The Tred Avon River—for an event he dubbed the Oxford FunAthlon. The event continued to morph, first online in 2020 and then to Baltimore in 2021 for a one-mile swim and a 20-mile bike ride.

Following Steve's fundraising lead, a number of other board members have also organized major fundraising events, including the Cycle (and Walk!) 4 CMT spearheaded by Elizabeth and Chris Ouellette and Gilles Bouchard, Herb and Rachael Beron's Team Julia swim and Phyllis Sanders' and Alan Korowitz's New York City Gala.

It would be hard to enumerate all of the good Steve does in the name of the CMTA, from inspiring the kids in his neighborhood to raise CMT research funds with a lemonade stand to working with physical therapist and neurologic clinical specialist Mike Studer to create a comprehensive fitness program for CMT patients of all levels and abilities. Not to mention the countless people he encourages, inspires and helps. Here are just a few:

Molly Fernandes, mother of our cover model Quinn, 3, says "We met Steve

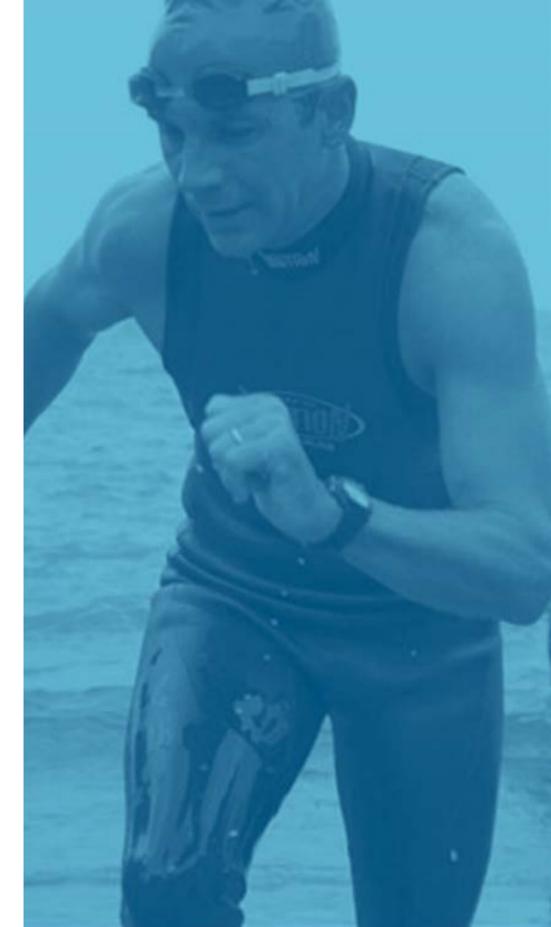
less than six months after Quinn's diagnosis with CMT1B and our introduction to CMT. It was September 2019 at NBC4 Washington, just moments before our live interview to raise awareness of CMT and the DC Walk 4 CMT the following weekend. Steve's passion for this cause was infectious and, for the first time, I was convinced we can find a cure for this cruel disease. Steve and Quinn became pals instantly. She even gave him a hug and kiss before parting! Over the subsequent months, it was clear that our Mighty Quinn worked her magic and inspired Steve as well. He checks in on her often and celebrates her every milestone. It's so nice to have met such a positive role model, inspiring leader, and all-round good guy so early in our CMT journey. And Quinn is honored to be the first female and the first child to receive the 'Man of Steel' award."

Steve inspires CMTA Board Member **Dr. Steve Scherer** "because he takes such good care of himself and cares deeply about others. He is the embodiment of how well a person can maintain his physical abilities despite having CMT. His long-standing commitment and leadership in the CMT community highlight what one person can do. Thank you, Steve."

"Unstoppable" is the word CMTA Development Director **Jeana Sweeney** uses to describe O'Donnell: "Everything that Steve does, from getting up very early in the morning to go for a swim to helping others, and of course his drive to raise funds needed to cure CMT, he does with his whole heart. Steve refuses to quit, no matter the roadblock. His determination not to give in and not to give up has inspired so many, with or without CMT (me included). I feel very fortunate to have worked with Steve for so many years. However, I feel luckier to call him my friend. I do not doubt that I, my daughter Rylee, and the 3 million people living with CMT will benefit from his refusal to give in."

CMTA Advisory Board Member **Clark Semmes** said, "When I was depressed following my diagnosis with CMT, a good friend told me about a guy in my neighborhood who had CMT and swam across the Chesapeake Bay every year to raise funds to find a cure. His name was Steve O'Donnell.

continued on page 6



Steve O'Donnell emerges from the Chesapeake Bay after his July 2002 fundraising swim.

"Steve is known for his boundless energy, his fierce competitiveness and his ability to inspire others. But what has touched me so many times is that he also has such a BIG HEART. It's this unique combination that has made Steve such a valuable member of our team for so many years, fueled his countless contributions for those affected by CMT and makes him such a fun and interesting person to work with."

—Gilles Bouchard,
chair of the CMTA
Board of Directors





Steve with CMTA CEO Amy Gray at the 2018 NYC Gala

“Steve is an incredible ambassador for the CMTA community. He leads by example and has done so for over 20 years through his fundraising efforts and role on our Board of Directors. His passion is unparalleled and we are so grateful to him for all he has done to further our mission.”

—Amy Gray, CMTA CEO

CELEBRATING STEVE

continued from page 5

I decided I had to meet this guy, got his phone number, and gave him a call. He immediately invited me over to his house. Despite a serious case of CMT, Steve is a successful businessman, an amazing athlete and a devoted husband and father. Once I met Steve, I quickly decided I could no longer feel sorry for myself.”

According to camp counselor and Harrisburg branch Leader **Erin Weierbach**, “Steve is as dedicated to the community living with CMT as he is to the CMTA’s mission. He’s a natural relationship builder and a genuine listener, which always makes me feel comfortable to be myself around him and empowered to not let CMT stand in the way of a beautiful life. I appreciate his commitment to raising funds and awareness, but more importantly, I appreciate his positive energy and the authenticity he brings to the CMT community!”

Steve’s kids, **Jamie**, 27, and **Sean**, 25, told the CMTA Report, “For as long as we can remember, we watched our dad devote himself with unparalleled passion to the CMTA. He set his goal of finding a cure for CMT over 30 years ago and hasn’t given up since. Seeing him work tirelessly towards bettering the lives of those afflicted with CMT taught us a number of important life lessons: how to pursue something you care deeply about, how to persevere when it seems like your goal is just out of reach, and most importantly, the value of believing in something that benefits a greater good. We are so proud to see how far research and treatments have come, and are excited to see a future with no CMT!”

“UNSTOPPABLE!” is the word CMTA Development Director **Jeana Sweeney** uses to describe **Steve O’Donnell**.



The O’Donnells: Steve, Sherri, Sean and Jamie

Long-time friend of Steve (FOS) **Steve O’Connell** is “inspired by Steve’s dedication to the cause. Year-after-year Steve would prepare for the Chesapeake Bay swim and I was always amazed at the effort he put in. At the time I had no idea about the disease he was battling. I knew he had issues but was not aware of CMT.

Clearly, he had skin in the game. Eventually, Steve got me involved in the bay swim and later the FunAthlon. He inspired me to take the next step and sponsor a golf tournament to further support the cause. I can see in Steve a deep desire to find a cure for CMT and it makes me want to help him as much as I can.”

For the 2021 event, Sherri and Steve O’Donnell have committed to donating \$5 per lap swum, up to \$20,000; and \$5 per mile biked, up to \$20,000. Between now and September 30, we’re asking everyone to DIVE in and celebrate Steve’s 20 years of fundraising efforts by starting their OWN Virtual Swims 4 CMT.

Let’s meet this amazing \$40,000 challenge and show the O’Donnells our thanks and support! To register, go to: www.cmtausa.org/funathlon

FUNATHALON CELEBRATIONS

Below: Steve with CMTA Development Director **Jeana Sweeney**. At right: Steve and friends in 2018.



CMTA AWARDS ZÜCHNER \$300,000 FOR GENE DISCOVERY WORK

The Charcot-Marie-Tooth Association May 12 awarded Dr. **Stephan Züchner** and his team at the University of Miami \$300,000 for a project aimed at increasing understanding of the genes that cause CMT, a critical step in the drug development process.

The three-year project will support data sharing, curation of existing data, and the development of web-based access for CMT patients to participate in genomic studies. In addition, the funding will support the implementation and validation of a machine-learning algorithm for CMT genetic variations.

The first generation of genetic therapies is now available for neuromuscular diseases like spinal muscular atrophy (SMA) and hereditary amyloidosis with neuropathy or in clinical trials for diseases like giant axonal neuropathy (GAN), and a flurry of similar projects will begin soon. There is a new urgency to uncover the complete genetic basis of

inherited neuromuscular diseases, a prerequisite to finding treatments. CMT is one of the most common inherited disorders in neurology, affecting one in 2500 individuals, yet less than 50 percent of CMT2 patients receive a genetic diagnosis.

Dr. Züchner’s previous work has contributed to the discovery of more than 25 novel, mostly axonal, Type 2 genes. He and his team have built extensive discovery resources, including the largest collection of CMT exomes/genomes and GENESIS, a data analysis platform that allows for real-time data sharing and genetic matchmaking.

Building out the CMTA’s bioinformatics abilities, which are available to the Inherited Neuropathy Consortium (INC) and other CMT collaborators in GENESIS, will result in a continued high pace of gene/allele discovery. Züchner and his team recently identified mutations in the SORD gene that cause a recessive form of CMT2.



The future focus will be on advanced techniques such as machine learning, non-coding space, complex structural variation and more. These cutting-edge techniques will ultimately allow for better diagnosis of patients with unknown variants and support important gene therapy projects.

CMTA AWARDS \$100,000 TO EXPLORE POTENTIAL 1X TREATMENT

The Charcot-Marie-Tooth Association announced a \$100,000 grant May 25 that will fund a study into whether a common food additive can be used to treat CMT1X.

John Svaren, PhD, of the University of Wisconsin (the head of the CMTA’s Scientific Advisory Board) and investigators at the Jackson Laboratory will use a mouse model of CMT1X to perform the studies, which will take about a year. If successful in demonstrating proof of concept, these studies could lead to an accelerated path to the clinic.

CMT is a degenerative neuromuscular disease that kills the long, or peripheral, nerves to the hands and

feet. As the nerves die, the muscles around them follow suit. All of the CMTA’s research efforts are consolidated under its Strategy to Accelerate Research, or STAR—which brings together the world’s largest network of biotech research partners, research scientists, clinicians and patients—and funds more CMT grants than any other philanthropic organization to increase the likelihood of finding a cure. Since 2008, the CMTA has invested more than \$17 million in STAR, with plans to invest another \$10 million in the next few years.

CMT1X is a demyelinating CMT that accounts for roughly 15 percent of all cases. It is caused by mutations in the gap junctions that form channels

that allow transport of metabolic substances across the many layers of myelin. Recent studies have highlighted the important role of metabolic exchange between the axons of nerves and the myelin sheath made by Schwann cells, and the lack of functional channels could be the key factor that drives the deterioration of axons in this type of CMT.

Investigators will test whether the food additive can prevent metabolic starvation and maintain healthy nerves when channels are blocked by the mutations that cause CMT1X. The food additive has been proven to be safe at even high doses in preclinical/clinical studies.

CMTA-STAR AWARDS \$1.1 MILLION IN GRANTS TO RESEARCHERS PREPPING FOR CMT1X, CMT2A CLINICAL TRIALS



The Charcot-Marie-Tooth Association Strategy to Accelerate Research (CMTA-STAR) announced \$1.1 million in grants March 23 aimed at helping top CMT scientists prepare for clinical trials for CMT1X and CMT2A.

Because CMT typically advances slowly, measuring progression during a multi-year clinical trial is challenging. Biomarkers measure changes over shorter periods of time than self-reported measures like clinical outcome assessments so that researchers can quickly and precisely measure whether a treatment or drug had a positive impact on neuropathy. A shortened timeline keeps costs down for companies interested in investing in CMT research.

The latest grants will fund two studies that will collect patients' natural history data over a two-year period.

Dr. Michael Shy at the University of Iowa and John Svaren, PhD, at the University of Wisconsin will use a \$601,407 grant for a project aimed at developing outcome measures, plasma biomarkers and a nanostring platform for skin biopsy in 60 CMT1X patients. CMT1X currently affects about 15 percent of all diagnosed cases of CMT.

Another grant of \$559,555 will enable Shy and Svaren to begin a project taking the same state-of-art approach to prepare for clinical trials in CMT2A, which affects about 5 percent of all patients with CMT and up to 25 percent of patients with CMT2.

The findings from the two projects will be critical in advancing clinical trials in CMT1X and CMT2A.

For more information on how to get involved in these studies, please visit www.cmtausa.org.

INTERIM ANALYSIS SHOWS SUSTAINED BENEFITS OF PXT3003 FOR CMT1A PATIENTS



Pharnext SA announced April 28 new results suggesting that PXT3003 has a good safety profile and sustained efficacy in the treatment of CMT1A after 4.5 years of total trial time.

According to the company, the new results are from an interim analysis of an ongoing open-label follow-up extension study after the first double-blind, placebo-controlled Phase III study of PXT3003 for the treatment of CMT1A.

Based in France, Pharnext is an advanced late-stage clinical biopharmaceutical company pioneering new approaches to developing innovative drug combinations based on big genomics data and artificial intelligence.

In January 2020, the company reported interim results suggesting sustained safety and efficacy of PXT3003 in patients with mild-to-moderate CMT1A after 24 months of total trial time. The new results

continue to show sustained treatment benefits for CMT1A patients treated with PXT3003.

Adrian Hepner, MD, PhD, chief medical officer of Pharnext, said: "Although these new data were generated from an open-label study, the findings are consistent with the safety and efficacy results of PXT3003 observed in prior clinical studies in CMT1A."

Florian P. Thomas, MD, PhD, and U.S. lead investigator of the PLEO-CMT trial, said: "These new results from the interim analysis of the ongoing open-label Phase III extension study show very promising safety and efficacy data of PXT3003 in CMT1A after more than four years of treatment. It reinforces our hope that PXT3003 could be the first treatment approved for patients suffering from this debilitating disease."

More information about enrollment in the PXT3003 study can be found at www.premiercmt1a.com/.



Seeking Participants for Biomarker Study: AN OPEN LETTER TO THE COMMUNITY

DEAR PATIENTS AND FAMILIES AFFECTED BY CHARCOT-MARIE-TOOTH DISEASE TYPE 2A (CMT2A), TYPE 1B (CMT1B) AND TYPE X (CMTX),

We are reaching out to you about your possible participation in a research project funded by the Charcot-Marie-Tooth Association called CMT Subtype Biomarkers and Outcome Measures. The three sites in the United States involved with this study are the University of Iowa, the University of Pennsylvania and the University of Rochester. We invite you to participate if you have been diagnosed with CMT2A, CMT1B or CMTX. Unfortunately, those are the only eligible participants at this time.

The purpose of this study is to determine the best way to measure the progression of these subtypes of CMT over time. In addition to the measurements that are currently used during regular clinical visits such as assessing strength and sensation, this study will also include the following:

- One questionnaire (the CMT Health Index) that explores how you think CMT affects you
- CMT Functional Outcome Measure (CMT-FOM), which assesses balance, walking, standing up from sitting in a chair, and manual dexterity
- Limited nerve conduction studies on one arm and one leg
- A sticker will be placed on your skin on one arm and one leg and an electrical impulse will be emitted. This measures the speed and strength of the signal in two nerves.
- An MRI scan of your lower legs

We believe this study is important to help us to prepare for clinical trials because we still do not know the best way to measure progression of symptoms in people with these subtypes of CMT. We appreciate your interest in our research and would like to invite you to participate in CMT Subtype Biomarkers and Outcome Measures, which requires two visits, a baseline and a follow-up, of up to four hours over a one-year period. You may also combine this with your annual trip to the CMT clinic and continue your participation in the Inherited Neuropathy Consortium (INC) (<https://www.rarediseasesnetwork.org/cms/inc>) if already involved or enroll in the INC while completing one of the visits for this study. If you are interested in this project, please contact our study coordinators via email:

University of Iowa:
CMTRes@healthcare.uiowa.edu

University of Pennsylvania:
dragan.vujovic@penmedicine.upenn.edu

University of Rochester:
Julie_Charles@URMC.Rochester.edu



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



THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS...

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Cinzia and Neal Anderson

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Mr. and Mrs. Jerry Bank

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MANAGING CMT SYMPTOMS WITH NUTRITION

Nutrition can't cure or stop CMT, but it can be very, very helpful in managing symptoms, registered dietitian Sara Kevern told more than 200 people watching a CMTA online education session April 1. On the flip side of the coin, poor nutrition can worsen symptoms, she said, "so it's definitely worth paying attention to and trying to develop good habits and really optimize your own nutrition even if it's not going to be curative."

Sara, who works in the Neuromuscular Clinic at Stanford Healthcare, outlined three symptoms of neuromuscular disease that can be ameliorated by good nutrition: inflammation, fatigue and vitamin/mineral deficiencies and toxicities.

Inflammation is basically a cascade of chemical reactions in the body that can cause oxidative stress, tissue damage, fat deposits on nerves or mitochondrial changes, she explained. These changes in the body can cause pain and affect nerve health, so it's important to reduce inflammation.

The second way that nutrition can help in neuromuscular disease is by optimizing energy and reducing fatigue with the right macronutrient balance. And the third way is by addressing any micronutrient deficiencies or toxicities.

Kevern explained that macronutrients—proteins, fats and carbohydrates—are the three nutrients in food that contain calories, which are the units of energy that our bodies create when digesting it.

While each individual's needs are different, in general people should consume less than a third of their daily calorie intake in protein—things like poultry, fish, eggs, soy products, lentils, beans, nuts and seeds. Protein is composed of amino acids, which are the smallest components of protein that the digestive tract can absorb. When we eat protein, she said, we digest it into amino acids, which the body then repackages into full proteins and sends where they're needed. "We really have very little control over what our body does with the protein that we eat," she said.

So, for example, taking collagen means that while you get the amino acids that make up collagen, there's no guarantee your body will use them to make collagen. The best course is to eat a good variety of protein sources so your body has the amino acids it needs to make the proteins that it needs. With CMT, you don't need extra protein, she concluded, noting that resistance training in addition to adequate protein is what builds muscle.

Most people should eat almost half of their daily calories in carbohydrates, Kevern said, which supply energy to muscles. The type and the amount are important—too many carbs or overly processed or refined carbs can make one tired. Carbs are found in three main food groups—starches and grains, fruits and dairy products. Simple carbs are generally more processed and do not contain fiber while complex carbs usually also have fiber, which is important for slowing digestion, regular bowel movements, heart health and colon health.

Kevern doesn't recommend a keto—or low-carb—diet for CMT patients. It's important to have adequate carbs for your muscles, she said, and putting the additional strain of a keto diet on the body is not optimal. Similarly, intermittent fasting is not always a good idea for someone with CMT, she said, because fasting for more than 16 hours is "a long time to not be giving your body energy."

Fat is "super important for nerve health," Kevern said, noting that the myelin sheaths surrounding nerves are about 70 percent fat. Again, the

type of fat is important: Saturated and trans fats and Omega-6 fats are more pro-inflammatory while monounsaturated fats and Omega-3s are anti-inflammatory. Healthy fats are found in foods like fatty cold-water fishes, avocado, walnuts, olive oil and flax, to name a few.

Micronutrients are vitamins and minerals. They don't have calories, Kevern explained, and they are best when they come from food rather than supplements because they then interact with other components in our food like phytonutrients. Essentially, she said, "You really cannot out-supplement a bad diet." Supplements don't go through the Food and Drug Administration's approval process, so "even pill to pill in the same bottle can have different quantities of that vitamin." She recommended only taking supplements that have gone through third-party testing.

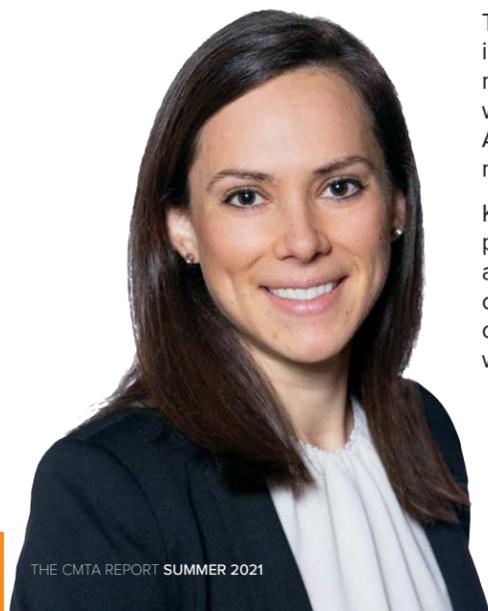
Kevern noted that while B vitamins play an important role in metabolism, B6 toxicity is possible and can actually cause neuropathy. Generally, she said, more than 200 milligrams a day can

result in toxicity. Curcumin, on the other hand, has been shown to reduce inflammatory markers and is "definitely worth a try," she said. Creatine has also been shown to be pretty helpful and worth investigating. She also recommended probiotic foods like kimchi, kefir and yogurt, but cautioned that it takes several weeks to get the gut population healthy.

Magnesium, which can help with both cramping and sleep, is fairly easy to get from food like legumes, nuts and seeds, but people can definitely take a supplement if they're not eating a lot of those foods.

Finally, Kevern said, avoiding chronic diseases like heart disease, cancer and diabetes is also critically important in helping optimize muscle health. "There are so many reasons to take care of your body, whether or not it's going to help your CMT. Optimizing your nutrition and your overall health is going to make everything better in the long run."

Watch the complete video at www.cmtausa.org/webinars.



DIETITIAN SARA KEVERN EDUCATES CMT PATIENTS AT STANFORD HEALTHCARE ABOUT USING DIET TO IMPROVE THE WAY THEY FEEL.

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OCCUPATIONAL THERAPY FOR CMT HANDS

More than 900 people joined a CMTA Zoom call on May 12 to hear occupational therapist Valery Hanks dispense numerous tips on aids, exercises and workarounds for people whose CMT affects their hands.

Hanks, a member of the CMTA Advisory Board, first defined occupational therapy (OT) for the audience: It is a practice that helps individuals recovering from an injury or illness or with disabilities participate fully in everyday activities. OT trains them to use adaptive equipment and techniques to improve function and independence. It also helps individuals develop strengthening and coordination programs and teaches family members how to support their loved ones effectively.

The difference between OT and physical therapy (PT) is that OT deals with self-care tasks, modifications for work, school or driving and home management, all tasks that involve arm and hand impairments. PT, on the other hand, involves walking and assistive devices to help with safety, balance, stairs and general mobility. It involves leg and foot impairments and decision-making with AFOs.

Hanks divided OT concerns into several primary areas—self-care, bathroom safety and work and home. In the self-care category, she said, people with difficulty using their hands might have problems with buttons, shoelaces, tying a tie, holding utensils, cutting fingernails, socks, and jewelry fasteners. She recommended tools for each. Foam tubing, for example, is cheap and comes in many shapes and sizes. It can be wrapped around a fork or a brush or a pen, making the object larger and easier to use.

A sock aid is another useful tool. Put a sock in the device, then drop it down to the floor and pull the strings so that the sock goes on without having to use your fingers. It's also beneficial for people with balance issues or who can't reach their feet.

A reacher/grabber also comes in handy for picking things up or pulling

up your pants, she said, while a zipper pull hooks into your zipper so you can use the full force of your hand and forearm to pull up the zipper, rather than having to use finger strength to pull it up.



ADAPTIVE NAIL CLIPPERS SUCTION TO ANY SURFACE.
www.rehab-store.com/p-nail-clipper-board.html

Similarly, she said, an adaptive nail clipper suctions to a table or counter, allowing people to use forearm rather than finger strength to push the device down to clip nails. More self-care tools include long-handled combs and one of Valery's favorites, a jewelry adapter that attaches to either end of a necklace or bracelet, then uses magnets to make the connection. Other effective self-care tools include buttonhooks, Velcro shoelaces and AFO assists that hold the brace still so that you can simply slide your foot into it and then do the straps.

Another area that OT focuses on is bathroom safety. A January 2018 study surveyed 252 people with CMT and 86 percent reported frequent falls or near falls. A 2014 study found that respondents were more likely to get injured if they fell in the bathroom.



A SOCK AID CAN TRANSFORM THE TASK OF GETTING DRESSED.
www.amazon.com/RMS-Deluxe-Sock-Foam-Handles/dp/B00U9TWCXU/



Valery recommended several tools for the bathroom: a toilet hygiene aid helps people reach around after a bowel movement and bidets make washing the genitals a breeze. You don't have to buy a \$700 bidet, she said: A \$50 or \$75 bidet seat is simple to install and does the job just as well. An elevated toilet seat with safety rails helps people without a lot of leg strength get up and down, while a bedside commode can help prevent falls in the night, then be stashed away during the day.



A JEWELRY ADAPTER ATTACHES TO THE END OF A BRACELET OR NECKLACE AND USES MAGNETS TO MAKE THE CONNECTION.
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Showering and bathing can also present challenges, Hanks said. She recommended putting a mat in the bottom of the tub and using a transfer bench, which allows you to sit outside the tub, then swing your legs over, and use a handheld shower.

The third area where occupational therapy can be helpful is home life and work. Helpful tools include battery-powered can openers, adaptive key rings and adaptive pill bottle openers. Hanks recommended that people who don't have small children at home simply ask their pharmacists to put on non-childproof lids.

In the kitchen, jar openers and rocker knives can both reduce the amount of effort required to use them, while an adaptive cutting



A ROCKER KNIFE SIMPLIFIES CHOPPING.
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board with prongs holds vegetables in place for cutting. At work, a keyguard over the keyboard can prevent you from accidentally hitting two keys at once and a color-coded keyboard with larger keys can help prevent mistakes when typing.

Hanks suggested using yoga bands for hand stretches. Equipment isn't a necessity for hand stretches, though: Simply spreading the fingers out as wide as possible and then pulling them back together is an excellent way to keep the intrinsic muscles of the hand firing. Making a "duck beak" also fires these

tiny muscles, which lie deep within the hand. She also suggested touching your thumb to the bottom of your pinky, if possible, and doing a "prayer stretch" for the wrist flexors, which stretches out the muscles down the arm that tend to get tight when the hands start to weaken.

Splinting is another area where occupational therapists specialize. The most common splint for CMT is a thumb spica splint, either off-the-shelf or custom, which can prevent deformity and help support the thumb. A dorsal blocking splint can be used when all of the hand muscles are atrophied and the fingers curl into a claw: It prevents hyperextension while still allowing the use of the hand. The goal is to prevent deformity from happening. When deformity has occurred, progressive splinting can help. New splints are made every six weeks or so that gradually ease the hands into a more stretched position.

To watch the entire Zoom, go to www.cmtausa.org/webinars/



Valery Hanks is an occupational therapist at Pi Beta Phi Rehabilitation Institute at Vanderbilt Medical Center Bill Wilkerson Center in Nashville, Tennessee. She provides outpatient services as part of an interdisciplinary team for adolescents and adults with neurological impairments. Valery graduated from the University of Tennessee Health Sciences Center in 2000 and has focused her entire career on helping people with neurological impairments.

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HEATED MASSAGER WARMES COLD LEGS

BY JANICE O'BRIEN,
DURHAM BRANCH MEMBER

At a recent Research Triangle branch meeting, I told Dr. Greg Stilwell, a podiatrist, that my legs are always ice cold from the knee down. He told me that this is not an unusual complaint from patients with CMT.

After the Zoom meeting, branch co-leader Jeanne Boehlecke suggested that I try a foot massager with a heat feature. After much research, I purchased a model that not only massages your feet but also has the capability of rotating 360 degrees so you can position it for your calves or arms, either sitting up or lying down. The massager can be programmed for five- to 30-minute massages.

I opted for five minutes for my trial run just to see how my feet would react. It was a bit more of a deep massage than I expected, but I soon got accustomed to it. I have been using the massager for 15 minutes on

my feet and 15 minutes on my calves three times a week and I'm very pleased with the results after such a short time. The circulation in my lower legs has improved, the skin color is better and my legs are markedly warmer. I have more sensation in the bottom of my feet and my feet feel very relaxed. I measured the circumference of my leg above the ankle before I started using the massager and I've lost half an inch on each leg, a decrease in swelling.

The massager I purchased has an adjustable bar that serves as a handle for ease of carrying as well as a support for the desired position. It also comes with a remote control.

I do not have a medical degree nor am I endorsing this product, and it's important to consult a physician before using it. People whose legs are numb may not be able to feel the temperature of the heat massager and need to be careful not to burn



themselves. I just want to share this with other CMT patients who experience the same symptoms that I do and who may want to consider trying a foot massager as a solution. I certainly hope that you get the encouraging results that I did.

The Tisscare foot massager can be found on Amazon, currently at \$179.99: www.amazon.com/dp/B07ZND8F8W/. Be sure to use Amazon Smile with the CMTA as the designated beneficiary: We'll earn 0.05 percent on your purchase.

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WHY SHE GAVE: JEAN NIBBE

HER MOTTO WAS "LIVE FOR TODAY," AND HER LEGACY WILL HELP OTHERS WITH CMT DO THAT.



It seems only fitting that the memorial service for Jean Nibbe included a game of Munzee.

Like the online/real-life scavenger hunt, Jean was vibrant, engaging and full of life.

Jean was born in 1965 in Salt Lake City, Utah. She spent three years there before moving with her family to Seattle, where she remained for the rest of her life.

Jean worked in the parts department at truck manufacturer PACCAR for 25 years, but she wasn't defined by her job as much as her outside interests and her volunteer work. She was an advisor with the scrapbooking company Creative Memories and she made greeting cards for Project "Write Home" for military personnel. She loved gardening and volunteered at the Bellevue Botanical Gardens for many years, even winning the President's Volunteer Award in 2012.

In addition to Munzee, Jean enjoyed traveling, the outdoors, spending time with friends and family and Geocaching, in which participants use GPS to hide and seek containers called geocaches at specific locations marked by coordinates all over the world.



Jean's father had CMT Type 2, as did his three siblings, so Jean knew she had it from a very early age. She didn't let CMT define her, or slow her down: In her youth, she was an avid softball player, though, like many people with CMT, she was often chosen last for teams.

But she persevered, knowing how important it was to stay active and preserve her muscle mass. She participated in dragon boat racing and sled hockey and was invited to try out for the U.S. sled hockey team. She even led a Boy Scout troop on a hike from Seattle to the Golden Gate Bridge.

Ironically, Jean grew to love teams because they motivated her to stay active, take part in a group and contribute to society.

Jean and her husband Jim met on a blind date and it was initially unclear that there would be a second meeting. But Jim was persistent, and another date followed. Being the up-front kind of person that she was, Jean told Jim about her CMT and that she wouldn't have kids because of it. She was reluctant to begin a relationship, but Jim assured her that they were "just dating" and it would be okay. They married in 1998.

MAKING GREETING CARDS for Project "Write Home" for military personnel was one of the many ways Jean shared her generous spirit.

The two shared a love of travel and planned to go to the Greek Islands on their honeymoon, but then they won a contest for two round-trip business-class tickets around the world. Jim was excited at the thought of a world tour, but Jean said she knew she would be tired from the wedding festivities and just wanted to lie on a beach. They compromised by lying on beaches in Rio de Janeiro, Malta and Bali.

Jean began swimming more as her CMT progressed, loving the ease that being in water gave her. She often said that she "felt normal" when she was in water and loved to go snorkeling in places like the Virgin Islands and Hawaii.

There was a lot less travel in recent years, but Jean could still mountain bike and Whistler was another favorite vacation destination. She also continued making cards until just last year when she started to lose hand function.

An active member of the Seattle branch, Jean left more than \$70,000 to the CMTA because of the way CMT affected her and her family. Her motto was "Live for Today," and her legacy will help others with CMT do that. Her memory is most certainly a blessing—to all who knew her and to all who will benefit from her generosity.



AN OLD MAN'S JOURNEY WITH CMT



Jeff and Julie Dols

MY name is Jeff Dols,

I am 71 years old and I have Charcot-Marie-Tooth disease. I don't mean for that to sound like an AA meeting, but those are the basic facts.

I was diagnosed in 1964 at age 14. The clumsiness, sprained ankles, strange gait, hunched shoulders and spinal curvature were all there, but the dots hadn't been connected. A broken hip from a fall finally led me and my parents to Stanford University Hospital Clinics where I sat in an exam/conference room for five hours as teams of doctors poked, pricked, measured, prodded, tuning forked, zapped and generally explored. At the end of the day, I was excused and my parents were told I had CMT. I was told a few weeks later, but there were no details except that the disease was inherited, degenerative and had no treatment.

My CMT is fairly mild and I had a mostly normal childhood doing the things most kids did, just not very well or as fast. There were things I could not physically do and things I was not allowed to do. I was always just "a bit off!"

My diagnosis gave me the starting point for answers to the question of what was going on with me. I learned I was never going to make a living with my body, so the NFL was out. I figured I'd better get an education if I was going to make a living. I went

to college, then had a 40-year career in sales and marketing that took me around the world. I met all types of people and experienced many different cultures. I worked hard, had a good time (mostly) and learned a great deal about myself along the way. CMT taught me how to deal with people and made my career choice ideal.

This letter is about what I've learned in 55 years of dealing with CMT, lessons like:

- I don't use CMT as an excuse to get out of things. It's dishonest and an abuse of those around you.
- I learned to work around CMT issues because it was the only way I could live my life. Early on, when no one had answers, I had to be creative and make it up as I went along. That ability is key in dealing with CMT.
- I am not hesitant to ask for help when I need it, but I don't let people volunteer to help when they think I need it.
- If I can do something, I will do it, no matter how long it takes.
- When people stare at the way I walk or my leg braces or how my hands cramp up at the worst times, I make a joke about it or ask if they are having a bad day too. Not in a confrontational way, but with a smile and a genuine desire to help put both of us at ease and to remove the barrier CMT can be.
- Treat your doctors with respect, the same respect you show your plumber. You hire them both because they have the expertise you don't. Treat both with respect until it's no longer mutual, then tell them how you see things and find a new plumber.

At 71, I still manage an independent life. It's more limited than 20 or 30 years ago, but whose isn't. I rely on a number of tools and tricks that make life easier, including:

- A button hook for buttoning my shirts and pants.

- A small hook I keep on my key chain for those times when I can't manage to pull my zipper up. It's embarrassing to walk into a public restroom with your shirt tucked in and come out with it untucked—can be a bit drafty, too.
- A sock puller aid to get my socks on and off.
- AFOs allow me to walk in a mostly straight line. And I do walk, three to four times weekly with my special walking stick.
- AFOs are great shoehorns too.
- Velcro strap shoes save me time and frustration, limiting the use of bad words that come with trying to tie shoelaces.
- I drop things all the time and to pick them up, I keep BBQ tongs handy. My wife calls them my "Geezer Tweezers." I have four pairs scattered around the house and garage.
- Soft-handled knives and utensils make it possible to grip a knife so I can still cook.
- My Kindle allows me to read almost any book I want without the struggle of turning actual pages.
- I love my glass of wine and I found a cork puller I can use. Because of balance issues, I limit it to just one glass and only with dinner. I really miss that second glass though.
- I still drive. Thank God for all the safety features cars have now. They keep innocent people safe.
- I type 22 words a minute with seven errors. Voice-to-text software is in the very near future.
- An often-used tool of mine is a large master closet with no exterior walls. On bad days, when things really get to me, that's where I go to shut myself in and rail at the gods and yell at the top of my lungs. Never mind the words I use; the neighbors can't hear me and why would I care anyway.

The secret weapon that really makes my life work is my wife, Julie. We have been married for 30 years. She has seen the best and the worst of me and she is still here. She knows what may be coming and she is still here.

When I am being an ass, she points it out—not always in the most tactful manner—but she has rights and I tend to be "insensitive" on occasion. Remember the closet.

She laughs at me regularly, even when I can't see the humor. Julie always has my back and will help when asked, even when she doesn't think I deserve it. Everyone needs a Julie in their life. With CMT, the need is greater.

So, the advice I would give to anyone dealing with CMT based on my 71 years of dealing with it:

- CMT is eventually going to win most battles. The trick is making sure you lose on your terms. Don't just accept, fight back and look for workarounds.
- CMT affects many aspects of our lives, but it will not define who you are unless you let it.

- As much as possible, don't let CMT limit or constrain your life.
- Don't be afraid to ask for help but always look to yourself first.
- Keep physically active and exercise regularly. CMT will rob your physical abilities so do all you can to keep the strength and muscle tone you have.
- Question your doctors and caregivers. If you don't understand the answers, ask again. Remember, you're the one paying the bills.
- Nurture friendships and make sure they feel free to call you an ass when you need it. If nothing else, it starts a conversation.
- On bad days, don't bring everyone around you down. You may have CMT, but the world does not revolve around you. Again, remember the closet.
- On the good days, share it with the people who make the days good.

A life well lived is an adventure. With CMT, it can be a bit more adventurous but that just means the rewards are greater and the memories more impactful.



Jeff and his walking stick

SAVE THE DATE - REGISTRATION WILL OPEN IN THE SUMMER

20TH ANNUAL CMTA PATIENT/FAMILY CONFERENCE VIRTUAL - SATURDAY, NOVEMBER 6

Bringing Together an International Community of Patients, CMT Clinicians, Scientists and Biotech Partners from Around the World





FIRST ANNUAL COLDIRON DERBY FUNDRAISER NETS \$30,823



8-year-old Hazel Coldiron was diagnosed with CMT five years ago.

CMTA Board Member David Coldiron and his wife Christina raised more than \$30,000 for the CMTA May 1 with a Kentucky Derby party in Nashville.

The outdoor, tented fundraiser featured live music, fabulous bites, mint juleps, Derby viewing, live and silent auctions and a bourbon tasting. Eighty-five people (following CDC pandemic guidelines) came out in their Derby finest, including hats.

The Coldirons love the Kentucky Derby and have an event at their home for family and friends every year. This year, they turned the event into a fundraiser for the CMTA. Their reason for fundraising is very

personal: 8-year-old Hazel Coldiron, a bright, beautiful and strong little girl who was diagnosed with CMT five years ago.

David and Christina thought that their annual Derby party would be a great way to raise awareness and funds for CMT research. "We want children like Hazel to have the same opportunities to have a fulfilled and happy life. The annual Coldiron Derby Fundraiser will help fund research for Charcot-Marie-Tooth disease by benefiting the CMTA," David said.

The Coldirons (and the CMTA) thank sponsors Crown Paving, Hanger Clinic and Pennington's Distillery for supporting the event.

Students at St. Rocco Parish Raise Pennies for the CMTA

Students at Saint Rocco Parish School in Cleveland held a Penny War to raise funds for charity this past Lenten season and the CMTA was one of the lucky beneficiaries. Students at the small, urban, high-poverty school battled grade against grade to bring in pennies, silver change and paper money to raise over \$1,500! The money was divided among three charities that affect students in the school: The Charcot-Marie-Tooth Association, Autism Resources and Alex's Lemonade Stand.

For every \$500 raised, assistant principal and seventh-grade homeroom teacher Brent George agreed to dress as the Easter Bunny for a day. It was quite an incentive: He greeted students for three days before Easter. The third graders who raised the most money earned a pizza party, a dress-down pass and a homework pass.

Principal Renee Corny said she is extremely proud of these 135 kids for their generosity in helping others.



VIRTUAL BRANCH MEETING NOTES

ORANGE COUNTY, CA

Seventeen people, including new Branch Leader Beth Dorin, came out for the inaugural meeting of the Orange County branch on March 2. All of the attendees have CMT (mostly 1A) and a couple of them have young adult children with CMT. The parents of children with CMT mentioned how great it would be to connect their kids with others in their age group. Members also talked about topics of interest for the year and future guest speakers.

DENVER, CO

Members of the Denver branch shared local resources for bracing at their April 15 meeting. They also welcomed two representatives from the CMTA Center of Excellence at Children's Hospital of Colorado, which is led by neurologist Dr. Michelle Yang, who joined the meeting to introduce themselves to branch members.

DESTIN, FL

Three presenters from GeneDX dazzled members of the Destin, FL branch at their last meeting with a wide-ranging presentation on genetic testing. They described the company's neuropathy test offerings, including a hereditary neuropathy panel (64 total genes), a core CMT panel (four genes), an axonal CMT panel (32 genes), a demyelinating CMT panel (23 genes), a CMT panel (43 genes) and a hereditary sensory and autonomic neuropathy panel (14 genes). Members learned that genetic testing can lead to a positive diagnosis, a negative diagnosis, or an inconclusive result and discussed the importance of seeking professional genetic counseling.

PORTLAND, ME

Ten members of the Portland branch welcomed guest speaker Laurel Richardson, CMTA director of community outreach, to their January 12 meeting. Laurel shared updates on the CMTA's education and community programs. Members also spent time catching up with fellow CMTers and planning for the year. They decided to meet every month or so this year because Zoom makes it so easy. They also agreed to work on building a "local resources" list for the branch.

LAS VEGAS, NV

Seven members of the Las Vegas branch welcomed orthotist David Kovach to their meeting on January 23. David shared valuable information on bracing and orthotics and emphasized the importance of finding the right brace for each individual, a lesson borne out by the fact that everyone in the group wore a different type of brace.

NEWBURY, NH

Six members of the Newbury branch welcomed guest speaker Jacqueline Piazza to their April 10 meeting. Jackie was diagnosed with CMT

when she was 19, and after a challenging journey spent trying to understand her body and CMT, she discovered the benefits of meditation and mindfulness. She has been meditating for the past 10 years and even became a professional meditation/mindfulness instructor with advanced training in trauma-sensitive mindfulness. Jackie shared how meditation changed her relationship with her body and her diagnosis, as well as some meditation and mindfulness practices.

The branch also gathered on February 17 to catch up as a branch and welcome new members. The seven attendees played a great introduction game called 2 Truths & 1 Lie. Members briefly explained their journeys with CMT and what's been helpful, as well as what hasn't been. Members also discussed local resources for surgeries, AFOs, doctors and specialists.

NEW MEXICO

Nineteen members of the New Mexico branch welcomed first-time actor Joy Perry to their February 6 meeting. Joy, who has CMT, recently appeared in a Hallmark movie, *The Christmas Bow*, playing a character who has the disease. Joy shared her history with CMT as well as her experiences as someone without previous acting experience in making this TV movie. The Zoom session was recorded and will be available at a later date for individuals and other branches to view.

SYRACUSE, NY

The Syracuse branch met on February 6 with 40 people present to welcome special guests Drs. David Herrmann and Katy Eichinger from the CMTA Center of Excellence at the University of Rochester. Dr. Herrmann, the clinic director, gave a great presentation defining CMT, explaining genetic testing and inheritance patterns and describing how CMT affects patients. Dr. Eichinger, a physical therapist and clinical trial evaluator, discussed physical therapy and the importance of physical activity. She also talked about the sensor gait study being conducted at the Rochester Center of Excellence.



CMTA Director of Community Outreach Laurel Richardson has participated in many branch meetings over Zoom this year.

WESTCHESTER, NY

A dozen people came out May 1 to hear guest speaker Laurel Richardson, the CMTA director of community outreach, give a high-level overview of the STAR research initiative. She detailed the many ways the CMTA is tackling research for nearly every subtype.

On March 6, 27 people came out to hear guest speakers Ken Cornell and Laurie Lasky take part in an in-depth discussion on bracing and AFOs. Ken is a certified orthotist in Boston and works with the CMTA Center of Excellence team at Mass General. Laurie, the NE district manager for bracing manufacturer Allard, told the group she finds it

especially meaningful to watch the life-changing difference that great braces make for people living with CMT.

RESEARCH TRIANGLE/WILMINGTON, NC

The Research Triangle and Wilmington branches held a joint meeting on May 1 with 12 people present to welcome special guest speaker David Tannenbaum. David, a psychotherapist who has CMT, serves on the CMTA Advisory Board and writes the "Ask David" column in *The CMTA Report*. He led the group through a meaningful discussion on emotional wellness in which many shared their sadness, guilt and fears surrounding their disease. It was a productive and valuable meeting with great takeaways about letting go of fear and staying in the present.



New Mexico branch members welcomed actor Joy Perry, who has CMT, to their February meeting.

CHESTER COUNTY, PA

Two orthotists from ABILITY Prosthetics and Orthotics presented on bracing solutions and getting the most of a visit with an orthotist at the Chester County branch's March 20 meeting.

The 22 members in attendance shared their experiences with this company as well as various types of orthotics, shoes and devices for daily living that work for them.

PITTSBURGH, PA

Nine people welcomed guest speaker Julie Tarle, the CMTA's special events manager, to the April 17 meeting of the Pittsburgh branch. Members debated whether to have their WALK 4 CMT in-person or virtually, with the majority saying they felt comfortable holding an in-person walk using state guidelines for COVID-19. Members also discussed date, time and location possibilities and got excited about planning the annual walk, though no final decisions were made.

DALLAS/FT. WORTH, TX

Dr. Sharique Ansari, a neurologist and the director of the CMTA Center of Excellence at Kane, Hall, Barry Neurology in Bedford, was the guest speaker at the Dallas/Ft. Worth branch meeting May 1. Twelve people listened as Dr. Ansari shared an incredible presentation on CMT with detailed information about the disease, the diagnostic process, genetic testing and much more and then answered questions from the group.

MADISON, WI

Twenty members of the Madison branch welcomed special guest speaker John Svaren, PhD, to their March 4 meeting. Svaren chairs the CMTA Scientific Advisory Board and is very involved with advancing CMT research. He is a professor in the Department of Comparative Biosciences at the University of Wisconsin and serves as director of the Cellular and Molecular Neuroscience core at the UW Waisman Center, where his laboratory is located. Since 2000, he has focused his research on the genetic basis of peripheral myelination and the disruptions found in peripheral neuropathies such as CMT. Svaren shared a STAR research update and then took questions from the group.

WHAT'S ON YOUR MIND? ASK DAVID.



David Tannenbaum answers questions from readers in his column "What's On Your Mind? Ask David" regularly in The CMTA Report. David has an LCSW degree and has been a psychotherapist in New York City for the past 30 years, specializing in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life," says David.

Dear David,

My wife and I have been married for 22 years. I am blessed to have a good marriage. We have no children by choice and have been fine with that decision. Although I have known about my CMT for years, it's only recently that I have had a tough time of it. My balance seems to be worsening, and there has been some weakening in my hands. I have always been very active and take pride in being able to fix things around the house and would never think of calling and paying a handyman to do what I think I can do just as well. My wife tells me it's a matter of my "macho pride." The other day my well-meaning wife offered to help me with a difficult project. I snapped at her and told her I didn't need any help! I apologized later, but I felt terrible that I lost it with the most important person in my life. I always think of myself as a gentle and soft-spoken guy but these outbursts seem to be happening more often. What's going on?

David Replies:

I've always been useless around the house, better at breaking things than fixing them, and I've never had any trouble calling a handyman for help so I think I can shed some light on this.

I suspect that your feelings around losing some ability to help around the house have been building for some time. Since CMT progresses so gradually, we often don't recognize in the moment when we are not able to do something that we could previously do without any trouble. In that moment of awareness, we can experience a sinking feeling that makes us feel awful and causes us to project into the future some worst-case scenario.

Your lashing out at your spouse is not about her but about some pain or fear you have probably been suppressing. Our anger is more accessible than the sadness of acknowledging our physical losses and sadness and fear often gets expressed as anger. Allowing these feelings to surface means that we have to experience emotions that make us feel weak and out of control, feelings that we don't like acknowledging to ourselves, let alone to our intimate partners.

In truth, these are human emotions that everyone has throughout life. Your anger at your wife is about pushing away someone who knows you well at a time when you want to remain invisible. Perhaps in that moment of experiencing these difficult feelings, you actually needed a loving embrace from someone who knows how hard it is for you and wants to assure you that you are not alone. That could have been a very tender moment for both of you. When we don't let our loved ones see what we are going through, we remain isolated. In addition, those feelings of unexpressed fear or sadness can turn into depression if they remain frozen.

If you are able to express some of these uncomfortable emotions, you can then make room for other feelings like acceptance, peace, intimacy and the motivation to live the best life you can with what you have. For those of you reading this who have friends or loved ones with CMT, take a moment to ask them once in a while, "Are you ok?" Just those simple words can convey a lot of caring and love. If the response you get is a quick, "I'm fine," don't be afraid to ask again. Let's not be afraid of feelings. Once acknowledged, we can then let them go. It's only when we deny their existence that they prevent us from feeling truly alive.

CMTA CENTERS OF EXCELLENCE

CMTA CENTERS OF EXCELLENCE are patient-centric, multidisciplinary CMT clinics where children, adults and families affected by CMT can be assured of receiving comprehensive care by a team of CMT experts. The Centers roughly correspond to the 21 international sites that make up the NIH Inherited Neuropathy Consortium (INC)—a group of academic medical centers, patient support organizations and clinical research resources sponsored in part by the CMTA. The centers are becoming even more important as the CMTA begins clinical trials, which depend on how much we know about the "natural history" of CMT—how different types of CMT progress over time and whether novel medications are slowing the course of the disease. Much of that information will be supplied by the Centers of Excellence.



CALIFORNIA

LOS ANGELES (ADULT & PEDIATRIC)
Cedars-Sinai
Clinical Directors:
Matthew J. Burford, MD, and
Richard A. Lewis, MD
Appts: Tara A. Jones, MS, CGC,
310-423-4268

PALO ALTO (PEDIATRIC)
Stanford Children's Health*
Clinical Directors: John Day, MD, PhD,
and Ana Tesi Rocha, MD
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PALO ALTO (ADULT)
Stanford Neuromuscular Program*
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COLORADO

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University of Colorado
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AURORA (PEDIATRIC)
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CONNECTICUT

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Connecticut Children's Medical
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FLORIDA

ORLANDO (PEDIATRIC)
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MICHIGAN

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Medicine and Detroit Medical Center*
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MINNESOTA

MAPLE GROVE (ADULT)
University of Minnesota*
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MISSOURI

COLUMBIA (ADULT & PEDIATRIC)
University of Missouri*
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ST. LOUIS (ADULT & PEDIATRIC)
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NEW JERSEY

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NEW YORK

ROCHESTER (ADULT & PEDIATRIC)
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OREGON

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PITTSBURGH (PEDIATRIC)
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TEXAS

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University of Texas Southwestern
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BEDFORD (ADULT 16+)
Kane Hall Barry Neurology
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UTAH

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WASHINGTON

SEATTLE (ADULT)
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WASHINGTON, DC

(PEDIATRIC TO AGE 21)
Children's National Hospital
Clinical Director:
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* Denotes the CMTA Centers of Excellence that are included in the National Institutes of Health Inherited Neuropathy Consortium (INC). The INC is co-sponsored by the CMTA and the MDA. Worldwide more than 10,000 patients with CMT have been enrolled in protocols, and their data, de-identified to protect patient privacy, is housed in a common repository. As a result of this collaboration, a new CMT evaluation scale for children has been established, along with a new evaluation system for adults, and an infrastructure has been developed to perform natural history studies and clinical trials for CMT.

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Contact CMTA Director of Community Outreach
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Email the CMTA at info@cmtausa.org



CMTA BRANCHES

**CMT PATIENT
MEDICATION ALERT:**



**Definite high risk
(including asymptomatic CMT):**

Taxols (paclitaxel, docetaxel, cabazitaxel)
Vinca alkaloids (Vincristine)

Moderate to significant risk:

Amiodarone (Cordarone)
Arsenic Trioxide (Trisenox)
Bortezomib (Velcade)
Brentuximab Vedotin (Adcetris)
Cetuximab (Erbix)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Eribulin (Halaven)
Fluoroquinolones
Gold salts
Ipilimumab (Yervoy)
Ixabepilone (Ixempra)
Leflunomide (Arava)
Lenalidomide (Revlimid)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Nivolumab (Opdivo)
Pembrolizumab (Keytruda)
Perhexiline (not used in US)
Pomalidomide (Pomalyst)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Thalidomide
Zalcitabine (ddC, Hivid)

**Uncertain or
minor risk:**

5-Fluorouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in US)
a-Interferon

**Negligible or
doubtful risk:**

Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clloquinol
Clofibrate
Cyclosporin A
Enalapril
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

The medications listed above are potentially toxic to CMT patients. Vincristine has been proven hazardous and should be avoided by all CMT patients, including those with no symptoms. Taxols also pose a high risk to people with CMT. The remainder of the medications listed above present varying degrees of potential risk for worsening CMT neuropathy. Before taking any medication or changing medication, all CMT patients should make sure the treating physician is fully aware of their medical condition.

WHAT IS CMT?

More than 3 million people worldwide have CMT, which 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.

Men and women 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 Taxols. See full list (at left) of medications that may pose a risk.

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.