

THE CMTA Report

WINTER 2018/2019

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NEW ADVANCES IN GENE THERAPY

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And Counselors

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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.

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Andi Cosby *National Events Manager*, andi@cmtausa.org
Frank Gaidjunas *Director of Marketing and Communications*, frank@cmtausa.org
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Registration for Camp Footprint is now open!

THE CMTA Report

Kerry Ludlam *Executive Editor*
Karlyn Rosen Aires *Designer*
Dana Schwertfeger *Contributing Editor*

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Email the CMTA at
info@cmtausa.org

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A Message from CEO Amy Gray



DEAR FRIENDS,

Happy New Year! At the CMTA, we are looking forward to another promising year of working alongside you, and so many others in our community, to live out our mission to support the development of new drugs to treat CMT, to improve the quality of life for people with CMT and ultimately, to find a cure. From another year of hosting Camp Footprint to expanding our own footprint through events like Walk4CMT, 2019 is bound to be a year we will make more progress toward our vision of a world without CMT.

Perhaps one of the most energizing projects we are engaged in is our work with some of the world's top CMT researchers on gene therapy. Simply put, gene therapy is the practice of using healthy genes in the place of defective genes often found in genetic disorders such as CMT. Fortunately, we already know many of the genes associated with various types of CMT, so researchers are that much closer to discovering genetic solutions to treat—and possibly cure—the disease. Gene therapies have begun to receive FDA approval, and many gene therapies are in clinical trials. At the CMTA, we are proud to invest in the pursuit to investigate gene therapy further by expanding our Strategy to Accelerate Research (STAR) program and the STAR Advisory Board. Our hope is that in the not too distant future, gene therapy for CMT will be a reality beyond the lab.

While we advance research for treatments and a cure, we also understand the responsibility and opportunity we hold in improving lives today. In this issue of *The CMTA Report*, you'll learn more about the basics of ankle-foot orthoses from our friends at Allard. You'll get an update on our events throughout the country that raise funds while also expanding our engaged and supportive CMT community. You'll also read about how Camp Footprint, our camp created specifically for adolescents with CMT, continues to change lives and form lifelong bonds among campers and counselors.

Finally, we don't take for granted the trust you put in the CMTA when you donate, participate or communicate with or about us. That's why we're proud to have earned Guidestar's Platinum Rating for Transparency. Transparency by a nonprofit indicates the organization is voluntarily publishing pertinent information about itself, so donors know that their dollars are being used properly. To earn this honor, we share information about our mission, programs, audited financials and operations, plus metrics about our progress and results. You can trust the CMTA to make the best choices to drive toward our shared vision of a world without CMT.

Thank you for all of the ways you support the CMTA.

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

AMY GRAY, Chief Executive Officer

THE CMTA IS ACCELERATING RESEARCH THROUGH GENE THERAPY

BY JOHN SVAREN, PHD,
U. OF WISCONSIN-MADISON

As a CMT researcher and chair of the Charcot-Marie-Tooth Association's Scientific Advisory Board, I look forward to a time when doctors are able to use genetic therapies to treat the root cause of CMT rather than prescribing medications or recommending surgery. At the CMTA, we are already envisioning the possibilities that gene therapy holds for our community of 2.8 million people worldwide living with CMT. In fact, we're leading the pursuit to explore gene therapy in CMT by expanding our Strategy to Accelerate Research (STAR) program and our STAR Advisory Board.

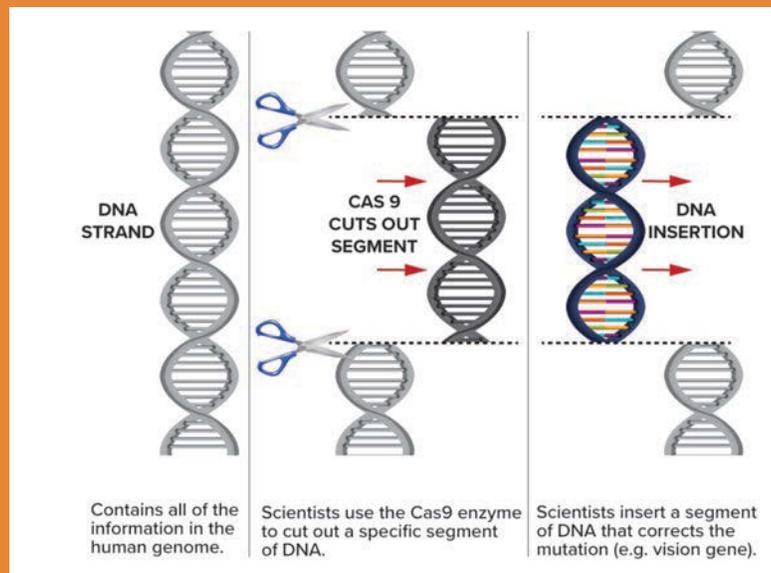
In CMT, the genetic causes for many types of CMT are

already known, which allows us, as scientists, to more efficiently zero in on genetic solutions to treat—and possibly cure—the disease. As we continue gene therapy research inside the lab, our ultimate goal is to transform it into effective treatments for people living with CMT.

Given the increased feasibility and applicability of gene therapy to CMT, the CMTA hosted a Gene Therapy Workshop this summer. In response to invitations from CMTA board member Dr. Steven Scherer, more than 20 of the top gene therapy experts gathered for the inaugural CMT-centered workshop on gene therapy. This meeting included experts who have worked in related genetic and neuromuscular

WHAT IS GENE THERAPY?

Our genes dictate many of our personal characteristics; however, mutations in genes cause genetic diseases, such as CMT. Scientists have been working for decades to modify or replace faulty genes with healthy ones to treat, cure or prevent disease. Fortunately, we are seeing significant progress on these efforts to provide gene therapy options for CMT. In fact, recent studies have provided an effective gene therapy for spinal muscular atrophy (SMA), a devastating disorder that affects the same motor neurons that are affected by CMT.



GENE EDITING AND GENE REPLACEMENT

Sometimes the whole gene is duplicated, as in CMT1A, where a chromosome segment around the *PMP22* gene is present in three copies instead of two. Alternatively, a part of a gene is defective or missing from birth, causing many of the other known forms of CMT. Any of these variations can disrupt the structure of the protein that is encoded by the affected gene, causing cellular problems that ultimately lead to disease.

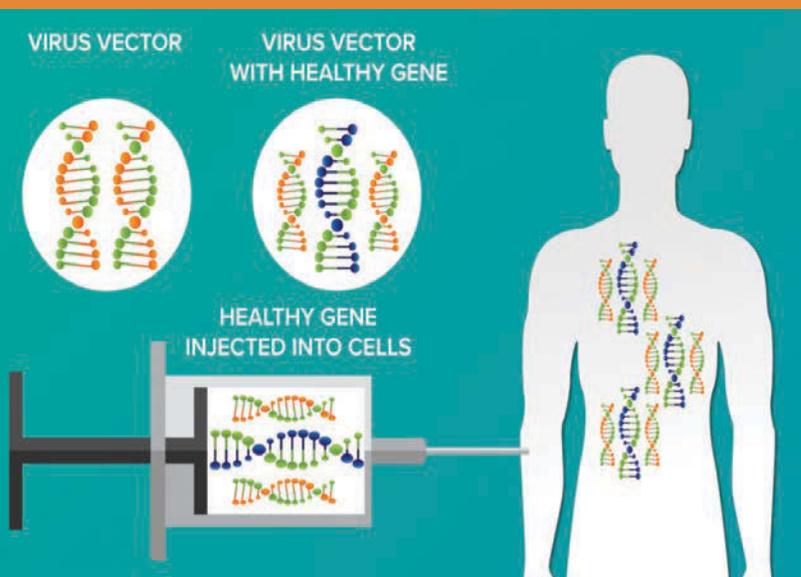
In gene therapy, scientists can do one of several things depending on the problem with the gene. The simplest form of gene therapy is to simply provide a correct copy of the gene, which is the basis of the gene therapy for SMA. In variations of this approach, genes that are causing problems can be suppressed. One example of this was the recent demonstration that antisense oligonucleotides can be used to improve the neuropathy in rodent models of CMT1A. In addition, the exciting new field of genome editing using CRISPR technology has now made it possible to correct disease-causing mutations, and collaborative projects have already been initiated with leaders in this field.

disease areas, as well as clinicians and scientists spearheading efforts toward gene therapy for CMT2D and CMT4J.

Building on this meeting, the CMTA is assembling the best experts to formulate gene therapy strategies for CMT2 and CMT1 subtypes. Two gene therapy experts, Beverly Davidson, PhD, at the University of Pennsylvania, and Kleopas Kleopa, MD, at the Cyprus Institute of Neurology & Genetics, have now joined the Scientific Advisory Board of the CMTA. Dr. Davidson is an acknowledged leader in this field based on her extensive experience in this area, including interactions in both academic research and commercial translation gene therapy approaches. Dr. Kleopa has

shown proof of concept that gene therapy works in two mouse models of CMT, CMT1X and CMT4C. This strategy can capitalize on the CMT animal models that have been developed and characterized with CMTA support.

At the CMTA, we believe gene therapy holds the promise to provide effective therapies for people living with CMT. As we continue to make great strides in this area, the CMTA—and researchers like me—are committed to helping speed the development of gene therapy approaches by investing in the most promising and groundbreaking gene therapy treatments that have the potential to benefit our community. ★



GENE THERAPY DELIVERY

In order to insert new genes directly into cells, scientists use a vehicle called a vector that is genetically engineered to deliver the correct version of the gene. For example, viruses have a natural ability to deliver genetic material into cells, and therefore, can be used as vectors. While some viruses cause disease, virus vectors are highly modified to remove their ability to cause disease so that they can be safely used to carry therapeutic genes into human cells.

Gene therapy can be used to modify cells inside or outside the body. When it's done inside the body, a doctor will inject the vector carrying the gene directly into the part of the body that has defective cells.

Before a company can market a gene therapy product for use in humans, the gene therapy product has to be tested for safety and effectiveness so that the Food and Drug Administration (FDA) can evaluate whether the risks of the therapy are acceptable in light of its potential benefits. Gene therapies have begun to receive FDA approval, and many gene therapies are in clinical trials.

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THE CMTA'S STAR ADVISORY BOARD INCLUDES A SCIENTIFIC ADVISORY BOARD, A THERAPY EXPERT BOARD AND A CLINICAL EXPERT BOARD.

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Consultant, University of Rochester Medical Center

*Also a member of the Clinical Expert Board.

Research Partnerships Accelerating Progress

The CMTA has spent over \$8 million in recent years and expects to spend about \$10 million in the near future to help bring CMT drugs to market. We are working vigorously to find treatments, and ultimately a cure for all types of CMT. In fact, we currently have over 25 active research projects with top labs around the world, all vetted through our STAR Advisory Board, which is comprised of the top CMT scientists and clinicians from across the globe. Below are some updates of the work funded through STAR by disease type:

TYPE 1A

CMT1A is caused by the duplication of the Peripheral Myelin Protein 22 (*PMP22*) gene, which leads to the demyelination of the peripheral nerves. One recently announced breakthrough came from our partnership with Ionis, which has pioneered development of antisense oligonucleotide (ASO) technology. Rodent studies showed a dramatic improvement in two models of CMT1A, and Ionis is currently working on developing refined versions for testing in clinical trials. Our partnership with Genzyme, a Sanofi

company, enabled us to screen their entire compound collection, and we are now testing a leading candidate in a variety of secondary assays and animal models. In addition, the alliance has now expanded to the evaluation of additional molecules that have emerged from other Sanofi programs, and a number of these drug prototypes are being tested as well. Laboratory and animal models of CMT1A have been made available to five additional CMTA alliance partners for testing of therapeutic compounds. Dr. Michael Shy, together with the members of our Clinical Expert Board (CEB), is leading the effort to develop the best outcome measures and biomarkers for clinical trials of CMT1A therapeutics.

TYPE 1B

This CMT subtype is caused by mutations in the Myelin Protein Zero (*MPZ*) gene. Scientific Advisory Board members Drs. Michael Shy, Lawrence Wrabetz and Maurizio D'Antonio are experts in this area. In partnership with InFlectis BioScience, we are engaged in further testing of a novel molecule called Sephin, which has shown dramatic improvement in the S63del mouse model of CMT1B. Also, we now have mouse models of all three major clinical presenta-

tions of CMT1B. In the late onset type, we are testing how inhibiting axon degeneration pathways can stabilize motor and sensory neurons, an approach which is the focus of pharmacological development by several CMTA partner companies. This will be the first test of such pathways in a CMT model, and it is possible that this approach may have broad applicability to other types of CMT.

TYPE 1X

Until now, there was only one mouse model of CMT1X, but it was not a direct replica of the human mutations in GJB1. Therefore, the CMTA has sponsored the development of four mouse models of CMT1X, one of which has been developed in partnership with Dr. Robert Burgess at the Jackson Laboratory. These models will be used to test therapeutic approaches such as the inhibition of macrophages. Dr. Rudolf Martini at the University of Würzburg, Germany has found that reducing this type of inflammation has a very positive effect in a mouse model of CMT1X. In addition, CMT1X also is characterized by degeneration of motor neurons and is therefore an ideal target for the axon degeneration therapies mentioned above for CMT1B. Finally, the work of



STAR Advisory Board members Drs. Robert Baloh, Kleopas Kleopa and Steven Scherer are collaborating to advance CMT research.

Dr. Kleopas Kleopa at the Cyprus Institute of Neurology and Genetics has shown the first example of a successful gene therapy in a CMT1X mouse model, and he is continuing these studies toward clinical trials with this novel type of therapy for not only CMT1X but also CMT4. The CMTA convened a workshop with some of the world's top gene therapy experts to help identify the key steps in translating these findings into human clinical trials for CMT1X. Again this approach can be applied to other types of CMT.

TYPE 2A

CMT2A is caused by dominant mutations in Mitofusin 2 (*MFN2*). The STAR team has developed two excellent rat models for CMT2A which are being made available to the research community and represent an important tool to test potential new modulators of mitofusin activity. Stem cell models of CMT2A have also been developed for CMTA-sponsored research in

the laboratory of Dr. Robert Baloh at Cedars-Sinai Medical Center. As part of its Patients as Partners in Research initiative, the CMTA has sponsored a study with the University of Iowa CMT Clinic and CMTA Center of Excellence to look at pulmonary function for people who have CMT2A. To fund this important study, J.D. and Brenda Griffith made a donation to the CMTA in memory of their daughter Marah. In partnership with several companies, therapeutic approaches under study include inhibition of axon degeneration, as well as the development of gene therapy, which has recently been shown to be successful in another motor neuron disease known as Spinal Muscular Atrophy (SMA). Finally, other candidate molecules have emerged from academic research and animal studies, and planning is underway to test these as well.

TYPE 2E

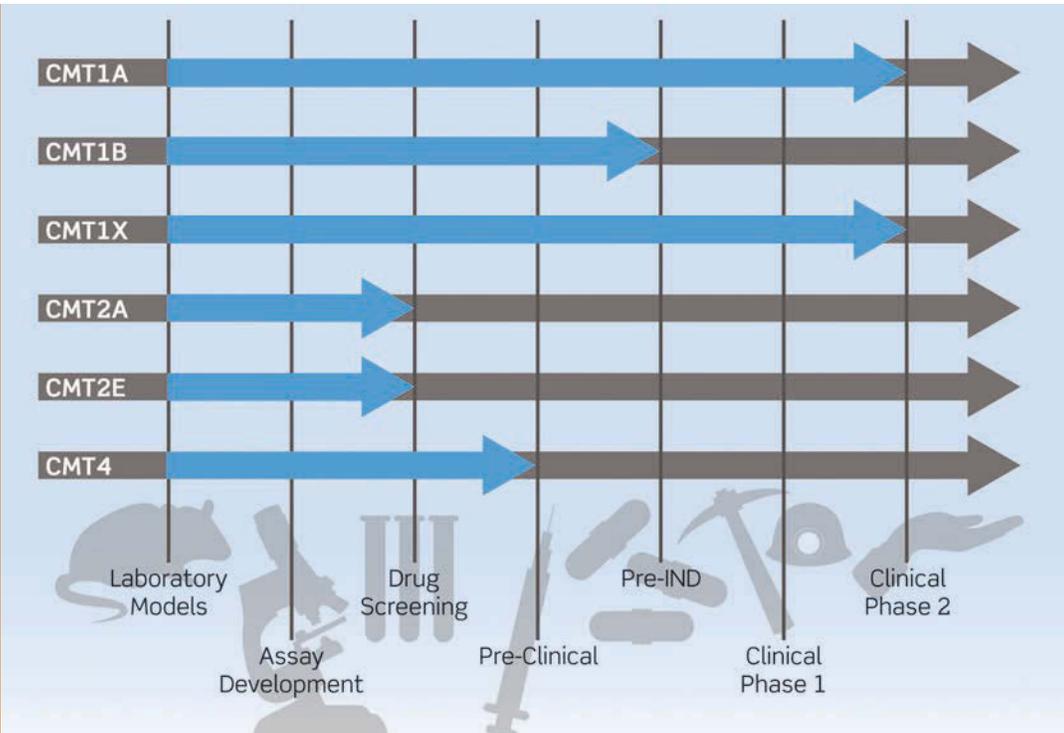
CMT2E is caused by dominant mutations in the neurofilament

light protein (*NEFL*) gene. With support from the CMTA, one of the best mouse models of CMT2E, made by Dr. Ronald Liem at Columbia University, has been extensively characterized in collaboration with Dr. Steven Scherer at the University of Pennsylvania. Both human and mouse stem cells containing CMT2E mutations have been differentiated into motor neurons and are being used in drug screens to identify therapies that prevent aggregations of neurofilaments seen in CMT2E.

TYPE 4

CMT4C is caused when both versions of an important gene (*SH3TC2*) required for healthy myelin are deficient. To restore function of these genes, the gene therapy approach described above for CMT1X has also been tried for CMT4C by Dr. Kleopas Kleopa and has shown very positive results. We anticipate this approach will be applicable to other forms of CMT4. ★

The CMTA is working vigorously to find treatments, and ultimately a cure for all types of CMT. We are investing in projects that will benefit virtually all people with CMT. This chart shows the progress made along the path to clinical trials.



My Life As A CMT Lab Rat

BY CLARK SEMMES

When I got the email inviting me to take part in a clinical trial for a new drug to treat CMT,

I could not reply fast enough. “Yes! Yes, yes, yes! I would love to participate in a new drug trial! Absolutely yes!”

Once I signaled my willingness to serve as a CMT lab rat, I began to research the drug trial. I learned that I was being invited to take part in phase two of a three-phase process. In my phase, 40 people at 10 sites around the country with either CMT1 or CMTX would test the viability and potential side effects of the drug. The catch, and there’s always a catch, is that for the first six months of the trial, half the volunteers would get the drug and half would get a placebo. For the remaining six months, everyone would get the drug. Also, when the trial ended, all 40 of us would be taken off the drug as the trial moved on to phase three with new volunteers. Despite these caveats, I remain thrilled to be invited to participate and eager to get started.

On August 30, my wife Marcia and I drove from our home in Maryland to the University of Pennsylvania in Philadelphia, which is a CMTA Center of Excellence, so that they could assess my suitability for the drug trial. Apparently, there is a wide range of variables that could have rendered me ineligible for the study. Over

the course of the next three hours, I was pricked, poked, prodded and questioned. My complete medical history was reviewed, my muscle strength was tested in multiple scenarios and samples of my various body fluids were taken. It was a draining day in more ways than one, but according to all the feedback received, I was deemed a good candidate. We made plans for a three-week cycle of injections and intermittent medical tests. I was also told I would be receiving a 24/7 monitoring device.

About a week after our visit to the University Pennsylvania I got a call from Kelsey, my drug trial coordinator, asking if had I ever had a malignant cancer. The answer was yes, I had a malignant melanoma skin cancer removed from my neck 23 years earlier. Kelsey sadly informed me that this rendered me ineligible for the drug trial. I was out of the study.

As I pondered my ouster from the drug trial, I found that I was sad but also somewhat relieved. Driving three hours to Philadelphia every 21 days would have been difficult, and even if the drug worked, I would not be allowed to stay on it for more than a year. Three hours later, Kelsey called back to report that because my bout with cancer was more than five years ago, I was still eligible for the study. I was back in.

As I awaited my first injection, a package arrived at my home. I opened it up to discover a new Samsung Galaxy 8 cell phone. This was odd because I had not ordered a new phone, and my birthday had been more than a month ago. I emailed all my

friends and family and asked if anyone had bought me a phone—they had not. I even posted a picture of the phone on Facebook to try to determine its origin, but to no avail. Then a week later, I got an email from a stranger at an unknown company asking me why I had not activated my 24/7 medical monitoring device. I wrote back a snarky email stating that I would happily activate my device when I received it. Turns out the Galaxy 8 cell phone, plus a small necklace and pendant, were my 24/7 medical monitoring device. I now keep the cell phone in my pocket and the pendant on at all times.

In a few weeks, I am scheduled to go in for my first injection. The timeline is brutal. I have a CAT scan at 6 a.m. Then I get the injection. Next, I will have blood drawn every two hours for the remainder of the day to monitor my reaction to the drug. No one said being a lab rat was easy!

Overall, I find the life of a lab rat simultaneously fascinating, exhausting and incredibly encouraging. If all goes according to plan, this drug, which I think should be called Muscle Blaster 6000, could be available to the public in a few short years. And, this is just the start of the pipeline. Thanks to the CMTA’s farsighted partnerships with a wide array of drug companies, there are many, many more drugs under development, including not only drugs to treat the symptoms of CMT, but also to fix the root cause. When I gaze into the future, I see a world without CMT coming into clearer focus every day. It is a brave new world, and this lab rat is honored and humbled to be a part of it! ★





Leave a Lasting Legacy & Maximize Your Philanthropic Goals

Make a difference in people's lives and always be remembered for your contribution. Benefit yourself, your family and the Charcot-Marie-Tooth Association with your planned gift. Help us fulfill our mission for many years and generations to come.

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

With the help of an advisor, you can include language in your will or trust specifying a gift be made to family, friends or the CMTA as part of your estate plan.

What are your options?

1. You can gift a specific dollar amount or asset.
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.

*With Your Kindness,
the Promise of a Brighter Future
for So Many is Close at Hand*



To learn more or have a confidential conversation about making a bequest, please call CMTA Director of Development Jeana Sweeney at 1-800.606.2682 x106.

My Allard ToeOFF makes me...



FIERCE

allard | **USA** www.allardusa.com

ALLARD USA, INC.
300 Forge Way, Suite 3
Rockaway, NJ 07866-2056

info@allardusa.com
Toll Free 888-678-6548
Fax 800-289-0809

The ABCs of an Ankle-Foot Orthosis

The goal of all Ankle-Foot Orthoses (AFOs) is to help you achieve as close to normal gait as possible, prevent tripping which could lead to falls, and increase stride length and walking distance capacity. The degree of ankle instability, amount of deformity (if any), weaknesses in anatomy above the ankle, and your lifestyle and personal goals should all be considered when the provider determines the AFO and what modifications are required to best meet those goals and your needs. There are several types of AFOs that may be considered (see below).

Finding an Orthotic & Prosthetic (O&P) Provider

Once you have a prescription from your physician, a good starting place is visit www.bocusa.org or www.abcop.org. These websites will list all certified O&P providers in your area. If you are considering an Allard AFO to meet your needs, email info@allardusa.com or call 888-678-6548 and ask for the contact information for your Allard District Manager. He or she will provide you the name(s) of O&P providers in your area that have shown experience fitting Allard AFOs.

What Questions Should I Ask the Provider Prior to Scheduling an Appointment?

- Do you carry my insurance?
- Do you have a practitioner who has experience fitting AFOs for patients with CMT?
- Do you fit both plastic and carbon composite AFOs?
- Do you have samples of both plastic and carbon composite AFOs?
- Will I be able to try on a couple different AFOs?
- How long before I can get an appointment?
- What is the warranty period for the AFO selected?
- If the AFO cannot be fitted at time of your initial visit, ask how long it will take to get it.

What are the Different Types of AFOs?



Solid plastic AFO
Immobilizes the foot and ankle in neutral position



Plastic AFO with articulating joints
Immobilizes the foot but allows some flexion and extension of the ankle



Static carbon composite AFO
Functions like a plastic AFO but lighter weight



Dynamic response carbon composite AFOs
Provide ankle stability along with dynamic response when the foot hits the ground to help lift the foot

Allard's Dynamic Response Carbon Fiber AFOs provide a natural biomechanical response similar to the movement of your own muscles. The unique carbon fiber shape of the Allard AFO enables it to act like a lever; the carbon material stores energy that is used to assist in the forward propulsion of the leg during ambulation. The carbon fiber construction adds extraordinary strength that provides stability and durability and is very lightweight in addition to being very thin in its configuration.

The warranty for Allard's custom fitted dynamic response AFOs for adults is two replacements within one year from the date of initial fit, and for children it is one replacement within six months of initial fit. Allard offers a 30-day Patient Satisfaction Guarantee. If the AFO does not provide the function or comfort you require and the provider cannot make adjustments to address either of these issues, the provider may return for a different type of Allard AFO or Allard will refund the cost the provider paid for the AFO.

What Should I Bring to the Initial Visit?

- Bring your prescription.
- Prepare and bring a list of what you are hoping an AFO will do for you.
- Be sure to wear the shoes you wear most often, as well as a couple of your other frequently worn shoes. The shoe is an integral component of the orthosis, so it is important the orthosis be designed to accommodate that shoe.
- Bring any walking aids your currently use.
- If you have previously worn an AFO and still have it, take it.

What Happens During an AFO Fitting and Delivery?

- When the orthosis is in the shoe, the foot should be in neutral position.

SEATTLE CMTA PATIENT & FAMILY CONFERENCE CONNECTS AND EDUCATES

The Seattle CMTA Patient & Family Conference was an enormous success with people traveling from as far away as Los Angeles and Vancouver, BC to participate in this educational day. The entire line-up of presenters was phenomenal. We are incredibly grateful to all of the clinicians and corporate partners who spoke at the conference and took time to answer questions from the patient community.



A couple of highlights from the Seattle Conference include Dr. Glenn Pfeffer's talk on "Surgery vs. Bracing," Dr. Tom Bird's discussion about the "History of CMT," Lauren Brown's presentation on "Genetic Testing and CMT," and Dr. Greg Carter's slide show on "CMT and Pain Management." These presentations and more from the conference are available on our YouTube channel: www.cmtausa.org/seattle-pfc

The 2019 CMTA Patient & Family Conference line-up will be announced soon. Please stay tuned! If you have questions regarding conferences, please reach out to CMTA Director of Community Outreach Laurel Richardson at Laurel@cmtausa.org.

- It should be determined when standing without the orthosis if your foot goes into supination (tends to lean to the outside of your foot) or pronation (tends to lean to the inside of the foot).
- It should be determined when standing without the orthosis if your knee tends to bend forward or backward too much.
- The strength of your calf, thigh and hip muscles should all be taken into consideration.
- All of these factors should be used to determine what additional modifications, such as heel wedges, metatarsal pads or other foot plate modifications will be necessary to achieve the desired functional goals. In the case of Allard dynamic response AFOs, they should always be fitted with some type of padding between the anterior/front section and your tibia but also typically require the addition of an orthotic insert to be used

with the Allard AFO. If an orthotic insert is not required, the insole of your shoe should be placed on the footplate to protect the foot from the carbon composite.

What are Some of the Issues You Should Immediately Bring to the Attention of Your Provider?

- You continue to trip/fall.
- You feel any pain or even discomfort from the orthosis or pressure from your shoes.
- You can't walk as far as you can without the AFO.
- You feel any pain/discomfort in your knees, hip, or back that you don't feel when not wearing the AFO.
- If you are wearing an Allard AFO, you start to feel you do not receive as much "push-off" assist as you initially did. ★

Article provided by Allard USA, Inc.

UNDERSTANDING CMT: A GUIDE FOR PATIENTS, PHYSICAL THERAPISTS AND OCCUPATIONAL THERAPISTS

Having a hard time finding a physical therapist (PT) or occupational therapist (OT) who knows about CMT? Fret no longer! Thanks to our expert clinicians, the CMTA has published a guide for patients, PTs and OTs outlining the assessment and care of people with CMT. Because CMT manifests so differently from person to person, this guide, based on research, experience and patient input, will optimize collaboration between physical and/or occupational therapists and patients, delivering the best possible care for an individual's specific needs. This document will empower people with CMT and their health care professionals to make safe, educated decisions regarding a rehabilitative plan of action to maintain function and quality of life. To access *Understanding CMT: A Guide for Patients, Physical Therapists and Occupational Therapists*, visit www.cmtausa.org/pt-ot-guide, or for a print version, please email Laurel Richardson, Director of Community Outreach, at laurel@cmtausa.org.



New CMTA Centers of Excellence Provide Highly Specialized Care for Patients with CMT

WAYNE STATE

The Charcot-Marie-Tooth (CMT) Clinic at Wayne State University/Detroit Medical Center is specifically designated to patients with inherited peripheral nerve diseases. This multi-disciplinary clinic takes place every Wednesday morning at University Health Center-8B, 4201 St. Antoine, Detroit, Michigan 48201.

Every patient is evaluated by CMT specialist, Jun Li, MD, PhD, the director of CMT clinic, followed by electrophysiological studies, physical therapy/orthotic evaluation, genetic counseling and relevant laboratory testing. This one-stop-shop process offers the



The CMT clinic at the University of Pittsburgh Medical Center specializes in diagnosing and treating people with CMT.

highest quality and convenience of care for patients.

It is a part of the NIH-supported Inherited Neuropathies Consortium. This clinic conducts research in a variety of areas, including:

- genotype/phenotype correlation

- identification of novel genetic mutations causing CMT
- understanding pathogenic mechanisms of CMT, developing cutting-edge MRI imaging techniques to reveal anatomical changes of peripheral nerves and using human skin biopsy as a

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).....	Drs. Robert Baloh and Richard Lewis
Children's Hospital of Philadelphia (Philadelphia).....	Dr. Sabrina Yum
Children's Hospital of Pittsburgh (Pittsburgh)*	Dr. Hodas Abdel-Hamid
Connecticut Children's Medical Center (Farmington).....	Dr. Gyula Acsadi
Hospital for Special Care* (New Britain, CT)	Dr. Kevin J. Felice
Johns Hopkins University (Baltimore)	Dr. Thomas Lloyd
Lucile Packard Children's Hospital at Stanford (Palo Alto)	Drs. John Day and Ana Tesi Rocha
Massachusetts General Hospital (Boston)	Dr. Reza Seyedsadjadi
Nemours Children's Hospital (Orlando)	Dr. Richard Finkel
Northwestern Memorial Hospital (Chicago)*	Dr. Daniela Maria Menichella
Ohio State University (Columbus)	Dr. Amro Stino
Oregon Health & Science University (Portland)*	Dr. Chafic Karam
Stanford Neuroscience Health Center (Palo Alto)	Dr. John Day
University of Florida (Gainesville)*	Dr. James Wymer
University of Illinois at Chicago (Chicago)*	Dr. Charles K. Abrams
University of Iowa (Iowa City)	Dr. Michael Shy
University of Miami (Miami)	Dr. Mario Saporta
University of Minnesota (Maple Grove)	Dr. David Walk
University of Missouri (Columbia)	Dr. Raghav Govindarajan
University of North Carolina (Chapel Hill)*	Dr. Rebecca Traub
University of Pennsylvania (Philadelphia)	Dr. Steven Scherer
University of Pittsburgh Medical Center (Pittsburgh)*	Dr. Sasha Zivkovic
University of Rochester (Rochester, NY)	Dr. David Herrmann
University of Texas Southwestern (Dallas)*	Drs. Susan Iannaccone and Diana Castro
University of Utah (Salt Lake City).....	Dr. Russell Butterfield
University of Washington (Seattle).....	Dr. Michael Weiss
Wayne State University (Detroit)	Dr. Jun Li

*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

minimally invasive tool in evaluating peripheral nerve pathology

- gene therapy.

Those interested in studies, should contact Melody Gilroy at mgilroy@med.wayne.edu or call 313-966-0473. For patients who are interested in visiting the CMT clinic, please call nurse Theodora Nwamba at 313-966-0473 (tnwamba@dmc.org) for an appointment.

UNIVERSITY OF PITTSBURGH MEDICAL CENTER

The CMT clinic at the University of Pittsburgh Medical Center specializes in diagnosing and treating people with CMT, a form of peripheral neuropathy. The CMT Clinic for adult patients is located on the 8th floor of the Kaufman Building, and the CMT clinic for pediatric patients is located at Children's Hospital Pittsburgh. Adult patients are scheduled to see Drs. Zivkovic, Clemens, Lacomis or Puwanant on Mondays and Thursdays from 8 a.m.–12 p.m., and pediatric patients are scheduled with Dr. Abdel-Hamid on Fridays from 1–5 p.m. Clinical care of CMT patients is coordinated with physiatrists (physical medicine and rehabilitation specialists), physical and occupational therapists, genetic counselors and orthopedic surgeons.

UNC CHAPEL HILL

The Peripheral Neuropathy Center at the University of North Carolina at Chapel Hill offers subspecialty and multidisciplinary care in the treatment of patients with Charcot-Marie-Tooth disease. The center is headed by Rebecca Traub, MD, who specializes in treating patients with peripheral neuropathy, and is staffed by the full neuromuscular division, including adult and pediatric neurologists. The UNC

NEW ADVISORY BOARD MEMBER SPOTLIGHT Ashraf Elsayegh, MD, FCCP

Ashraf Elsayegh, MD, FCCP, is a distinguished physician and researcher based in Los Angeles, California. Dr. Elsayegh is a foremost expert in the field of pulmonary medicine as it relates to neuromuscular disease. He currently practices at Cedars-Sinai Medical Center and is an associate clinical professor at UCLA School of Medicine. His clinical and research interests revolve around respiratory function in the neuromuscular patient with special interest in diaphragm dysfunction. Dr. Elsayegh has authored and published numerous articles and textbooks in pulmonary medicine and pulmonary complications in neuromuscular patients. In addition, he has lectured worldwide on these topics. Dr. Elsayegh has been treating neuromuscular patients, including those with Amyotrophic Lateral Sclerosis (ALS) and Charcot-Marie-Tooth (CMT), for more than 15 years. He is an adviser on numerous boards in the fields of pulmonary medicine, critical care medicine, sleep medicine and neuromuscular disease.



neuromuscular division strives to provide high quality comprehensive neuromuscular care to CMT patients, as well as to provide educational programs to physicians in training and build research programs dedicated to the treatment of neuromuscular disorders.

OHIO STATE

Ohio State University has historically been at the center of advancements in the field of Charcot-Marie-Tooth through the work and contribution of such individuals as Jerry Mendel, MD, and John T Kissel, MD. OSU provides multidisciplinary care to a large population of CMT patients, complete with multiple providing physicians, a dedicated neuromuscular genetics counselor, a respiratory therapist, a physical/occupational therapist, a social worker, an orthotist and a strong working relation with foot surgeons in the department of podiatry. The team also collaborates with Jerry Mendel, MD, and Zarife Sahenk, MD, PhD, of Nationwide Children's Hospital

Center for Gene Therapy, who are investigating genetic therapies through different delivery mechanisms. Ohio State is also involved in national and international multi-center CMT studies and conducts investigator initiated studies of its large CMT population. Ohio State is excited to now be part of the Inherited Neuropathies Consortium (INC), as well as the CMTA.

The mission as neuromuscular providers for a large population of CMT patients is to first and foremost provide care, comfort and 'cure,' when possible. Given the lack of a proven 'cure' for CMT at present, the latter goal of providing a 'cure' is best served by enrollment of patients in promising drug studies when available. Through the multidisciplinary clinic, the team aims to bring as much normalcy to patients' lives as possible. Working with a genetics counselor, the team always aims to identify the genetic mutation underlying the patient's heredity, so as to guide counseling, prognosis and study enrollment. ★

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



Write to David at info@cmtausa.org.

David Tanmenbaum 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.

Dear David,

I have two sons with CMT. I am a 56-year-old woman who also has CMT, but thankfully, I am not severely affected. My sons, who are in their early thirties, are beginning to experience some limitations. They were both diagnosed in their early teens. One son talks openly about it and has sought out support, but his older brother does not want to talk about it, and I feel like he is in denial. I am not sure how much to push him to get help since he is high functioning and has friends. Although I am not a mental health professional, he appears somewhat depressed.

David replies:

I am hesitant to state there is only one way to correctly handle having CMT. I do know that for many, denial can have a useful function. Personally, I was in my late forties before I sought out emotional support because of my CMT. I simply wasn't ready to deal with it before that. Your son has developed his own coping

style, and that needs to be respected. Perhaps his depression is connected to CMT, but there could be other reasons for his state of mind. Let's also keep in mind that depression is a normal response when coping with a chronic illness.

I didn't even know I was feeling isolated for years. It was only when I finally reached out to the CMT community that I realized that I had really needed to talk about CMT to others who really knew what it was like to live with CMT on a daily basis. Sometimes we fool ourselves into thinking that we are perfectly okay, feeling alone with CMT until we experience a profound sense of belonging by talking to others who truly understand our experience.

You have mentioned that your son is high functioning and has friends. I would trust that since he has a mom and brother who are able to talk about it, he has great role models in place for when he is ready to live more openly with CMT. I have always

believed in the concept of "what we resist persists," but I also know that timing is everything. Even as a therapist in practice for many years, I have made mistakes in pushing people to talk about issues before they were ready. I have learned over the years that simply providing a safe, loving and accepting space for clients to bring up difficult issues is the most effective way to help. My clients will tell me in their own way when they are ready.

Many of us also feel it is a show of strength to be able to handle stuff on our own and not ask for help. I suffered from that delusion for years. I am sorry that I didn't see my vulnerability as a powerful way to connect with others. You would think I would know better as a therapist! I do know, however, that we all have to come to that understanding in our own time. Love your son and accept where he is at in his life. Trust that life will bring him the right circumstances to nudge him to reach out for support when he is ready. ★

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: _____

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- Birthday Holiday Wedding
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Memorial Gift:

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Camp Footprint Creates a Safe Place for Adolescents with CMT

Being a teenager is tough. Add to that a diagnosis of CMT, and adolescence can be downright daunting.

Just ask Joe Krukar. Now 21 and a college graduate, Joe began experiencing symptoms of CMT when he was 13. His mom also has CMT, so they long suspected Joe also had the disease before being diagnosed at age 17.

“We held off on a formal diagnosis, but deep down, we knew that’s what was going on,”

Joe recalls. “I wasn’t really ready, and I didn’t want to have to wear braces on my legs yet.”

At the time, Joe didn’t know anyone with CMT other than his mother. In an effort to change that, Joe’s mom invited him to a meeting of the local CMTA support group.

“To be honest, I didn’t really want to go,” Joe says. “There are often mostly older people there, but my mom said, ‘I really want you to go to this one.’”

Once at the meeting, Joe met camp director Jonah Berger, another younger guy with CMT. Jonah told Joe about Camp Footprint, the CMTA’s annual, free, five-day sleepaway camp held at Camp Kon-O-Kwee in Fombell, Pennsylvania for youth, ages 10-18 who have CMT. Though Joe had aged out as a camper, there was still room for him at camp—as a counselor.

Joe was a counselor in the Upper Boys Cabin, which is home



REGISTRATION for Camp Footprint, slated for August 12-16, 2019 is now open. Spots fill up quickly, so don't wait! Campers and counselors should sign up today at cmtacamp.org

for the week for boys ages 14-18. He led the boys through activities such as fishing, archery and kayaking. Particular favorites were the rock wall and zip line.

“The coolest thing with the activities is the awesome dynamic the campers create,” Joe explains. “Five to six campers go at a time, and other campers cheer them on. Some kids don’t need a nudge at all, but others really need a supportive push from their fellow campers.”



Counselor Joe Krukar, left, welcomed the opportunity to encourage campers.

Emily Blackwell, now 14 years old, attended Camp Footprint for the first time this past summer. Diagnosed with CMT in second grade, Emily had never met anyone with CMT other than her dad. While skeptical at first—she had to fly there on her own—once she attended Camp Footprint, she gave it rave reviews.

“It was a really fun and amazing camp,” Emily says. “It was exactly like regular camp with archery, riflery, hiking, paintball, fishing and tie-dying, but they accommodated our needs completely. We were able to get around on golf carts, and if we needed to sit down for a bit, that was totally fine.”

Though they experienced camp from different perspectives, both Joe and Emily remarked that in addition to all of the fun, what

they appreciated most was being understood.

“It was really nice to be around other kids who understood what I am going through,” Emily says.

For Joe, he experienced Camp Footprint as an opportunity to give campers the experience he didn't have as a teenager.

“I'd wake up in the morning at camp, put my braces on, look around and realize that everyone else was doing the same thing,” Joe says. “I wasn't different. I'd never felt that before. I wanted to be there for my campers in a way that I didn't have anyone there for me. Even as a counselor, Camp Footprint was the one week I felt normal. It was amazing.”

When asked if they'll be back at Camp Footprint next year, Joe and Emily have the same answer: “Definitely.” ★



Emily Blackwell attended Camp Footprint for the first time in 2018, and she plans to go again this summer.

5TH ANNUAL CYCLE 4 CMT RAISES \$150,000, BRINGING 5-YEAR TOTAL TO \$800,000!

The phenomenal success of this year's 5th Annual Cycle 4 CMT event reflects our supporters' ever-increasing dedication, enthusiasm and commitment toward funding treatments to end to CMT.

We want to whole-heartedly thank our 70 superstar event sponsors, 500 generous supporters/donors, 165+ enthusiastic participants (cyclists, walkers, after-party attendees, invaluable volunteers and virtual trailblazers) as well as every single person who helped spread the word of the event and brought awareness to our cause.

Together, we have raised right around \$150,000 this year, bringing our 5-year total to a whopping \$800,000! That's \$800,000 to advance the CMTA's STAR research program, bringing us that much closer to clinical trials and ultimately, pharmaceutical treatments to stop the progression of CMT.

Reflecting upon the increasing popularity of the Cycle 4 CMT event, organizer Chris Ouellette noted, “This event would not have been such a success without our growing community's financial backing, involvement and ongoing partnerships. Your gifts of time, energy and enthusiastic support are truly making an indelible impact on the lives of Yohan, Riley and the 3 million children and adults who struggle with the progressive symptoms of CMT every single day.”

Thank you for caring and believing in the CMTA's vision of a world without CMT. There's never been a better time to get involved and invest in treatment-focused research to thwart the biggest little-known genetic disease of all time—Charcot-Marie-Tooth disease or CMT. Get ready for the 2019 Cycle 4 CMT on August 25, 2019!



The fifth annual Cycle 4 CMT had 165 participants, including cyclists, walkers, attendees and volunteers.



Community Involvement Drives Walk 4 CMT

The Rustici's battle with CMT began long before they even had a name for it. Their now seven-year-old son, Mason, had struggled to pull up on his own as a baby and then was late to walk or put any weight on his feet. His parents, Lara and Chad, suspected that something—a disease or maybe an injury—was affecting Mason, but doctors, even specialists, told them their son was just fine. Only through genetic testing did they find out that Mason has CMT1A.

"This was a total shock to us," Lara recalls. "No one in our family has anything like this, but Mason had a spontaneous mutation that led to CMT. We were all in shock."

Like most parents after a child receives diagnosis, Lara frantically began researching to find more information about CMT. There were Facebook support groups and online resources, but she wasn't finding anything uplifting as she planned for her son's future. Her husband connected with CMTA CEO Amy Gray on LinkedIn. Through a phone call with Amy, they learned about the promising research the CMTA is involved with, as well as awareness and

fundraising events such as the Walk 4 CMT, a volunteer-led national fundraising campaign for the CMTA. When Lara learned there wasn't a Walk 4 CMT in South Florida, she saw it not only as a challenge, but also as a way to focus her energy and attention on helping her son and the 2.8 million people affected by CMT.

"I'll do it,"

Lara said. With those three words, the Parkland Walk 4 CMT was born.

At this point in the year, it was already July. The Parkland Walk 4 CMT was scheduled for October 21. With just three months to plan, Lara got to work forming a committee, booking an event venue and soliciting donations from local businesses such as photographers, food trucks and DJs.

"I thought, 'What better place to hold this event in our home-

town?'" Lara says. "It's such a family-oriented community that we hoped we'd have a lot of support from our neighbors and our kids' classmates. We focused on making

it family friendly, and it really just exploded from there."

With the walk in its first year, Lara set a goal to raise \$5,000.

"We figured this first year, the event was all about raising awareness," Lara says. "But, we quickly surpassed \$5,000. I was blown away. By the time the Walk was here, we were approaching \$20,000."

The event provided a perfect fall activity for families.

Not only was there a

walk, but there were also characters onsite to greet the children, arts and crafts, games and food trucks. A team of dedicated volunteers helped the event run smoothly. Lara also credits CMTA National Events Manager Andi Cosby for providing resources, advice and support as she planned the walk.

For those thinking of hosting a Walk 4 CMT in their community, Lara offers the following advice:

"Just do it. I know it can be intimidating to start, but know that it will all come together. Planning events is totally out of my comfort zone, but people are more than willing to support a good cause. I learned that there really are a lot of good people out there." ★

In 2018, leaders from across the country hosted 27 Walk 4 CMT's, raising over \$270,000!!! We thank all of the leaders and participants for making 2018 the biggest and best yet! If you want to be part of this amazing success, look for a 2019 Walk 4 CMT in your area at www.Walk4CMT.org. Or if you're ready to host a Walk 4 CMT in your community, contact CMTA National Events Manager, Andi Cosby at andi@cmtausa.org about holding a Walk 4 CMT in your hometown.

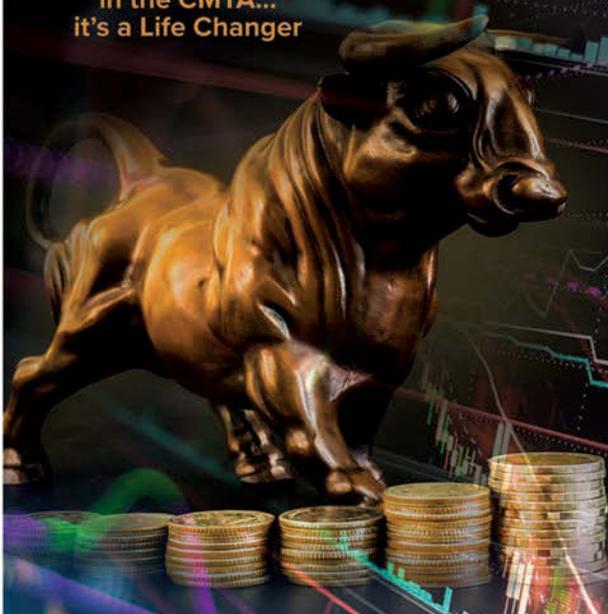
Lara Rustici launched Walk 4 CMT in South Florida in honor of her son Mason.



The Parkland Walk 4 CMT was family-oriented and fun!

YOUR INVESTMENTS TODAY WILL PROVIDE DIVIDENDS FOR OUR COMMUNITY TOMORROW

Wisely Invest
in the CMTA...
it's a Life Changer



As the stock market has been on the rise for more than 10 years, giving the gift of stock or mutual funds today will benefit you, and the CMTA!

Donating appreciated securities such as stocks or mutual funds to the CMTA is a tax-wise approach to the vision of a world without CMT. Many donors choose to give gifts to the CMTA using appreciated stocks and mutual funds due to the attractive tax advantages associated with such gifts.

The benefits available to you when making a charitable contribution of stock or mutual funds may include:

- Avoiding federal and state tax on the capital gain
- Receiving an income tax deduction (federal and most states) for the full market value of the gift
- Making a larger gift at a lower original cost basis to you

For appropriate tax advice, please consult your tax advisor. For more information on how to donate stock or mutual funds to the CMTA, please contact Jeana Sweeney, Director of Development at jeana@cmtausa.org.



EAST COAST GALA THROUGH WEST COAST EYES

"Taxi! Taxi! The Essex House please." We're going to the 9th Annual CMTA Gala! It's the 10th Anniversary of STAR! Trip to New York in the fall? Yes please! What should I wear? How about the shoes? That's always the stressful part. Oh wait, most of the people there will be in the same boat. After weeks of planning, this west coast couple hopped on a plane and headed east for a few days. We are so glad we did!

The taxi pulled up to the Essex House, and we stepped into the VIP reception where 10 leaders of the CMTA community were honored. We enjoyed cocktails and chit-chat with the who's who of the CMT world. Wide-eyed, we wandered around the beautiful room where it was obvious that so much thought and care had gone into every detail. There we were having cocktails and mingling with the people whose names you read in this newsletter, some of the doctors you hear about but wouldn't think you'd ever meet let alone have a casual conversation with, and the honorees who give so much of themselves through their volunteer work. The program opened with a few words from our gracious event chairpersons followed by "The promise of a brighter future" video. (Honestly, it was a bit of a tear-jerker!) Then the 10 honorees were each recognized and given an award for all of their hard work and dedication to further the work of the CMTA.

We were so touched by the stories of determination and tireless efforts.

Following the reception, we made our way to the ballroom for the dinner and auctions. Again, what a beautiful room! Phyllis Sanders, Alan Korowitz and Jeana Sweeney outdid themselves making all the arrangements. It was such a fun and lively evening of eating delicious food, meeting people and bidding for items at both the live and silent auctions. (Personally, I got some Christmas shopping done!) We chatted the night away, met new people, saw familiar friendly faces, and bid on auction items! The live auction was particularly fun! "Napa vacation? We should bid on that! I mean, it's just a car ride away after all. What happened? It's gone! Someone else got that one, and all the west coast vacations!" \$1,000! \$4,000! \$14,000 for the Italian villa! Hands were flying fast and furious as items got snatched up—all in the name of CMT research!

In addition to all the excitement, we learned a bit about what's going on in the CMTA, the STAR program and research. The well-spoken and extremely dedicated



Chairman of the Board, Gilles Bouchard, gave a great overview, while the knowledgeable Dr. Scherer gave updates on research, providing hope for all. The efforts, work and strides made by the CMTA are remarkable.

What an evening! My only regret is that I didn't get to meet everyone! (And maybe that I didn't manage to get one of those great vacations!) I was struck by the fact that this is where different interests and talents come together to strive toward a common goal and form a strong community. The commonality is a true heart's desire to find a cure and to come along side each other and make life just a little easier in the meantime. For me, being at this event was like going to camp where you form bonds with people with whom you have a great deal in common (even if it is just leaning against the same table for stability). And just like the last day of camp, it was sad to say goodbye. But it's already on my calendar for next year!

—Suzanne Stucky, CMTA Volunteer

C E L E B R A T I N G AWARENESS MONTH 2018

The energy and momentum from the CMTA community during CMTA Awareness Month 2018 was one for the record books! The “Community Powered” theme was exactly that—powered by the CMT community. Thanks to the incredible community for reaching far and wide to share their CMT story with people who aren’t aware of the disease. We appreciate all who helped increase the awareness base. The CMTA’s vision is to live in a world without CMT, but until that time, the CMTA community are making sure everyone knows what CMT is.

The branches and community members did a phenomenal job sharing the 2018 CMTA campaigns which highlighted the remarkable ways in which CMTA members spread awareness, not just in September but year-round.

Here are some of the highlights from CMTA Awareness Month 2018:



LINCOLN, NEBRASKA

Laurel Richardson, CMTA Director of Community Outreach, joined the Lincoln, Nebraska Branch for their September meeting via video conference. Branch Leader Brandon Lederer opened the meeting with a welcome and introductions. Laurel presented a STAR research update and had a great Q & A session with the group. They continued their meeting with an awareness celebration that included a custom CMT cookie cake.



GRAND RAPIDS, MICHIGAN

The Grand Rapids, Michigan CMTA Branch had a fantastic turnout for their September meeting. Laurel Richardson, CMTA Director of Community Outreach, attended the meeting and shared some 2018 highlights with the members. They also had a wonderful

open forum discussion during the second half of the meeting. Branch Leader Gabrielle Rudisell had a great selection of educational materials available. She also brought delicious snacks to share with the group.



CHARLOTTE, NORTH CAROLINA

The Charlotte, North Carolina CMTA Branch had a fantastic meeting with 15 participants on September 22! Carrie Johnsen, the new branch leader, started the meeting with group introductions and also with thanking former leaders, Todd Long and Tricia Hirsch, for doing a superb job building the branch. Following introductions, the group jumped right in to a chair yoga class taught by a wonderful teacher, Marie Theriault. Marie spent almost an hour teaching the class about the benefits of both mental and physical exercise, as well as leading a chair yoga

session. Following Marie’s instruction, Laurel Richardson, CMTA Director of Community Outreach, provided a CMTA update and overview of the mission and focus of the CMTA. Laurel spent time after the meeting with each member answering questions, establishing rapport and inquiring how the CMTA can best support their needs.



SOUTHERN CONNECTICUT

The Southern Connecticut Branch, led by Lynne Krupa, had a very informative meeting on August 27 when Kate Lair, CMTA Advisory Board member and former disability claim manager, spoke to the 15 members in attendance. Kate shared her personal story of having CMT1A and her knowledge of navigating the disability claims process. Members of the branch, as well as Kate, also shared their

(continued on page 22)



UNCORKED FOR A CURE

On September 27, the Madison Branch held its inaugural fundraiser, “Uncorked for a Cure.”

In total, the branch raised more than \$26,000.

Approximately 125 guests attended, purchasing tickets that included passed appetizers, two drinks and live music. The event included a Wine Pull, where guests paid \$10 to pull a cork, which were numbered between 1-100. The guest won a bottle of wine valued between \$10 and \$40. There was a Silent Auction with more than 55 items along with a live auction with six items. The grand prize was a long weekend in Nashville, with hotel accommodations, food gift certificates and a \$500 travel voucher! There also was a 50/50 Raffle, where the winner was kind and generous and donated his winnings back to the CMTA!

A special thank you to our sponsors: First Weber Foundation, Virtual Properties, Fuhrman & Dodge, SC., All City Exteriors, Luna Circle Farm, Preferred Title and Universal Home Protection!! Also, a huge shout out to the committee that worked tirelessly to make this vision come to life!

—Deb Weber, Madison WI Branch Leader





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
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

Naples
Ernie Hinds
916-205-5682
Michael Huff
408-674-1281

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
Kait Lair
412-427-7281
North Haven
Lynne Krupa
203-288-6673

DISTRICT OF COLUMBIA
Washington, DC
Steven Weiss
Kimberly Hughes
301-962-8885

FLORIDA
Central Florida
Linda Davis
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

Naples
Ernie Hinds
916-205-5682
Michael Huff
408-674-1281

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

HAWAII
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

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

LOUISIANA
Baton Rouge Area
Corey Dalfrey
Danielle Dalfrey
318-294-1976

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
Amy Reynolds
616-916-6732

MINNESOTA
Central Minnesota
Jo Smith
612-807-4729
Minneapolis Area
Duane Hodges
612-325-5448

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

NORTH CAROLINA
Charlotte Area
Carrie Johnsen
704-904-2828
Durham Area
Jeanne Boehlecke
919-942-7909
Rick Nelson
919-889-9776
Wilmington Area
Laurel Richardson
910-515-8488

NEBRASKA
Lincoln Area
Brandon Lederer
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

NEW YORK
Buffalo Area
Peter Morris
716-866-3519
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 Stuhlmuehler
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
Bucks County Area
Julie FitzGerald
315-573-3919
Chester County
Ashley Trout
484-364-9334

Harrisburg
Erin Weierbach
717-379-7504
Johnstown Area
J.D. Griffith
814-539-2341
Jeana Sweeney
814-269-1319
Northwestern Area
Joyce Steinkamp
814-833-8495
Pittsburgh
Debra Czarnacki
412-331-6744

SOUTH CAROLINA
Columbia Area
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
Dallas/Fort Worth
Amy DeSilva
770-826-6007
Thomas Roderiguez
817-913-8477

El Paso Area
Jo Ann Longoria
915-526-0676
Olivia Longoria
915-491-0786
Houston Area
Kristin Leard
713-516-8630
Benjy 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
Denise Snow
206-321-1261
Emily Osborne
425-220-4225

WEST VIRGINIA
Charleston Area
Karen McClure
304-548-4413

WISCONSIN
Madison Area
Debi Weber
608-712-8709
Milwaukee Area
Lois Hawkins
414-249-0390

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 Outreach
Laurel Richardson at laurel@cmtausa.org.

BRANCH MEETINGS

(continued from page 20)

positive experiences with medical providers at a local neuromuscular program that treats CMT patients—the Hospital for Special Care in New Britain, Connecticut.

★

ALBUQUERQUE, NEW MEXICO

The Albuquerque, New Mexico Branch, led by Gary Shepard, met on August 4 with nine members present. We had a superb talk via Skype from London by Bethany Meloche. She spoke on the topic “How Should a Body Be?” that included some readings from her book of the same name. Bethany is a fabulous storyteller who has learned how to deal with CMT and knows how to convey these ideas to others. The entire group was very grateful to Bethany for a wonderful and inspiring presentation.

★

DENVER, COLORADO

The Denver, Colorado Branch, led by Ron Plageman, had a great meeting! They had a nice group of about 14 members, with a couple of first-time attendees, as well. They managed to keep the technical glitches to a minimum, thanks to Larry’s expertise and



The El Paso Branch started out with a bang, raising close to \$5,000 at their first fundraiser.

The El Paso, Texas CMTA Branch held its first fundraiser in October 7, 2018. Friends and family came out to support Car Wash for a Cause. High students of Coronado High School led this fun event and waved cars in with signs and flags. With the help of Garrett North of Black Diamond Detailing and 15 volunteers, Olivia Longoria washed more than 40 cars! Donations total close to \$5,000. Olivia, who is a high school senior, and her mom, JoAnn Longoria, recently started the El Paso Branch. They both have CMT1A and look forward to growing the branch through support meetings and more fundraisers.

everyone’s patience. A big thanks to Bethany Meloche for her generous time. Bethany spoke with the group from London, and she shared some very inspirational personal triumphs and she showed how she chooses to live and thrive with CMT. It was a great morning and thanks to everyone for making it a success. Don’t forget to get a copy of Bethany’s book, *How Should a Body Be*. Bethany is a CMTA Advisory Board member and will be donating 20 percent of her sales to the CMTA. Thank you, Bethany! Link to purchase her book: www.cmtausa.org/HowShouldABodyBe

★

SOUTH LOUISIANA

The South Louisiana Branch had a fantastic meeting during CMTA Awareness Month. Branch leaders Corey and Danielle Dalfrey opened the meetings with a welcome and introductions. They shared CMTA news and a STAR research slide show with the group. Also presenting was orthotist Josh Millet from South Mississippi. Josh spoke with the attendees about AFOs and shared some excellent resources in terms of good sneakers, how to reduce swelling and the benefits of good inserts. The group also talked about future meeting and fundraising ideas.

★

WILMINGTON, NORTH CAROLINA

The Wilmington, North Carolina Branch had a very informative meeting in October where they welcomed speaker Matt Murphy from the local Hanger Clinic. Matt was kind enough to bring nearly every type of bracing available to the meeting so the group could have a full overview of AFO options. He talked about what type is right for each person and saved time for many questions. Huge thanks to Matt for taking the time to attend. The second half of the meeting was spent getting CMTA updates and resources from Laurel Richardson, CMTA Director of Community Outreach. There were 15 people in attendance with a few new faces joining the group.

★

EL PASO, TEXAS

It was the inaugural meeting of the new El Paso, Texas CMTA Branch. There were more than 20 attendees with a lot to share and discuss. The group made a list of discussion topics and speakers for future meetings: bracing options, different types of CMT, diagnostic tools, lists of specialists available, activities for people with CMT, genetic testing options, family planning with CMT, CMT and effects on the respiratory system, physical therapy and exercise, vitamins and supplements, dietary needs, etc. It was great to speak with others affected by the disease. Members look forward to growing the branch!

★

So What?

I have CMT
So what?
I can’t jump
I can’t run, even though I try my best
I can’t play sports
So what?
Certain things are harder for me
Like walking, dancing, writing
So what?
I’m a bit clumsy
Okay, I am a little clumsy,
Okay, I’m the clumsiest person here, but
So what?
I get hurt walking
I can’t always wear regular shoes
Sometimes, no matter how hard I try, my stupid toes
just don’t wanna stay flat
So what?
I get tired walking sometimes
I trip over nothing
I lose my balance just standing in one spot
But so what?
That’s normal...at least that’s what I tell myself
I have to be in a wheelchair at amusement parks
So what?
It’s great to cut the lines and let’s be honest,
Watching people get annoyed that they have to wait
longer is kind of funny
All the time people tell me they feel bad for me
That they’re sorry that I’m in a brace or whatever
it is this week
But they don’t see the other side.
They don’t see the friends I’ve made because of this
They don’t see the amazing support that my friends
give me
They don’t see the late nights at camp,
Where so many others like me are laughing and dancing
They don’t see all of you, coming together to support
an amazing foundation
CMT is part of me, but it isn’t me
I am Kristyn and I have CMT
So what?

—Kristyn Finelli, Westchester NY Branch

WESTCHESTER, NEW YORK

The Westchester, New York Branch held its sixth fundraiser for the STAR program on November 4, 2018. This year’s luncheon was held at Banchetto Feast in Nanuet, New York. As in years past, there was an auction of gift cards and gift baskets. Most of the bidding was over face value. There was a 40,20,20,20 raffle and the group had their first “big hat contest,” which was a lot of fun! Beautifully donated, hand-crafted floral centerpieces adorned each table, as well as seasonal candy, adding to the festive feeling. A delicious donated sheet cake was decorated with the CMTA logo and read “we’ll succeed.” With donations still coming in, the branch is close to achieving the goal of \$10,000. In addition, there is a CMTA match until the end of the year, so the branch is able to double the STAR contribution for 2018. A poem written by Camp Footprint camper and branch member, Kristyn Finelli, was read at the luncheon. It was a very touching moment for our group.

★

Members of the San Diego branch tried out chair dancing at their most recent meeting.



SAN DIEGO, CALIFORNIA

It was an incredibly fun November branch meeting! Members of the group participated in chair dancing led by CMTA Camp Footprint counselor Bridget Savant. Chair dancing is how the campers start their day each morning at camp. It was so fun for the group to experience this. Jeana Sweeney, Laurel Richardson and Frank Gaidjunas from the CMTA were in town and able to join the group for this fun event. There were a few new faces, too. It was a great time!

HOUSTON, TEXAS

It was great to gather as a branch again—what an excellent turnout! The group was joined by a wonderful guest speaker, Eddie Patton, MD who talked about CMT from the neurological perspective. There was a wonderful Q & A session, too. The group met at Hermann Memorial. It was fantastic to welcome new faces, too.

TORONTO

Linda welcomed everyone after a long, hot summer. The mission statement of the CMTA was read. The guest speaker, Darryl Tracy, was introduced. Darryl specializes in neurorehabilitation physiotherapy and is an independent dance artist. He practices physiotherapy at Physio-Logic Neurological Rehab clinic, specializing in spinal cord injuries, stroke, MS, peripheral nerve injuries and many other related disorders. Darryl's presentation was extremely informative. He talked about selective muscle activation vs. strength. He advised individuals to enhance what they already have, and to try to make muscles work as best as they can. He suggested to not make too many reps, but do more variety so the nerve won't get depleted. Variety is better than repetition. Quality is more important than quantity when exercising, because it does not exhaust the nerves. Darryl advised the group to exercise arms, legs, core and do at least 20 minutes of car-



dio. Cardio wellness is important for nerves and muscles. For balance training, vision and the inner ear are very important, especially when turning or rotating in position. Sensory input is crucial.

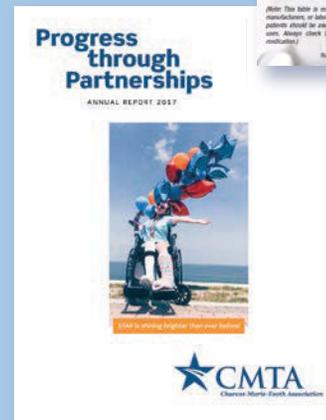
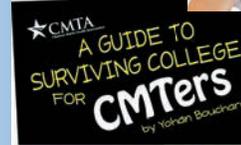
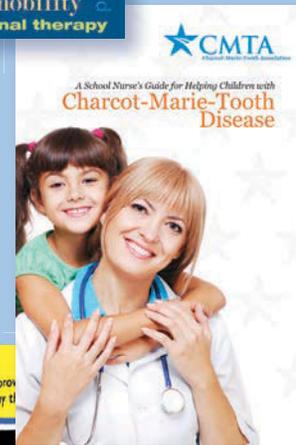
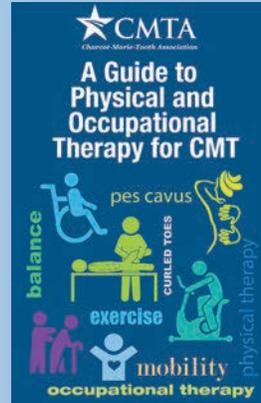
Toronto Raffle: Many thanks to Mike Driedger for arranging to get the tickets for the fundraiser raffle this year. The tickets were larger and easier to fill in. Tickets sold for \$4 each or 3 for \$10. It was a 50-50 draw again, and twice the amount was raised as last year! Tickets were distributed to members, with a copy of the CMTA's booklet "What is CMT?" that can be used to educate our ticket buyers. The branch will be sending \$530 US dollars to the CMTA for research. It was a great day!

CMTA YARD & BAKE SALE

Quentin Martin of Georgia held a Yard and Bake sale to raise money for the CMTA on September 15. Quentin says it was the most incredible day, not only because he raised money for the CMTA, but because he also talked and answered many questions about CMT. Quentin's efforts to raise awareness and funds for research and his positive outlook on life not only inspired CMTers but also touched and inspired the lives of a family living with another syndrome. It was a lot of work, but Quentin is grateful he was able to give back.

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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 (ddl, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Eribulin (Halaven)
Fluoroquinolones
Gold salts
Ipilimumab (Yervoy)
Ixabepilone (Ixempra)
Leflunomide (Arava)
Lenalidomide (Revlimid)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Nivolumab (Opdivo)
Pembrolizumab (Keytruda)
Perhexiline (not used in US)
Pomalidomide (Pomalyst)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:

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

The Charcot-Marie-Tooth Association
P.O. Box 105
Glenolden, PA 19036
1-800-606-CMTA (2682) FAX (610) 499-9267
www.cmtausa.org

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WHAT IS CMT?

- ▶ More than 2.8 million people worldwide have CMT, which is one of the most commonly inherited nerve disorders and affects the motor and sensory nerves.
- ▶ CMT is slowly progressive, causing the loss of muscle function and/or sensation in the lower legs and feet, as well as hands and arms.
- ▶ Men and women in all ethnic groups may be affected by CMT.
- ▶ CMT is genetic, but it can also develop as a new, spontaneous mutation.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT causes structural deformities such as high-arched or very flat feet, hammertoes, hand contractures, scoliosis (spinal curvature) and kyphosis (rounded back).
- ▶ CMT can also cause foot drop, poor balance, cold extremities, cramps, nerve, muscle and joint pain, altered reflexes, fatigue, tremor, sleep apnea, hearing loss and breathing difficulties.
- ▶ CMT rarely affects life expectancy.
- ▶ Some medications are neurotoxic and pose a high risk to people with CMT, notably Vincristine and Taxols. See full list (at left) of medications that may pose a risk.
- ▶ More than 100 different genetic causes of CMT have been identified.
- ▶ Many types of CMT can be determined by genetic testing. Please consult with a genetic counselor or your physician for more information (www.nsgc.org).
- ▶ Although there are no drug treatments for CMT, a healthy diet, moderate exercise, physical and/or occupational therapy, leg braces or orthopedic surgery may help maintain mobility and function.
- ▶ The CMTA's STAR research program and extensive partnerships with pharmaceutical companies are driving remarkable progress toward delivering treatments for CMT, bringing us closer to a world without CMT.