Our Mission: To support the development of drugs to treat CMT, to improve the quality of life for people with CMT and, ultimately, to find a cure.

Our Vision: A World Without CMT.
DEAR FRIENDS,

I couldn’t be more excited about the projects and initiatives the CMTA has planned for 2018. With a number of these endeavors underway, including increasing the involvement of patients as partners in our research program, developing new online tools and expanding our educational programs, I am convinced 2018 will be a tremendous year for the CMT community.

Our Strategy to Accelerate Research (STAR) is expanding like never before. With major breakthroughs in science, we are seeing more and more pharmaceutical companies interested in developing treatments for the community. In the past year, we have more than doubled the number of industry partners we are working with, and this number continues to increase every month.

Not only is our network of partners expanding, but so is the impact of our research breakthroughs. Last July, a research paper was published on the success of a CMTA-funded project to build a rodent model for CMT2A. Now that companies are aware of this tool, we are receiving calls to initiate new CMT2A projects. In December, we announced a major breakthrough for CMT1A in partnership with Ionis Pharmaceuticals. In two animal models, a drug developed by Ionis not only stopped the progression of CMT1A, but also reversed some symptoms of the disease. Never before have we been able to so successfully demonstrate that the extra copy of the PMP22 gene present in CMT1A patients can be targeted by a drug. These promising results show that the possibility of symptom alleviation and reversal is real.

This year, we are further refining our patient engagement strategy for research. Patients have always been at the heart of the CMT’s research program—from our founding in 1983 to the present day—the voices of patients have been heard. We plan to further enhance our focus on patients in 2018, initiating a new program where patients will be our partners in drug discovery and development.

On our path to a cure, we see our website as a vital educational resource for the community. Although we have made some enhancements over the last couple of years, we still have a lot of work to do to facilitate patient access to the most up-to-date information and resources. We are embarking on a major project to rebuild our website in 2018, and we hope to launch the new site this fall. We will be adding a resource center, a clinical trial finder and much more.

We also are holding two national patient and family conferences this year, one on the east coast just outside of New York City and one on the west coast in Seattle. These conferences feature talks by CMT experts and specialists, and they are an important part of our mission to help improve the quality of life of everyone living with CMT.

We hope you enjoy this newsletter, which is designed to share information with you on how to live your best life, to inspire you with profiles of those living courageously with CMT and to keep you informed of the many milestones we have reached this year.

Amidst these major breakthroughs, exciting projects, and visible progress, I want to thank you for your generosity, support, and participation that makes it all possible.

With sincere thanks,

AMY GRAY, Chief Executive Officer
On November 2 and 3, 2017, the CMTA hosted a meeting of physical and occupational therapists from CMTA Centers of Excellence around the world. Therapists from 12 different states and four countries came together in Phoenix, Arizona to discuss the assessment and management of individuals with Charcot-Marie-Tooth disease (CMT).

Five experts in the field—Joshua Burns, PhD, Gita Ramdharry, PhD, Katy Eichinger, PT, PhD, DPT, Tim Estilow, OTR/L, and Amy Warfield, PT, DPT—led the meeting of 17 physical therapists and four occupational therapists who are all dedicated and interested in working together to bring the best available care to individuals with CMT.

“We realize that many persons affected by CMT are not geographically near a CMTA Center of Excellence; therefore, they do not have access to a clinician who consistently works with individuals affected by CMT,” says CMTA board member Elizabeth Ouellette. “Our goal was to have these experts discuss clinical practice and experiences supported by research to identify practice points to share with the CMTA community. We plan to include these and what we understand regarding the natural progression of CMT to create a guide for patients to provide to community clinicians. This guide can then be used to assist patients in managing CMT symptoms and rehabilitation needs.”

Following an overview of CMT and an update on the work of the Inherited Neuropathies Consortium by Michael Shy, MD, the development, validation and use of disease-specific assessment scales, such as CMTNS, CMTPeds and CMTHI were presented. Joshua Burns, Gita Ramdharry, Katy Eichinger, Tim Estilow and Amy Warfield presented on symptoms of CMT that have been noted to have an impact on quality of life. They covered topics including mobility, balance, foot and ankle weakness, hand function, and health and wellness topics such as exercise, pain and fatigue. Discussions among the attendees identified the practice points highlighted on the facing page.

Together with Acceleron, PharNext and TheraBand, the CMTA is proud to have sponsored this meeting of allied health care professionals, and we look forward to publishing the assessment and treatment recommendations in a guide that you can share with your local care team.
DR. AMY WARFIELD reviewed mobility assessment throughout the lifespan. Therapists agreed that risk of falls, orthotic assessment and assistive device assessment should be included within patient evaluation. The goal of a physical or occupational therapist working with a person with CMT should be to provide strategies and compensatory techniques for maintaining and improving a person’s ability to participate in activities of daily living and all environments for as long as possible.

DR. KATY EICHINGER presented on balance assessment and intervention strategies for individuals with CMT. Clinicians agreed that individuals with CMT may improve their balance abilities with therapeutic intervention, such as education, falls management and task specific interventions to address the specific problems the patients are experiencing.

DR. JOSHUA BURNS presented on assessment and interventions for foot and ankle weakness. His team recently conducted a randomized controlled trial showing that six months of progressive resistance exercise of ankle dorsiflexors was safe and effective in delaying strength loss in children and adolescents with CMT (www.thelancet.com/journals/lanchi/article/PIIS2352-4642(17)30013-5/abstract). In-shoe foot orthoses and ankle-foot orthoses are also often prescribed for people with CMT (www.mcri.edu.au/news/practice-brief-charcot-marie-tooth-disease). Clinicians agreed that it would be helpful to convene a working group to help determine who needs what and when.

TIM ESTILOW, occupational therapist, presented on assessment and interventions to improve hand function. He reviewed key areas for assessment, including sensory and motor function, muscle atrophy and ability to use hands for completion of activities of daily living (ADL). Hand weakness, management of contractures and decreased dexterity were identified as limiting factors for ADL performance. The group discussed intervention strategies, such as splinting, casting and progressive strengthening. The group also discussed the identification of candidates and timing for referral to a hand surgeon.

DR. GITA RAMDHARRY presented on health and wellness, including exercise and managing pain and fatigue. The group agreed that there is evidence of good results from strengthening proximal muscles—muscles situated nearer to the center of the body—for this patient population. There is also promising evidence of peripheral muscles—muscles nearer the ends of the limbs—continuing to stay strong in children who have the proper exercise program. Providing people with optimal strategies to implement an appropriate exercise program and providing the support for these patients was also discussed.

A GROUP DISCUSSION: Managing fatigue symptoms related to CMT can be challenging. To help manage fatigue, therapists can assist individuals by implementing activity pacing, instructing in self-management of symptoms and rate of perceived exertion, adaptations, energy conservation techniques and goal setting. Pain and cramps can also be significant issues for patients, and therapists are often consulted for treatment. Neuropathic and musculoskeletal pain are different in nature, and different strategies can be used to manage them. Cramps can be persistent, but, unfortunately, evidence is lacking on how to best manage them.
Fourteen years ago, I wrote an article for the CMTA on my work as an integrated exercise instructor with N., a client who has CMT. In the intervening years, she and I have continued to work together in my Pilates studio, and I can now speak with more confidence on the long-term benefits of this practice.

N. has CMT Type 1A, which appeared in her 40s during an active career as a school principal. At the time of diagnosis, she was told to be prepared to be in a wheelchair within 10 years. Now, at age 65, not only is N. not in a wheelchair, but she also travels frequently to different countries and continues to enjoy an active life, albeit with some limitations.

From the very beginning, I treated N. as I would any other client. I never assumed there were things she wouldn't be able to do. Instead, I found ways to make movements and exercises possible and safe for her. She is naturally adventurous and curious, two qualities which have contributed to the success of our work together.

One of the most important aspects of our work is stretching, especially in keeping her calves, hamstrings, quadriceps, adductors, IT bands and psoas muscles flexible and strong. Twice a week, N. uses the Reformer, Wunda Chair, Cadillac and Ladder Barrel Pilates machines. Because CMT affects dorsiflexion, we do a lot of work to keep her shin muscles awake and strong as possible. She had surgery in her left knee prior to meeting me, and she had a right hip replacement two years ago due to arthritis in the hip joint. Leg and hip strengthening exercises are also part of our weekly routines.

Our strategy includes maintaining spinal flexibility as well as building core strength in three planes of movement. This is crucial for balance and agility. Because N. cannot rely on her feet and ankles for proprioception, she has learned to feel where her body is in space with accuracy and respond appropriately by moving against resistance in different places. This means she performs movements that go forward and backward, side to side and with rotation. Pilates allows her to explore three-dimensional movement in various planes and on different equipment. N.'s ability to feel her body master these movements has boosted her self-confidence.

Hand and arm strength are also an issue for CMT clients. N. uses both free weights and Pilates springs to keep her arms and hands strong while challenging her core, balance and proprioception.

Over the years, N. has had some falls, including a couple that have resulted in a dislocated elbow and sore knee, as well as a hip replacement. I'm always delighted at how quickly N. bounces back, and how her dedication to Pilates pays off in resilience. I have also worked with clients who have other neurological disorders, including cerebral palsy and Guillain-Barré. It's important to stress that while Pilates can be of help in all of these conditions, the extent of help Pilates will afford depends on the dedication and passion of both the client and teacher. It's also important to check with your doctor before starting any new fitness routine, including Pilates.

While people with neurological disorders like CMT have some specific challenges, in the end, they share many of the same issues as those without neurological challenges. It's important that we never lose sight of our shared humanity as we navigate life together.

Lavinia Magliocco is a certified Pilates instructor and specializes in chronic injuries and pre-and-post-op rehabilitation and conditioning. She teaches dancers and non-dancers at her studio, Equipoise, in Portland, Oregon, where she combines various disciplines and a holistic approach to encourage body awareness, integrated movement and well-being.
Dear David,

Over the years, having been diagnosed with CMT2A many years ago, I have developed a phobia of going to the doctor. I have been wrongly diagnosed so many times that I just don’t trust doctors anymore. I now become extremely anxious when I have to go to the doctor. I don’t want to be negligent with my health, but how do I get over my distrust?

David replies:

I completely understand your feelings because I also have been told some pretty ridiculous things over the years. Many of us have been traumatized by well-meaning, but sometimes overzealous doctors who know very little about CMT. I have heard many times, “I learned about CMT in medical school, but I have seen it very few times.” This statement does not exactly create confidence. Those early years before we received an official diagnosis were terrifying, and those fears simply lodged in our brains. It was a very lonely and scary time for many of us. To acknowledge our fears and to develop compassion for ourselves is an important first step. Considering what you have experienced, your anxiety is a normal reaction. It may take a few sessions with an understanding therapist to get to a point where you are comfortable seeing and trusting a doctor. Talking with a mental health counselor about your feelings might help because, as you stated, never going a doctor is not the answer.

From my own experience, I know how frustrating it is when I go to a doctor for something unrelated to CMT. My CMT is not invisible, yet I’m never asked why I need a cane. I expect a good doctor to ask because I want a doctor who notices all of me, not just one particular ailment.

One thing you can do is search for caring physicians, particularly those who are associated with CMTA Centers of Excellence. You can find a list of Centers of Excellence at www.cmtausa.org/coe. Talking to professionals who really understand CMT makes a world of difference. If you belong to a CMTA branch, ask members for recommendations. If you don’t live near a CMT specialist, it is worth the trip to see one. Finding a doctor who is warm and caring and knows what we go through on a daily basis will help you feel less isolated. Even a doctor who is not a CMT specialist, but who is willing to research the issues surrounding CMT, will help you feel more like you’re getting the best care.

We are fortunate to live in a time where there is so much information available about CMT. Avoid isolating yourself because you have had bad experiences with the medical profession. You deserve the best medical support available, so stand up for your right to find it.

David Tannenbaum 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.
How Balance Walking Can Help Fitness and Living with CMT

The start of a new year often brings with it resolutions to become more fit. It can be exciting to start something new, but by the time spring rolls around, many of us are asking whether our goals are reasonable and if our expectations are still on target. Setting reasonable expectations is especially important when living with a condition like Charcot-Marie-Tooth (CMT) that can make starting or maintaining a fitness program challenging.

One tool that can help with some of those challenges is Balance Walking with Nordic walking poles—a great way to not only get and stay fit, but also to make getting around much easier overall. Balance walking poles can help people with CMT get fit while also aiding with regular walking and overall balance.

“Medical studies on pole walking uniformly show better breathing, less stress on joints and other significant advantages over running, including more calories burned in less time,” says podiatrist and CMTA Advisory Board member Joseph Gregory Stilwell, DPM, FACFAS. “Using a tempo like a simple musical rhythm helps with neurological re-training.”

Walking poles—which are relatively inexpensive and easy to use—also offer other benefits, including:

- The ability to help smooth nerve conduction.
- The ability to be “push-pulled” to use the stronger shoulder and trunk muscles and relieve the stress of tired legs and feet.
- A three-piece strap that allows the user to push down with an open palm to lift the rib cage and increase the room for lung expansion.
- The ability to add rubber tips that help prevent slipping and balance walking on a variety of surfaces.

Dr. Stillwell recommends the true Nordic poles with hook and loop wrist straps and recommends testing different poles to see whether the one-piece fixed or two-piece adjustable models...
work best for your needs. While adjustable models collapse for easy transport, you will want to test the locks on the adjusting mechanisms. Dr. Stillwell reports good results with both models.

Other reasons to add Balance Walking poles to your walk include:

• Burning calories at a faster pace than ordinary walking.
• Making walking feel easier overall.
• Keeping the body aligned and the core engaged.
• Maintaining the heart rate in the fat-burning zone.
• Improving posture.

They can also help you work through pain, motivating you to exercise even when you’re not feeling your best. Other advantages of adding poles include:

• Reducing impact on your joints and feet.
• Helping to prevent lower body issues due to foot challenges.
• Distributing weight among four points of contact rather than just two feet to increase and improve balance.

You can read an article by Dr. Stilwell and view Balance Walking for CMT videos at www.cmtausa.org/balancewalking.

To learn more about Balance Walking and purchase Nordic Walking poles, visit www.balancewalking.com. If you are a member, please use the code CMTA when ordering. Balance Walking is honored to partner with CMTA to serve the Charcot-Marie-Tooth community, so you’ll receive a 10 percent discount, and Balance Walking will donate a percentage of every sale to the CMTA.

You’ll also need proper footwear for walking, so set yourself up for success with comfortable shoes and customized foot supports. Find your nearest Foot Solutions store at www.footsolutions.com. You will get a full holistic foot analysis, expert fitting and knowledgeable recommendations for CMT-friendly footwear for fitness, work and other occasions.

Balance Walking and Foot Solutions are proud to partner with the CMTA.
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CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone’s memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank-you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, PO Box 105, Glenolden, PA 19036.

Honorary Gift: In honor of (person you wish to honor)

Send acknowledgment to:
Name:___________________________________________
Address:_________________________________________

Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding ☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift: In memory of (name of deceased)

Send acknowledgment to:
Name:___________________________________________
Address:_________________________________________

Amount Enclosed: ____________________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card #_________________________________________
Exp. Date _______________________________________
Signature _______________________________________

Gift Given By:
Name:___________________________________________
Address:_________________________________________
The Magic of iGive.com

Recently, my friend Quentin Martin contacted me to remind me to spread the word about an easy way to raise money for the CMTA when shopping online: Use iGive.com, the world’s first online shopping mall that has turned internet shopping into a philanthropic activity. A portion of your everyday online purchases is sent to the CMTA—at no cost to you. On the iGive.com website, you will find more than 1,800 participating merchants, including the Apple Store, Best Buy, Drugstore.com, Eddie Bauer, Enterprise Rent-a-Car, GAP, Hilton Hotels, Kohl’s, Land’s End, L.L. Bean, Macy’s, Nordstrom, Office Depot, Radio Shack, Target and so many more. Signing up is easy! In fact, the whole process can be completed within 90 seconds. Go to www.igive.com. Choose the Charcot-Marie-Tooth Association (CMTA) as your cause. Install the iGive.com button, and start shopping!

The button is an almost imperceptible addition to your browser, and it automatically tells participating stores that you want your shopping to support the CMTA. In fact, statistics show that members with the iGive button installed raise three times more for their causes than those members without.

“Wouldn’t it be great if you could push a magical button to find a cure for CMT?” asks Roy Behlke, one of the CMTA’s branch leaders.

Well, installing the iGive button is a very good start. Fundraising for CMT cannot get any easier. To date, we have raised more than $8,000 for the Charcot-Marie-Tooth Association. Quentin and I hope to see that number double this year. With your help, we can make that happen! Go to iGive.com, sign up and install the magical button. Then, ask 10 friends, co-workers and family members to sign up, too. Spread the love! You have nothing to lose, and the CMTA has a lot to gain. Let’s use the power of iGive to generously support the CMTA today and every day. —Elizabeth Ouellette
Since launching its Strategy to Accelerate Research (STAR), the CMTA continues to shorten the timeline for finding a treatment—and eventually a cure—for CMT. Our development of a toolkit of assays (tests), animal models and CMT cell lines has earned the CMTA a sterling reputation in the pharmaceutical and biotechnology industries, leading top pharmaceutical companies to seek partnerships with the CMTA. Those partnerships will be particularly important as we move forward with clinical trials, always the riskiest and most expensive part of drug delivery.

In addition to partnerships with premier scientists, doctors and companies, we are also exploring new ways to involve people living with CMT in our research. After all, people with CMT are at the core of all we do. 2018 promises to be a big year for patient engagement in research. We look forward to sharing more information about our plans later this year.

With the world’s top scientific partners joining forces with our CMT patients, the potential for breakthrough treatments is real. The CMTA’s approach is working, and together, we will create a world without CMT.

“The Transformation Project

In 2012, the STAR Advisory Board (SAB) decided that to further validate candidate drugs, researchers needed human cell lines. The project transformed human skin and blood cells from CMT patients into stem cells, and from there, into neurons (nerve cells) and Schwann cells (which make myelin). STAR developed CMT1A and CMT2A cell lines for investigative use and made them available to researchers around the world.

“Patient groups like the CMTA bring funding, expertise in disease biology and advice on meaningful intervention approaches and the National Center for Advancing Translational Sciences brings expertise in therapeutic development. The result is a more patient-relevant and efficient route to new treatments—true translational innovation.”

—CHRISTOPHER P. AUSTIN, MD, DIRECTOR
National Center for Advancing Translational Sciences at the National Institutes of Health
Thanks to your support, Charcot-Marie-Tooth Association’s STAR research program is where it is today – on the verge of delivering treatments for CMT, the progressive neuromuscular disease that affects more than 2.8 million people worldwide.

BUT OUR WORK IS FAR FROM DONE.

In the next three years, the CMTA will need $10 million in funding from people like you to maintain the quickened pace of its research. With these funds, the CMTA will be able to:

• Conduct clinical trials on drugs already identified to treat CMT, poising them for Food and Drug Administration approval.
• Continue the search for other treatments for 1A, 1B, 2A, 2E, 1X, 4C, and other types of CMT.
• Continue to pursue every promising avenue toward a cure until we reach our goal of ending CMT.

More than most people, you know what a drug treatment for CMT will mean. You undoubtedly have your own living example. Give today, because there are 2.8 million reasons to end CMT.

Your gift is welcomed and appreciated and is tax-deductible as allowed by law.

Please donate online at [www.cmtausa.org/cmtbreakthroughs](http://www.cmtausa.org/cmtbreakthroughs) or complete the form below and mail to:

CHARCOT-MARIE-TOOTH ASSOCIATION
PO Box 105 • Glenolden, PA 19036

Yes, the CMTA can count on my contribution to be the breakthrough in their lives and accelerate research for a treatment for CMT!

☐ $75  ☐ $150  ☐ $300  ☐ Other: $___________

☐ I am interested in learning about leaving a legacy gift to the CMTA.

☐ Check enclosed, payable to the Charcot-Marie-Tooth Association, or

Please charge my: ☐ Visa ☐ MasterCard ☐ American Express

Name____________________________________________________

Card #________________________________ Exp. Date_____________

Signature__________________________________________

Address___________________________________________________

City___________________________State___________Zip__________

Phone________________________________
Even though I don’t have CMT, I faced a problem similar to many of you—if and when to have foot surgery. I waited too long, and I don’t want you to make the same mistake. Ever since I can remember, I had pain and stiffness in my left foot and was unable to do certain things that came easily to my friends. My father, a professor of surgery in New York City, knew the best doctors for me to see. I saw countless specialists, but no one could ever come up with a diagnosis.

There was nothing wrong and nothing to be done, they said. I came to accept my problem as normal, even though my symptoms worsened over the years. Ultimately, after I specialized in orthopaedic foot and ankle surgery, I made my own diagnosis. I had a tarsal coalition, a condition where some of the bones in the foot are joined together and do not move properly. It was not until 2004, the year that my term as president of the American Orthopaedic Foot and Ankle Society came to an end, that I decided to have surgery. By then, however, the damage was already done. The foot joints that could have been saved when I was 17 were unsalvageable.

So, how do you know if you should have surgery? The key to making an informed decision is to understand what is happening to your foot. Your doctor may be able to help, although many are not familiar with CMT. The most common deformity in about 80 percent of patients with CMT is a cavovarus foot (pictured at right). The arch is high (cavus), the heel is turned inward (varus), and the toes are contracted (clawed). This abnormal foot shape results from years of imbalanced muscle-pull. The peroneus brevis muscle that stabilizes the ankle is often the first to weaken, followed by the tibialis anterior muscle that lifts up the ankle. The small intrinsic muscles that keep the toes straight also become weak. The result is a deformity caused by the over-pull of the muscles that remain strong (the posterior tibial, peroneus longus and extensor longus).

In mild cases, there may only be some slight imbalance and fatigue with walking. Often no treatment is needed, except for a physical therapy program directed at muscle strength (especially the peroneus brevis and tibialis anterior muscles) and balance. A high-top shoe or a simple off-the-shelf brace may be sufficient.

As the muscles weaken and the deformity worsens, a bulkier and more complex brace is often needed. The goal of the brace is to stabilize the ankle and bring the foot into a plantigrade position, where it is flat on the ground. If you are not comfortable in the brace, it is probably because these goals are not being met. Every week I see patients in this situation who have given up hope of walking with any normalcy. Their feet remain twisted inside of braces that are heavy and cumbersome. They are in pain, which is often attributed entirely to their neuropathy. But the diffuse calluses on the bottom and sides of the feet, caused by the abnormal stresses from the deformity, would be enough to cause anyone pain. All too often, no one has ever told them that surgery is an option. Look down on your foot in the brace. If your foot is not flat on the ground it is time to consult with an orthopaedic surgeon who specializes in the foot and ankle.

Surgery is not for everyone, however. The 20 percent of CMT patients who don’t have a cavovarus foot deformity will almost always do better with a brace. These are usually patients with complete paralysis below the knee (except for the Achilles which often retains some function). They never experience the muscle imbalance that creates a deformity. These patients all have foot drop, and...
some surgeons still recommend an ankle fusion. I don’t suggest that approach. For these patients, a brace, specifically a ground-reaction-force brace (GRF), is by far the best option. While an ankle fusion is a great operation for someone who has a painful or deformed ankle from arthritis, without good muscle function in the rest of the foot, an ankle fusion does not do as well as a GRF brace. The GRF braces work by creating a spring action that comes from the stored energy within the brace as the patient bends the knee and flexes the brace. The brace stores energy with one step, and gives it back with the next, to create a remarkably fluid gait.

What are the goals of surgery for those with a cavovarus deformity? These feet are stiff, with little shock absorption. We don’t want to make them more rigid by fusing joints if we can avoid it. Instead, we want to preserve motion and get a foot that is flat on the ground with balanced muscle pull. Patients with CMT are generally otherwise healthy and tolerate surgery very well. We do these operations as an outpatient, with general anesthesia and a regional nerve block that provides post-operative pain relief for 24-72 hours. Typically, wedges of bone are removed from the heel and the big toe side of the foot to create a foot that is flat. The peroneus longus muscle is transferred into the weak peroneus brevis muscle to stabilize the ankle, and the posterior tibial muscle is brought from one side of the leg to the other to help lift up the ankle. Tight tissues are loosened, loose tissues are tightened, and the toes are straightened to fit into a shoe. It all sounds scary I suppose, but this is what orthopaedic surgery is all about. And, the results are excellent.

For the first two weeks after surgery, it is important to rest up. The sutures come out after two weeks and a short leg non-weight bearing cast goes on for a month. After that, weight bearing is usually possible in a removable cast boot, and physical therapy begins. It can take up to a year to get used to your new foot, but it is worth it. The opposite foot can be operated on as soon as six weeks after the first. Outcomes are excellent, and even if the disease progresses, the foot is better off than it would have been without an operation. Many patients are able to get out of braces entirely, or at the very least, decrease the size of their brace and walk with less pain.

It is important to remember that no one with CMT is born with a severe foot deformity. It develops over time. At some point, the reconstructive procedures discussed above become impossible. Chronic abnormal stress on the unbalanced cavovarus foot leads to ligament laxity, joint arthritis and fixed deformity. Joint fusions will then be the only option. That is what happened to me. Don’t let it happen to you.

Glenn B. Pfeffer, MD, is director of the Foot and Ankle Center at Cedars-Sinai Medical Center. He is also a co-director of the Hereditary Neuropathy Program and co-director of the Cedars-Sinai/USC Glorya Kaufman Dance Medicine Center. Dr. Pfeffer has written numerous scientific articles on orthopaedics and has edited seven academic textbooks on the foot and ankle. He has been treating foot and ankle problems in patients with Charcot-Marie-Tooth disease for 25 years. He is a past president of the American Orthopaedic Foot and Ankle Society and recently served as president of the California Orthopaedic Association. Dr. Pfeffer is frequently interviewed on foot and ankle topics and has been featured on CNN, Dancing with the Stars, Dateline NBC, Good Morning America, and in The New York Times.
The CMTA gratefully acknowledges gifts in memory of:

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Mr. Joseph Cutrufello
Ms. Mary Jo Defino
Ms. Stephanie Poper
The Stanley-Laman Group, Ltd.
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I had reconstructive foot surgery three weeks ago on my left foot, more or less five years after I had the same surgery done on my right foot. After a long day of scooting around on my bottom and hopping on one foot, I was in bed with my lower legs extended over the edge. I noticed a vein running along the back of my right calf, which I had not noticed before. My doctors always remark that my calves have exceptionally good muscle mass and tone for a 59-year-old male with CMTX, but my right leg has always been weaker than my left. Three plus weeks of relying on my weaker foot exclusively had obviously forced it to up its game, so to speak. Standing squarely on it with all my weight had produced a bit more muscle with enhanced muscle tone, a nice side benefit of the surgery.

This morning, I thought about how I could retain this muscle upgrade or maybe even advance it some more. One might think this would occur naturally since I will resume my active lifestyle once I am fully recovered. Walking, biking, weight training and yoga will contribute in different ways to this worthy cause, but here’s the catch: Any of these forms of conditioning involve standing squarely on my feet such that my weight is spread evenly across the foot only to a limited degree. How long can you hold a balancing pose in yoga, for example, even when you are steadying yourself with a hand against a wall? What you really need to do, it seems to me, is press firmly and squarely on the foot for an extended period of time to get the full effect, and it’s hard to do this except when you have no choice— when you can only stand on one leg, for example.

Fortunately, there is a way you can do this on a regular basis—

(continued on page 23)
The always amazing Jeana Sweeney spoke at meetings of the Baltimore and Easton CMTA Branches on November 19. Jeana quizzed the group about CMT and the CMTA and awarded Hershey’s kisses and t-shirts for correct answers. Jeana also updated the group on the current scientific advancements toward finding a treatment for CMT1A and a host of other CMT subtypes. Jeana also told the group about the current CMT campaign called Breakthroughs. (Donations can be made to Breakthroughs using the form on page 13 or on the CMTA website (www.cmtausa.org/cmtbreakthroughs).

CMTA board member Steve O’Donnell also attended the Baltimore meeting. Steve, who has personally raised more than $1 million dollars for the CMTA, provided more details on current CMT research, assured everyone that the CMTA’s operating expenses are very low and that almost all contributions go directly to CMT research.

Steve now fundraises with the Oxford Funathlon, the third largest CMT fundraiser in the country. The Funathlon will take place on June 9 in beautiful Oxford, Maryland. We are currently looking for sponsors and Silent Auction items. If you would like to help, please contact Clark Semmes (clarksemmes@gmail.com).

At the Easton meeting, Allard representative Laurie Lasky, who has family members with CMT, brought sample Allard braces for the group to examine and showed a short film about athletes with CMT.

Easton branch leader Missy Warfield also has passed the leadership baton to Clark Semmes, but her commitment to the CMTA and our cause is undiminished. Thanks to Missy and Seth for all they do to fight CMT and support the CMTA!

Other topics of discussion at the meetings included CMTA Camp Footprint and Maryland’s upcoming medical marijuana program.
Taylor Lee Hill Makes Every Second Count

Taylor Lee Hill is 10 years old and has been diagnosed with CMT4C through genetic testing. Taylor has been receiving physical therapy since she was four months old. With her strong mind and character, nothing seems to hold her back. She has the most beautiful smile and a never-give-up attitude. Neither “can’t” nor “cannon” are in her vocabulary. In fact, she often says those words don’t exist. Struggle is the preferred word.

With her zest for life, Taylor manages to do more than any child who does not have CMT. She races go-karts, which takes a phenomenal amount of energy and strength. She absolutely loves the sport. She has been driving for approximately three years, and she is improving daily on her speed and times. Because she has CMT and wears AFOs, she struggles with sensation in her feet and listens to the engine to know where her throttle is sitting.

Taylor believes the more people who know about CMT, the sooner a cure will be on the horizon. This year, she has decided to put the CMTA logo on her kart to create awareness of the disease. Taylor’s brother, who is the African Open champion for 2017, also will be putting the CMTA logo on his kart to show support for his sister.

Taylor has so much enthusiasm and zest for life. She will try anything! She believes life is for living, and she makes every second count—on and off the race track! Taylor has a need for speed and enjoys karting, jet-skiing and anything with a fast engine. She believes her kart engine serves as her legs, and she is finally on a level playing field once she is seated in a kart. At the beginning of the year, Taylor received a certificate of excellence at her school for karting. The principal even used Taylor as an example, saying: “No matter what your struggles are, Taylor is the perfect example of what can be overcome with your mind.”

Taylor recently put the CMTA logo on her go-kart to raise awareness of CMT.
of living with CMT, concerns of younger family members being affected by CMT, experiences visiting neurologists who gave limited information and/or negative information, as well as of experiences at the CMTA Center of Excellence at the University of Minnesota where many branch members have been evaluated by Dr. David Walk.

Guest presenter Dr. Phillip Haber shared his experiences of living with CMT and gave tips on how to ask for assistance from others when needed. Dr. Haber, who enjoys fishing and camping in the wilderness, spoke about his international travels and how people of different cultures extended him a helping hand. He also shared stories about local fitness centers and the importance of having an exercise program designed for his CMT needs. Dr. Haber’s talk encouraged attendees to overcome their fear of asking for assistance when needed, even if they are simply asking for help buttoning the top button of a dress shirt.

**NEW MEXICO**
The New Mexico CMTA Branch met on November 18 and welcomed two new members, for a total of 18. Branch leader Gary Shepard started off the meeting with an update on substantial CMTA research progress. He then talked about holiday gift giving and mentioned that people often get a lot of holiday gifts they really don’t need or want. He recommended suggesting to those giving gifts that they instead give a donation to CMT research in a loved one’s name. It’s easy, tax-deductible, and so much better than getting another unwanted tie or knick-knack.

Two members noted that Dr. Gandhi, a neurologist at DaVita Medical Group in Albuquerque is particularly knowledgeable in CMT.

CMT Advisory Board member and podiatrist Greg Stilwell, DPM, then gave an excellent presentation on many types of orthotic alternatives. He brought a number of samples that generated a useful discussion about orthotics, bracing and related topics. He noted that many of these types of orthotics are available from Mile High Orthotics (http://www.mholabs.com). Also available online is a gel pad that adheres to foot and ankle called Dr. Jill’s Footpad. The group also noted that New Balance is discontinuing extra-depth shoes. Apex and Brooks were mentioned as alternatives. Two members recommended Hanger (specifically the Martin Luther King location) as another possibility for bracing or special shoes.

The New Mexico CMTA Branch met again on February 3 at its new location, the Manzano Multicultural Center, with 10 members present. The group spent a lot of time reviewing the document CMT Challenges and Solutions, which was prepared by the branch some time ago. CMTA Board member Elizabeth Ouellette suggested that the material in this document be incorporated into the CMTA-managed Pinterest site (www.pinterest.com/cmtassociation).

**RESEARCH TRIANGLE, NC**
The Research Triangle Area, NC CMTA Branch met for the first time at the Carolina Meadows Retirement Community location on November 11. Approximately 15 people attended to hear Jane E. Andersen, DPM, talk about balance, braces and appropriate shoes for people with CMT. Attendees completed a brief written survey to gauge interest in topics for future meetings.

In addition, Margaret Lee, who led the branch for the past five years, was honored and given gifts of appreciation by members. The new branch co-leaders are Jeanne Boehlecke and Rick Nelson.

**PORTLAND, OR**
The Portland, OR CMTA Branch extended a very warm welcome to newcomers Karen and David from Hood River, as well as Natalie and Jeff. The two January meetings were productive and well-attended. The group met on Thursday evening at La Hacienda Real in Beaverton and discussed clinical trials, as well (continued on page 22)
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**Interested in starting a branch in your area?**

Contact CMTA Director of Community Engagement
Jeana Sweeney at Jeana@cmtausa.org.
as resources for children and teens with CMT. Please pass along any good suggestions for
care of people with CMT living their lives for a
2019 calendar. Nan has already submitted
photos of herself whitewater rowing and
horseback riding. People submitting photos
do not have to be athletes to make this a
successful project. Any enjoyable activities,
from reading to cooking or driving a hand-operated
car will serve to put faces on people with CMT and create more
awareness. The plan is to produce and sell
these calendars.

**SOUTHERN CONNECTICUT**
On November 13, members of the Southern
Connecticut CMTA Branch welcomed Eliza-
abeth Ouellette via Skype from California,
and she gave her presentation “Chronic Pain: A Patient Perspective.”

The 12 attendees listened to Elizabeth’s
personal journey of living with chronic neu-
ropathic pain and also what she has learned
by helping her son and many others in the
CMT community manage chronic issues
related to CMT. She gave an overview of
current medical, interventional, behavioral,
pharmacologic and rehabilitation therapies
that may be helpful in navigating the maze
of chronic pain and treatment options. Eliz-
abeth also shared the latest CMT research
news and answered questions.

**SOUTHWEST WISCONSIN**
Jonah Berger, CMTA Advisory Board mem-
er, CMTA Camp Footprint co-director and
motivational speaker was our special guest
on November 11. Jonah is the author of He
Walks Like a Cowboy, a book detailing the
life and lessons of his personal CMT jour-
ney. It was a treat to hear him speak openly
and honestly about the day-to-day strug-
gles of living with CMT. His focus was on
how he does everything he can to rise
above his CMT challenges to live a positive
and fulfilling life. Jonah helped everyone
see the positives of each day, and he
encouraged the group with an awesome
message of hope for the future.

Jonah’s visit was a thank you gift to the
Southeast Wisconsin CMTA Branch from the
CMTA for its successes in raising funds and
awareness over the past three years.

Donations from the branch, combined
with contributions from others in the CMTA
community, have helped fund every step of
the drug discovery program. The CMTA can
count on Southwest Wisconsin to continue
to fundraise and spread awareness until
CMTA is just a footnote in a dusty medical
journal.

Twenty-four people left the gathering
armed with hope and information about the
breakthrough research that is happening
right now. Studies in CMT1A have not only
stopped progression of the disease, but
they have also showed improvement in
some symptoms!

**TORONTO**
At the Toronto CMTA Branch meeting on
November 14, the group welcomed three
speakers from the Apollo Cannabis Clinic,
Dr. Tanny Raz, Shinelle Villafana, and owner
Bryan Hendin, who explained that he
opened Apollo because he is passionate
about helping people who are in pain. They
explained the difference between the com-
ponents of medical marijuana—cannabidiol
(CBD) and THC—how these components
affect the body and the various types of
products available for medical use.

Steven Baker, MD, an associate profes-
sor in the division of Physical Medicine and
Rehabilitation, Department of Medicine and
a research director at McMaster Health Sci-
tences Centre in Hamilton, will speak at the
April 28 meeting at 10 a.m.

Other 2018 meetings will at 1 p.m. on
March 24, September 8 and November 3.

The group discussed a fundraiser for
2018. Since the group is small and some
members are not very mobile, they decided
to hold another raffle. Please send Linda
any suggestions for raffle items other than
cash. Raffle tickets will be distributed at the
September meeting, and prize winners will
be announced at the November meeting.

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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 Neuropathies Consortium (INC)—a group of
academic medical centers, patient support organizations and clinical
research resources sponsored in part by the CMTA. The centers will
become even more important as the CMTA begins clinical trials, which
will 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.
scootering, I have an adult Razor scooter I use to get around the neighborhood. The great thing about scootering for someone living with CMT is that you are standing squarely on your foot, as you would with other activities, such as balancing poses in yoga. But the key difference is the movement, which enables you to keep your balance for an extended period without falling over. More importantly, though, the movement enables you to maintain this position without steadying yourself against a solid object. This way, you are pressing even more firmly than you would if you were doing exercises against a wall or using crutches or a knee scooter when you are non-weight bearing.

So, the first order of business for me once I am recovered will be to break out the scooter and head off into the distance. I realize, of course, this may be like flashing the home run sign for many of you. My symptoms are very mild. That, along with two surgeries correcting the alignment of my feet, makes it possible for me to scooter effectively. Clearly, it may not be right for you, or perhaps you can only do it on a more limited basis. I switch feet every block and a half or so, for example. Perhaps you would need to switch more often or take frequent breaks.

It’s important to check with your doctor before starting any new fitness routine, including scootering. You’ll also need to consider protective equipment, such as a helmet or knee pads. If it is possible to scooter effectively, however, please give it a try. It might be just the thing to build some much-needed strength in your calves while you reinforce the proper alignment of your feet. The best thing is that you might have some fun doing it. I certainly do! ★
WHAT IS CMT?

- CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- CMT may become worse if certain neurotoxic drugs are taken.
- CMT can vary greatly in severity, even within the same family.
- CMT can, in rare instances, cause severe disability.
- CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- CMT does not affect life expectancy.
- CMT is sometimes surgically treated.
- CMT causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- Although there is no drug treatment for CMT, physical therapy, occupational therapy, and moderate physical activity are beneficial.
- CMT is usually inherited in an autosomal dominant pattern, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- CMT Types that can now be diagnosed by a blood test include 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN.
- CMT is the focus of significant research, bringing us closer to a world without CMT.