

WINTER 2018

THE CMTA Report

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OUR VISION: A World Without CMT.

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A Message from CEO Amy Gray



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 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.

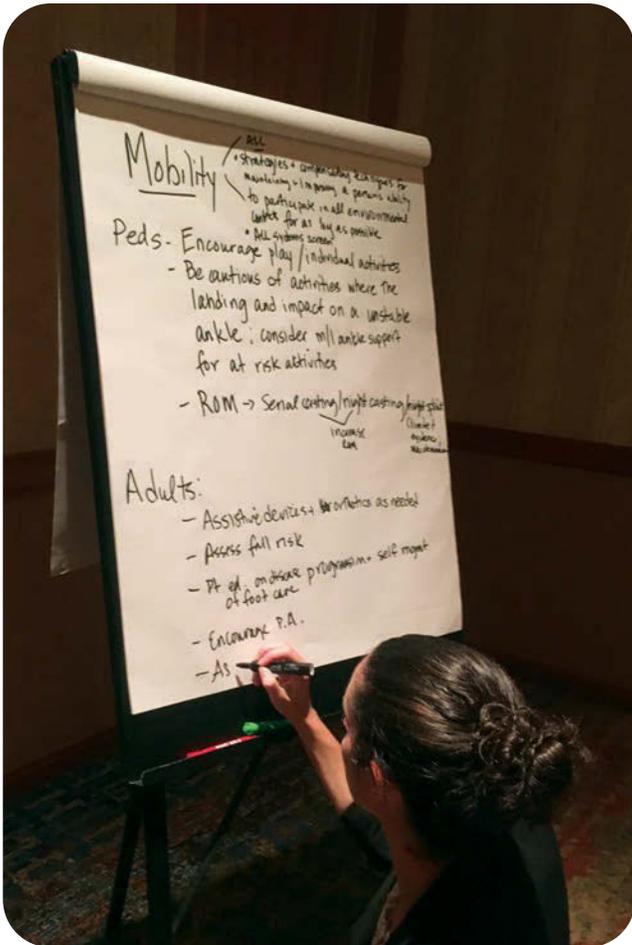
Amidst these major breakthroughs, exciting projects, and visible progress, I want to thank you for your generosity, support, and participation that makes it all possible.

With sincere thanks,

A handwritten signature in black ink that reads "Amy Gray". The signature is fluid and cursive.

AMY GRAY, Chief Executive Officer

CMTA Conference Brings Together Physical and Occupational Therapists from Around the World



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, CMTped 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 Accelaron, 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.

DISCUSSION HIGHLIGHTS



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](http://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.



How People with CMT Can Benefit from Pilates and Movement Therapy

BY LAVINIA MAGLIOCCO, PILATES INSTRUCTOR AT EQUIPOISE

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 as 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 appro-

priately 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 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.

? WHAT'S ON YOUR MIND? *Ask David.*

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 Excel-

lence 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.



Write to David at info@cmtausa.org.

DISABILITY INSURANCE EXPERT KATE LAIR JOINS THE CMTA ADVISORY BOARD

We are pleased to announce the addition of a new member to the CMTA Advisory Board. Kate Lair, a former disability claim case manager, brings a wealth of knowledge and experience to the CMT patient community in her new role.

Diagnosed with CMT1A in infancy, Kate considers herself a "professional patient" and has learned how to adeptly navigate the health insurance bureaucracy. After graduating with a master's degree in sociology, Kate went on to hold nonprofit and private sector jobs in a variety of fields, including individual disability insurance and employer-sponsored long-term disability insurance.

Kate lives in western Massachusetts with her husband and daughter, and she is excited to put her expertise to good use on behalf of her fellow CMT patients and their families. Welcome aboard, Kate!



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 con-

dition 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. Stilwell 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



Walking poles have many benefits, especially for people living with CMT.

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. ★



Walking poles can be used on a variety of terrains.

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

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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Shining a light on
the latest breakthroughs
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Saturday, June 16, 9:00 am - 1:30 pm

DoubleTree by Hilton Hotel Fort Lee

Fort Lee, NJ

Register now at www.cmtausa.org/njnyc

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Ages 10-18

We'll meet at the
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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.

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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



2018 CMTA
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Partnerships with Patients and Industry Leaders Drive Breakthrough Research

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.

“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

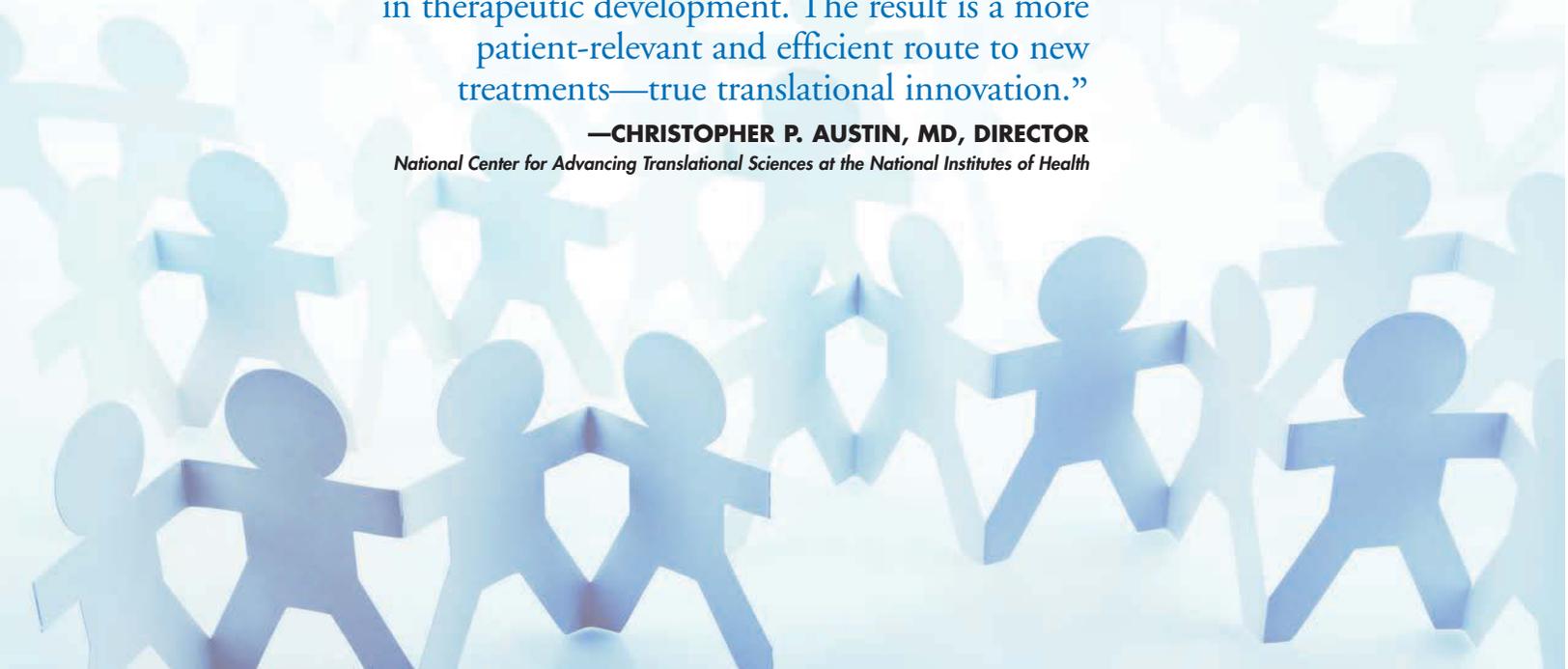
THE TRANSFORMATION PROJECT

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.

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. ★



be the breakthrough in their lives

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, poisoning 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 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 _____

How to Decide If Foot Surgery IS RIGHT FOR YOU

BY GLENN B. PFEFFER, MD, CMTA ADVISORY BOARD MEMBER

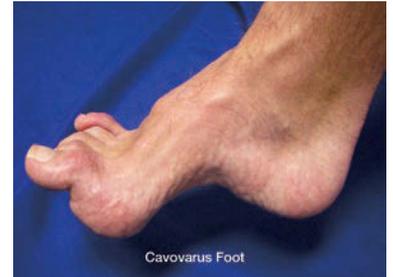
Even though I don't have CMT, I faced a problem similar to many of you—if and when to have foot surgery. I waited too long, and I don't want you to make the same mistake. Ever since I can remember, I had pain and stiffness in my left foot and was unable to do certain things that came easily to my friends. 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 planti-



grade 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



This patient's right foot has been surgically corrected.

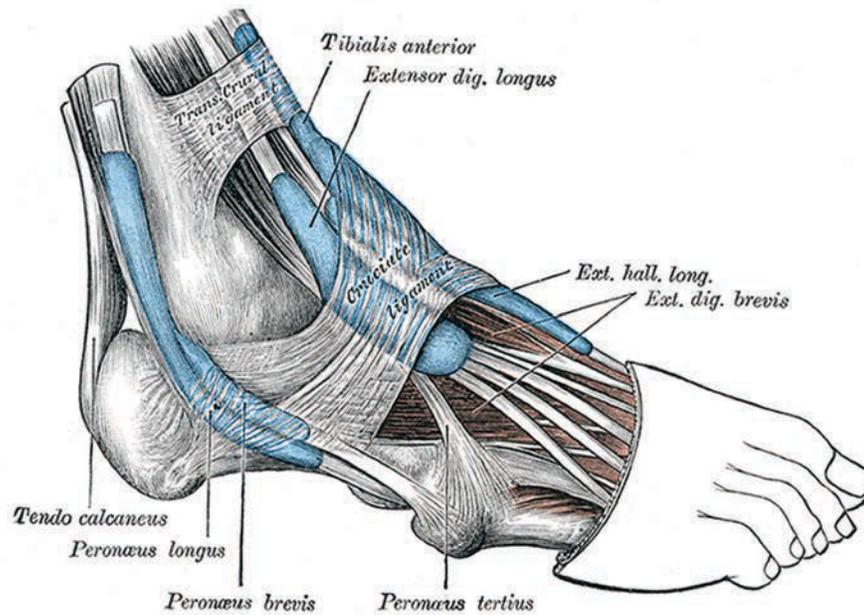


ILLUSTRATION BY HENRY CARTER

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 Glorja 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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One of the easiest and most meaningful ways to leave a lasting legacy is by making a bequest to the CMTA.

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What are your options?

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2. You can gift a percentage of your estate.
3. You can gift from the balance or residue of your estate.
4. You can make a beneficiary designation of certain assets.

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for So Many is Close at Hand*



To learn more or have a confidential conversation about making a bequest, please call 800.606.2682 x108.

Scootering into the Distance with CMT

BY JEFF SEITZER

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)



Jeff Seitzer heads out for a scootering adventure with his family.



CMTA BRANCH NEWS

BALTIMORE, MD/EASTON, MD

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 CMTA 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.



GRAND RAPIDS, MI

Angela McElroy and Tracy Thompson from Dorr To Eden—Animal Enhanced Naturopathy and Holistic Counseling—spoke to the group about equine assisted therapy, which can reduce stress within the body, as well as slow heart rates and breathing. Equine assisted therapy can help with grief, communication, confidence, trust and boundary issues.

Angela, who is a naturopathic doctor, talked about naturopathy, which can treat things like nerve pain, anxiety, depression and chronic issues. Additional resources for information:

- www.dorrtoeden.com/
- www.facebook.com/Dorr-To-Eden-557541261073515/
- <https://eagala.org/>
- www.naturopathic.org/content.asp?contentid=60

Meetings are held every third Wednesday at 6:30 p.m. in the second floor conference room at Mary Free Bed Rehabilitation Hospital.

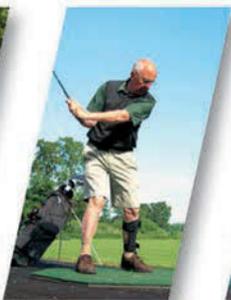


GREATER MINNEAPOLIS, MN

The Greater Minneapolis CMTA Branch meeting was informative, interactive and educational. The 90-minute roundtable discussion was of definite interest for the entire group, as they shared family stories

(continued on page 20)

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Taylor Lee Hill Makes Every Second Count

BY LEON HILL

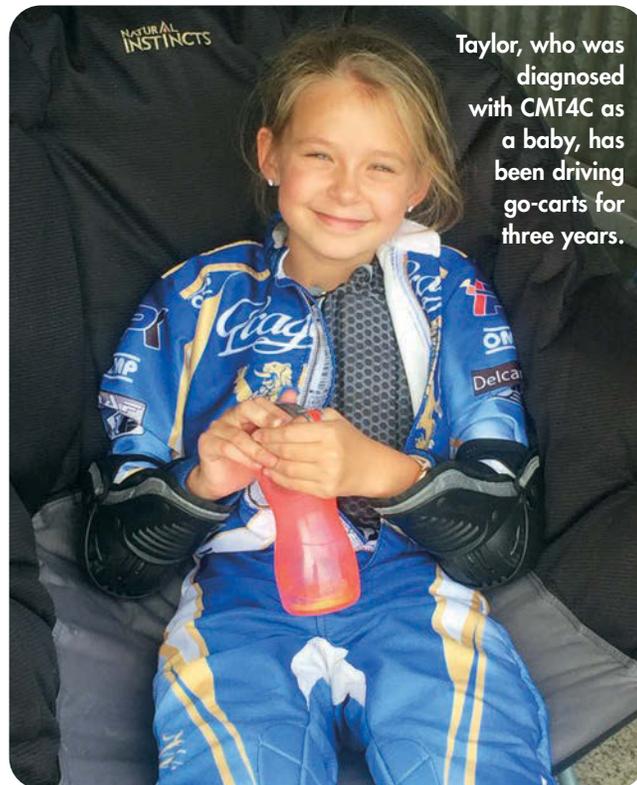
Taylor Lee Hill is 10 years old and has been diagnosed with CMT4C through genetic testing. Taylor has been receiving physical therapy since she was four months old. With her strong mind and character, nothing seems to hold her back. She has the most beautiful smile and a never-give-up attitude. Neither “can’t” nor “cannot” 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, who was diagnosed with CMT4C as a baby, has been driving go-carts for three years.



Taylor recently put the CMTA logo on her go-kart to raise awareness of CMT.

BRANCH NEWS

(continued from page 18)

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).

Gary will update to the document for Elizabeth, who will see that all the data is incorporated into the CMTA's Pinterest site. Going forward, please send all suggestions for "CMT-useful" items to Gary, who will forward them to Elizabeth for inclusion in the Pinterest site.

The next meeting of the New Mexico CMTA Branch will be at noon on May 5 at the Momentum Pilates Studio in Albuquerque, where a special presentation will be given on Pilates for those with CMT.

★

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)

SPRING STARTS THE CMTA FUNDRAISING FRENZY— START PLANNING YOUR WALK 4 CMT

Each year, thousands of people participate in Walks 4 CMT across the country to create awareness, renew hope and generate a community of support, all while raising funds for the CMTA and CMT research.

Many of the Walks 4 CMT are organized by 35 of the more than 70 CMTA branches, so if your branch is planning a walk, please check with your branch leader to see what you can do to help recruit participants



and sponsors. If your branch hasn't done a Walk 4 CMT yet, now is the time to get started! (You can find a complete branch list on page 21 or online at www.cmtausa.org/branches.)

No CMTA branch near you? Not a problem! We're making it easy for you to bring a Walk 4 CMT to your neighborhood. Just contact CMTA National Events Manager Andi Cosby at andi@cmtausa.org or 1-800-606-2682, ext. 111, and she will help you get started and set up a webpage where your friends and neighbors can register for your walk and/or make a donation to the CMTA.

Whether your event is big or small, you will have 100 percent support from the CMTA and tons of fun in the process!

Learn more about Walks 4 CMT at www.cmtausa.org/walk4cmt.





CMTA Branches

Most CMTA Branches can be accessed
online at www.cmtausa.org/branches

ALASKA

Anchorage Area
Megan Rodgers
907-244-2100

ARKANSAS

Little Rock
Lisa Jones
501-776-5364
Candice Cargile
501-516-5588

ARIZONA

Phoenix Area
Pamela Palmer
ppalmeraz@gmail.com
480-236-2445
Christina Fisher
623-742-8921

CALIFORNIA

Antelope Valley Area
Donna Murphy
661-317-6332
Danielle Metzger
661-317-6533
Los Angeles Area
Alani Price
310-710-2376
Sacramento
Holly Stevens
408-203-8804
Rashid Thomas
916-947-5377
Ernie Hinds
916-205-5682
San Diego Area
Annette Van Veen
760-473-5014
Kendall Trout
760-632-5654
South Bay Area
Ori Bash
408-829-4562
Tau O'Sullivan
916-806-2173

COLORADO

Denver Area
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CONNECTICUT

Hartford
Roy Behlke
239-682-6785
North Haven
Lynne Krupa
203-288-6673

DISTRICT OF COLUMBIA

Washington, DC
Steven Weiss
Kimberly Hughes
301-962-8885

FLORIDA

Melbourne Area
Clark Semmes
410-350-4812
Naples
Roy Behlke
239-455-5571
Sarasota Area
Rachel Rivlin
Manuel Goldberg
941-870-3326
Tampa Bay Area
Vicki Pollyea
813-251-5512
Edward Linde
813-712-4101
West Palm Beach
Phil Lewis
561-307-0100
Eileen Martinez
561-901-5566

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404-307-6519

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Honolulu Area
Bobbie Gomez
707-373-2357
James Cuizon
808-450-1236

IOWA

Iowa City Area
Jeffrey Megown
319-981-0171

ILLINOIS

Chicago Area
Jay Pate
630-888-4673
Doreen Pomykala
815-351-1328

INDIANA

Fort Wayne Area
Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488
Indianapolis Area
Nancy Allen
317-459-8773
Patricia Wood
317-345-2254

KANSAS

Kansas City Area
Tammy Adkins
314-608-6889
Aron Taylor
913-744-5674
Wichita Area
Karen Smith
316-200-0453

MASSACHUSETTS

Boston
Mimi Works
617-913-4600
Jill Ricci
978-887-1014

MARYLAND

Baltimore
Clark Semmes
410-350-4812
Easton
Clark Semmes
410-350-4812

MAINE

Portland Area
Mary Louie
207-450-5679

MICHIGAN

Grand Rapids Area
Cabrielle Rudisill
717-816-4986

MINNESOTA

Central Minnesota
Jo Smith
612-807-4729
Minneapolis Area
Marilyn Menser
320-522-0871
Mark Jeffris
651-222-4504

MISSOURI

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Payton Rule
618-401-4822
Amanda Rule
618-698-3039
Springfield Area
Jessica Brantner
417-468-8049
Jessica Hardy
417-434-1656

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Todd Long
704-902-4700
Trisha Hirsch
404-226-1389
Durham Area
Jeanne Boehlecke
919-942-7909
Rick Nelson
919-889-9776
Wilmington Area
Laurel Richardson
910-515-8488

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402-680-0502
New Jersey
Central New Jersey
Mark Willis
732-252-8299
Jacqueline Donahue
732-780-0857

NEW MEXICO

Albuquerque Area
Gary Shepherd
505-296-1238

NEVADA

Las Vegas Area
Sylvia Cross-Bias
775-537-8427

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Buffalo Area
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Maryann Ciskal
716-435-3899
Kristen Braun
716-270-3095
Upstate New York
Elizabeth Misener
David Misener
518-527-0895
Westchester Area
Beverly Wurzel
Frank Wurzel
201-224-5795

OHIO

Cincinnati Area
Jill Stuhlmueller
513-254-4065
Jo Koenig
513-607-2822
Cleveland Area
Heather Hawk Frank
440-479-5094
Shelly McMahon
440-781-8329
Columbus Area
Jessica Diamond
216-570-6432

OREGON

Grants Pass
Jessica Barton
541-218-5350 (cell)
541-846-8525
Portland Area
Debbie Mchugh
503-201-7284 (H)
503-310-7229 (M)

PENNSYLVANIA

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Tara Cave
856-361-5740
Julie FitzGerald
315-573-3919
Chester County
Ashley Trout
484-364-9334
Harrisburg
Erin Gaul
717-379-7504
Johnstown Area
J.D. Griffith
814-539-2341
Jeana Sweeney
814-269-1319
Northwestern Area
Joyce Steinkamp
814-833-8495
Philadelphia Area
Rhea Malaluan
Ronnie Mendoza
609-670-0870
Pittsburgh
Carolyn Roberts
704-919-1029
Debra Czarnecki
412-331-6744

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Zack Boyd
803-622-6565
Kyle Bryant
803-378-6202
Greenville Area
Rebecca Lauriault
864-918-2437
Amanda Jenkins
864-313-2872

TENNESSEE

Nashville Area
Bridget Sarver
615-390-0699
Teresa Shoaf
615-772-8810

TEXAS

Austin Area
Nate Halk
512-415-6097
Dan Gattuso
512-516-9161
Dallas Area
Michelle Hayes
214-529-3325
Gwen Redick
256-655-0391
Houston Area
Kristin Leard
713-516-8630
Benji Hershorn
832-731-0121
Meredith Wells
832-264-7312

UTAH

Orem Area
Melissa Arakaki
801-494-3658

VIRGINIA

Fredericksburg
Leigh Van Doren
540-370-1968
Harrisonburg Area
Jeanette Thompson
540-383-6195
Suffolk Area
Jordan Harness
843-303-0648

WASHINGTON

Seattle Area
Lynn Ronald
206-546-8923
Denise Snow
206-321-1261

WEST VIRGINIA

Charleston Area
Karen McClure
304-548-4413

WISCONSIN

Madison Area
Debi Weber
608-712-8709
Milwaukee Area
Susan Moore
414-604-8736
Frank Gess
414-475-1515

CANADA

Southern Ontario
Kelly Hall
519-843-6119
Toronto Area
Linda Scott Barber
416-997-5084

Interested in starting a branch
in your area?

Contact CMTA Director of Community Engagement
Jeana Sweeney at Jeana@cmtausa.org.

BRANCH NEWS

(continued from page 20)

as resources for children and teens with CMT. Please pass along any good suggestions for parents of kids with CMT to branch leader Debbie McHugh at mchugh6847@gmail.com.

The afternoon meeting on Friday produced a very exciting prospect to raise funds and put CMT on the radar! Fay suggested asking members to submit photos 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 to teaching 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.

★ **DALLAS, TX**

At the January 13 meeting, Michelle Hayes and Gwen Redick introduced guest speakers Sarah and Suzan Skelton and Melanie Farrar, physical therapists from Children’s Grapevine. They distributed a handout with tips for daily stretching with neuromuscular disorders. They also gave tips on what to avoid, balance concerns, proper foot attire and orthotics.

★ **SOUTHERN CONNECTICUT**

On November 13, members of the Southern Connecticut CMTA Branch welcomed Elizabeth 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 neuropathic 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. Elizabeth also shared the latest CMT research news and answered questions.

★ **SOUTHWEST WISCONSIN**

Jonah Berger, CMTA Advisory Board member, 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 journey. It was a treat to hear him speak openly and honestly about the day-to-day struggles 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 components of medical marijuana—cannabidiol (CBD) and THC—how those components affect the body and the various types of cannabis available for medical use.

Steven Baker, MD, an associate professor in the division of Physical Medicine and Rehabilitation, Department of Medicine and a research director at McMaster Health Sciences 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.

CMTA CENTERS OF EXCELLENCE (www.cmtausa.org/coe)

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.



CMTA CENTER OF EXCELLENCE

Cedars-Sinai Medical Center (Los Angeles)	Dr. Robert Baloh and Richard Lewis
Children’s Hospital of Philadelphia (Philadelphia)	Dr. Sabrina Yum
Connecticut Children’s Medical Center (Farmington)	Dr. Gyula Acsadi
Massachusetts General Hospital (Boston).....	Dr. Reza Seyedsadjadi
Johns Hopkins University (Baltimore).....	Dr. Thomas Lloyd
Lucile Packard Children’s Hospital at Stanford (Palo Alto).....	Dr. John Day and Ana Tesi Rocha
Nemours Children’s Hospital (Orlando)	Dr. Richard Finkel
Stanford Neuroscience Health Center (Palo Alto)	Dr. John Day
University of Florida (Gainesville)*	Dr. Nivedita Jerath
University of Iowa (Iowa City)	Dr. Michael Shy
University of Miami (Miami).....	Dr. Mario Saporita
University of Minnesota (Maple Grove)	Dr. David Walk
University of Missouri (Columbia).....	Dr. Raghav Govindarajan
University of Pennsylvania (Philadelphia)	Dr. Steven Scherer
University of Rochester (Rochester, NY)	Dr. David Herrmann
University of Texas Southwestern (Dallas)*	Dr. Susan Iannaccone and Diana Castro
University of Utah (Salt Lake City)	Dr. Russell Butterfield
University of Washington (Seattle).....	Dr. Michael Weiss

*These Centers of Excellence are not part of the INC.

INTERNATIONAL

The Children’s Hospital (Westmead, Australia)	Dr. Manoj Menezes
The National Hospital for Neurology & Neurosurgery (London, England)	Dr. Mary Reilly
C. Besta Neurological Institute (Milan, Italy)	Dr. Davide Pareyson
University of Antwerp (Edegem, Belgium)	Dr. Jonathan Baets

CLINICAL DIRECTOR

Dr. Robert Baloh and Richard Lewis
Dr. Sabrina Yum
Dr. Gyula Acsadi
Dr. Reza Seyedsadjadi
Dr. Thomas Lloyd
Dr. John Day and Ana Tesi Rocha
Dr. Richard Finkel
Dr. John Day
Dr. Nivedita Jerath
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<p>Subscription Membership Benefits:</p> <ul style="list-style-type: none"> • Online access to valuable information about living with CMT • An information kit and a 10% discount at the CMTA store • Quarterly delivery of <i>The CMTA Report</i>, (electronic and/or hard copy) 	<p>STAR Membership Benefits:</p> <ul style="list-style-type: none"> • All of the benefits of Subscription Membership <p>PLUS</p> <ul style="list-style-type: none"> • One free pair of Aetrex Shoes in the style of their choice (new STAR members only) • 50% off all Aetrex shoes (new and renewing STAR members) • An expanded and updated copy of the CMT Survivor's Guide • A 20% discount at the CMTA Store • One <i>You're a STAR</i> auto decal
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Mail to: CMTA, P.O. Box 105, Glenolden, PA 19036; or fax to 610-499-9267

A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling, toll-free within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

SCOOTERING

(continued from page 17)

scooter I use to get around the neighborhood. The great thing about scooting 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 scooting. 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! ★



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)
Ethinbutol
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)
α-Interferon

Negligible or doubtful risk:

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

THE CMTA Report

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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.