

THE

CMTA Report

SUMMER 2017

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SUMMER VACATION ISSUE



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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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A MESSAGE FROM CEO AMY GRAY

DEAR CMTA FRIENDS:

I firmly believe there couldn't be a more exciting time to become the chief executive officer of the Charcot-Marie-Tooth Association (CMTA). The CMTA has seen tremendous growth in the past five years: Thanks to the generosity of our loyal supporters and Pat Livney's leadership, we are on the brink of some major research breakthroughs that could potentially lead to a treatment for CMT.

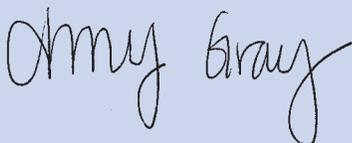
As I have begun reaching out to our longtime members and supporters, the question I hear most is: "How long will it take?" It pains me that I don't have a definitive timeline for finding a treatment, and ultimately a cure, for CMT. It is what we all want, as soon as possible. What I do know is that we can accelerate the timeline by having a robust research strategy, working with the best minds in the field and raising more revenue every year. These are all at the heart of CMTA's mission and overarching strategy.

Since my days at the Muscular Dystrophy Association (2000–2007), there have been many advances in CMT research. In the past 10 years alone, there has been an explosion in the identification and knowledge of genes that cause CMT. I was very proud to find out the CMTA funded these efforts. We now know of more than 90 genes that cause CMT. Knowing the causes, we can focus on trying to treat them with potential pharmaceutical therapies, gene therapy and other novel approaches.

The CMTA is more committed than ever to advancing science and leading groundbreaking research initiatives. The Scientific Advisory Board, comprised of the best minds in the field, is developing the research tools and resources needed to move forward. They have also worked closely with the CMTA's board of directors to put an infrastructure in place to support the Strategy to Accelerate Research (STAR), which is aimed at creating a world without CMT. Later this year, we will be launching a major fundraising campaign with one goal—driving breakthroughs to a cure.

I can't promise you we will have a cure for CMT in the next five years, but I can promise you we will be much closer. In the end, funding will be what advances the timeline. Like the Cystic Fibrosis Foundation and other organizations that have been instrumental in developing treatments for disease, the CMTA has decided to launch a major fundraising campaign this year that will allow us to accelerate the timeline. Securing the funding needed to drive breakthroughs in research will do that. From this day forward, I am committed to advancing the timeline and driving breakthroughs in research that lead to treatments, and ultimately a cure, for CMT.

All the best,



AMY GRAY



WHAT CMTers DO ON SUMMER VACATION...

CMTers ARE A DIVERSE GROUP WHEN IT COMES TO SUMMER VACATIONS.

Some use the time to challenge themselves and their limits. Some challenge others to raise funds for CMT research. Some take the educational route and use the time to improve their minds. Some choose to relax and some have "relaxation" forced upon them. However you spend your summer vacation, we hope you'll find reading about what other CMTers did interesting, if not downright inspirational.





Bethany (second from right) with some of her support crew: (left to right) Uncle Mike, dad Tom and friend Elizabeth

A 50-Mile Walk to Run in Ireland

BY BETHANY MELOCHE

On July 2, I set off on my 5th Annual “Walk to Run.” In honor of my fifth year, I decided to attempt 50 miles along trails in Ireland. The choice of Ireland seemed appropriate: It’s where we believe my CMT gene originated several generations ago. Maybe hundreds of years ago there were people who not only looked a little like me, but walked like me too. Maybe I would be walking in their footsteps.

When I started training for my 50-mile walk, I woke up early each morning to walk around the block. And though I could walk far, I didn’t walk without fear: I was too afraid to cross the London streets by myself, so even as my distances increased—from two miles, to four, to six, to eight—I stayed within the safety of my block. Around and around and around that block. Every day. It didn’t occur to me that people might be watching.

One day last year I was out walking when a woman I didn’t know ran up to me. She was beaming, and waving her arms as she said to me in a thick accent I didn’t recognize, “You are getting better!!” “What?” I said. I’d heard her fine, but I hadn’t yet processed what she was saying. “Your legs,” she said, excitedly. “They are getting much better!!” She was right. As I trained, my gait had gotten smoother, my balance better and my legs stronger. I was getting better and even strangers could tell.

The stranger’s assessment was in stark contrast to the news I’d gotten a couple weeks before from my neurologist. According to her, I was not getting better. From a neurological perspective, the nerve damage in my legs and arms is extensive and—at this time—irreversible. When I asked her for my “number”—the speed at which the nerves transmit messages—she

told me that she couldn’t give me one because the signals weren’t strong enough to be detected.

And yet, on July 2, I embarked on my Walk to Run, the culmination of a seven-year journey that began when I was in a wheelchair and couldn’t walk without pain. Major surgeries gave walking back to me, and now I “Walk to Run”—in celebration, to challenge myself, and to fundraise—so that maybe one day I will run.

I successfully completed the 50 miles in five days, surrounded by family and friends. Each of them took turns holding my hands the entire 50 miles. As I reached the end of that last mile, my dad—who also has CMT—pulled a medal out from his jacket and slipped it around my neck. His eyes were full of tears.

Bethany is the CMTA’s director of social media. Her 5th Annual “Walk to Run” raised \$11,120 for the CMTA.





Lily, triumphant!



Lily and her twin brother Jack

9-Year-Old Spartan Raises Funds for CMT Research

Lily Sander, age 9, kicked off the summer of 2017 by competing in her second Spartan Kids Race—and raising \$3,656 for the CMTA's STAR research program.

Spartan races typically include obstacles like hills, ladders and mud pits. Kids are encouraged to jump, run, get muddy, help each other and have a good time while conquering obstacles.

Last year, Lily and 31 friends and classmates did a half-mile race in Concord, North Carolina. This year, she and her friends and family doubled that effort and completed a 2K course. It's all part of Lily's philosophy of life—set a goal, reach that goal, set a bigger goal.

Five years ago, Lily, a CMTA Ambassador, couldn't walk, much less compete in a Spartan. After major foot surgery, she is now able to walk, sometimes wearing braces, sometimes not. She doesn't just walk though. She skips, runs and turns cartwheels. She loves gymnastics and dreams of competing in the Olympics. Because CMT is progressive, she'll need additional surgeries in the future, and her balance and hand strength are declining, making it hard to keep up with the other kids. This makes her mad and fuels her

determination to find a cure for CMT.

Lily wants to inspire others with CMT to be active and enjoy life to the fullest. As she likes to say, "I have CMT, but it doesn't have me." She wants to prove that she has the ability to do whatever she chooses to do and hopes others will follow her lead.

In addition to raising funds for CMT research, Lily and her mother Julie also focus on raising awareness about the disease. As Julie says, "We're trying to bring awareness because awareness drives funding, funding drives research, and research and drug development can dramatically impact the

lives of people with CMT." Lily was recently interviewed for the inaugural issue of *Springfield Living*, a glossy monthly that will be distributed to the 600 homes in her neighborhood. The magazine will feature Lily and include her donation link in the article.

Everyone Lily touches seems to want to get involved in her efforts. Her gymnastics studio, which last year raised \$3,000 for cancer research, has chosen the CMTA as the beneficiary of this year's fundraiser and will do a variety of events over the next six months to raise money. If you'd like to get involved, you can donate at www.cmtausa.org/give-5-for-lily/.

Lily wants to inspire others with CMT to be active and enjoy life to the fullest.



Ohio Branch Leaders Head to Prison

The CMTA's three Ohio branch leaders ran the so-called "Shawshank Hustle 7K" on June 17, starting and ending the race at the Ohio prison where the movie "The Shawshank Redemption" was filmed. Starring Tim Robbins and Morgan Freeman, the 1994 movie chronicles a wrongly convicted banker's experiences in the gloomy Shawshank jailhouse.

Heather Hawk Frank (Cleveland) and mother-daughter team Jo Koenig and Jill Stuhlmuller (Cincinnati) ran with Heather's husband Dave and Jill's dad/Jo's husband Steve. The race, now in its third year, passes other filming sites such as Brooks' bench, where a character played by James Whitmore goes to feed the birds. Before the race began, participants toured the reformatory, home to the longest standing (six-tiered) cell block in the world. The stairs and uneven ground gave the branch leaders and their "CMT legs" a workout even before the race began.

Built in 1834, the Ohio State Reformatory in Mansfield, Ohio, was once a jail for people to be



"reformed" before entering back into society. Several movies were filmed there after it closed. The producers of "The Shawshank Redemption" were told they could do whatever they liked to the site because the reformatory was going to be torn down after the movie, but an historic preservation team intervened to prevent its destruction. Now considered one of the most haunted sites in Ohio, the reformatory is visited by history lovers, movie buffs and ghost hunters alike.



The race began at 8:30 a.m. as runners and walkers left the reformatory and made a loop through downtown Mansfield, crossing a few sets of railroad tracks and conquering many hills. The last hill, also known as Road to Redemption Hill, was a one-mile, uphill journey back to the reformatory. The group of five had an excellent time visiting while exercising and pushing themselves to succeed. One of the best parts of the race was crossing the finishing line holding hands in triumph. Each participant earned a medal paying tribute to the Shawshank Oak Tree, which fell in a bad storm last year. Freeman's character found an important letter buried by Robbins' character underneath the 200-year-old oak tree in one of the final scenes of the film.

Want to join the CMT team next year? The next Shawshank Hustle will be held on Saturday, June 9, 2018, and a good time is guaranteed.

Ohio branch leaders Jill Stuhlmuller, Heather Hawk Frank and Jo Koenig show off their medals



A Visit to a Biomedical Research Facility

BY VITTORIO RICCI

While many families head to the beach for summer vacation, I visited a research laboratory that distributes mice models of human diseases, including CMT.

On June 22, my family and I had the amazing opportunity to tour Jackson Laboratories in Bar Harbor, Maine. For those who don't know, Jackson is the world's largest nonprofit biomedical facility that researches genetic disorders and breeds lab mice. The lab offers educational programs for high school, college and graduate students with housing on site. In one of the facility's 40 labs, researchers are attempting to use gene therapy to stop the progression of CMT2D. Our guide, Robert Burgess, PhD, was the head of this research study.

To get there, we drove a scenic six-hour coastal ride from Boxford, Massachusetts, to Bar Harbor, Maine. I made sure we stopped at a few of the countless flea markets along the way. Our first day was spent exploring Acadia National Park, driving to the top of Cadillac Mountain and stopping at the family-Christmas-card-backdrop of Sand Beach.

Jackson Laboratories is located next to Acadia National Park, making it one of the most photogenic places I've ever seen. We met Dr. Burgess in a lobby that seemed right out of the opening scenes of Jurassic Park. He led us throughout the main facility, stopping to discuss portraits of past Nobel Prize winners and show us a replica of all the lab buildings, including the mice breeding facility. We stopped outside a sterile room where afflicted lab mice are examined to track the effect of their treatments. But the research facility was the most anticipated stop of the tour. Burgess's lab was packed full of equipment I half-recognized from high school biology—centrifuges were spinning down mysterious fluids and interns were pipetting liquids from vial to vial. It was the kind of messy, complex space only a scientific researcher could find manageable.

We sat down in Dr. Burgess' office to talk about CMT and his research on type 2D. He explained to us how he is using gene therapy to stop the progression of CMT2D in lab mice, and results were looking good. Specifically, his team is working with Dr. Scott



Vittorio on
Sand Beach
and Vittorio
at Jackson
Labs



Harper at Nationwide Children's Hospital, using a specially manufactured virus to prevent the CMT2D afflicted mouse's cells from creating the faulty protein, effectively stopping the progression of the disorder. The virus contains a small, specific strand of the afflicted mouse's DNA that includes the mutation, which causes the immune system to respond and prevent that strand of DNA in the mouse from making proteins. Those faulty proteins are what cause the mice's nerves to degenerate. We watched several videos of CMT2D lab mice with and without treatment. It was exciting to watch a video of active mice and not see signs of CMT disease.

As a person who lives with CMT, I was amazed by the enormous efforts taking place at Jackson Labs. Our thanks to Dr. Burgess for his time, his work and explaining it all to me and my family. Nothing gives me more hope than to hear someone say that a mouse once had CMT. ★

Vittorio, 19, is a rising sophomore at Northeastern University and a member of the Boston, MA CMTA Branch run by his mother, Jill.



NEW MOBILE APP SIMPLIFIES SIGN-UP FOR PATIENT REGISTRY

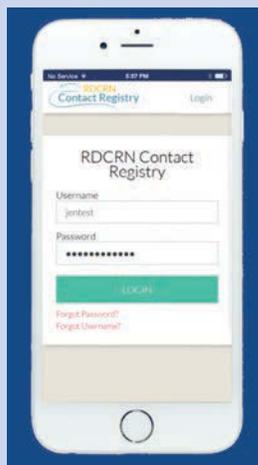
A new mobile app developed by the Rare Diseases Clinical Research Network (RDCRN) makes it easier than ever for CMT patients to sign up for and navigate the network's patient registry. The registry will play a key role in identifying patients for clinical trials as the CMTA moves forward with its research program, STAR.

The Inherited Neuropathies Consortium, which is partially funded by the CMTA, is one of 22 consortia that make up the RDCRN. More than 8,575 people with CMT have signed up for the registry since it began.

More information about the INC database, a critical component of the CMTA's research strategy, can be found at www.cmtausa.org/research/cmt-clinical-trial-registry/.

Signing up for the registry gives the user access to a list of current open studies and contact information. Current open studies include:

- 6601: Natural History Evaluation of Charcot-Marie-Tooth Disease**
- 6602: Genetics of CMT—Modifiers of CMT1A, New Causes of CMT2**
- 6603: Development of CMT Peds Scale for Children with CMT**
- 6610: Disability Severity Index (DSI) and Hereditary Motor and Sensory Neuropathy Overall Disability Scale (HMSN-R-ODS)**
- 6611: Charcot-Marie-Tooth Disease Infant Scale**
- 6612: Patient Reported Outcomes Measures (PROM) in Carpal Tunnel Therapies in Patients with Inherited Neuropathies**



Unlike most apps, the new RDCRN Contact Registry mobile app doesn't require users to download it from the app store. Users simply bookmark it. Once bookmarked, it shows up on the home screen of the user's phone, tablet or computer just like a regular app.

The RDCRN Contact Registry app is compatible with all mobile platforms. Clicking on it will take the user directly to the RDCRN Contact Registry login page.

The Contact Registry login page can be accessed at: <https://contactregistry.rarediseasesnetwork.org>.

CELEBRATING CMTAthletes

SURFER/OUTRIGGER CANOER DIANE WHITCOMB & MASTERS SWIMMER ALEX BEEMAN

ALOHA! I AM DIANE WHITCOMB. I was diagnosed with CMT when I was in the seventh grade. I could not run and had severe foot drop, so I could not do land-based sports very well. That is when I turned to water sports. In high school, I took daily swimming classes all year long in physical education. My hair was always wet—I'm surprised it didn't mildew. When I was 21, I took up scuba and free diving in Northern California with my Uncle Frank, who was an amazing waterman and shared his love for the ocean with me. I

longed for the much warmer waters of Hawaii, so I moved there in 1974 to continue my scuba diving and attend college.

After working in Europe and raising my daughter, I returned my focus to the ocean. In 2009, I started paddling outrigger canoe with the adaptive team Pure Light Racing. That first year I paddled in three long-distance races, including the Molokai Channel race. When I was introduced to AccesSurf Day at the Beach in 2014, I tried surfing on a wave ski and fell in love with it. The ocean is so healing, and when I am out there I feel pure joy. Not only does

surfing keep me active, it is my treatment of choice when I am feeling depressed or anxious. How can you feel down when the surf's up?

Through Pure Light Racing* and AccesSurf,** I discovered I can both have a disability and be an athlete. I have so much more confidence now. When AccesSurf formed the Surf team, they invited me to try out. Why not, I thought—what a great opportunity. Attending the first ISA International Adaptive Surf Meet in La Jolla, California, with the AccesSurf team in 2015 was the thrill of a lifetime.

*The nonprofit Pure Light Racing is at the forefront in the advancement of adaptive outrigger canoe paddling, as a recreational activity and competitive sport, both locally in Hawaii and worldwide (www.purelightracing.org).

**The nonprofit AccesSurf creates community-based programs that enable anyone with a disability to enjoy the water (www.accessurf.org). Based in Honolulu, Hawaii, AccesSurf offers a Wounded Warrior Program, a monthly "Day at the Beach" with assisted swimming, floating and surfing, and the Hawaii Adaptive Surf Team (HAST), which helped develop 15 competitive adaptive surfers by providing over 200 hours of coaching support and skills development since its inauguration in 2015.



Adaptive surfer
Diane Whitcomb



Masters swimmer
Alex Beeman

MY NAME IS ALEX BEEMAN.

I'm a 27 year old with CMT. However, I have never let that stop me. I started swimming at the age of 5 for a local summer team—nothing major, but enough to get my feet wet. Turns out, I love swimming.

As a freshman, I joined my high school's varsity swim team. I was one of two freshmen to qualify for sectionals. My sophomore year, due (at least partially) to CMT, I fell and shattered my kneecap and tore my patellar femoral ligament into several shreds. Even the surgeon was impressed with the extent of my injury! The doctor wasn't sure if I'd ever walk again without assistance. I've never been more determined to prove someone wrong. I came back and helped lead my team to a state championship my junior year and a sectional championship my senior year.

The next year I tried out for the team at Lafayette College, which competes at the Division 1 level. While I wasn't fast for this team, I still was nominated captain my senior year. After that, I continued swimming at the

masters level with a local team, Palmetto Masters, the largest U.S. Masters Swimming (USMS) team in South Carolina. With a teammate, I swam 12 miles in the ocean around Charleston, South Carolina, last year. We finished in around six hours. I have yet to compete in a meet where I have not earned high point winner in my age group.

This year we competed at USMS short course yards nationals. In my first race, I stepped up on the blocks, lost my balance, and fell in the water with a huge gash on my leg. (I have the scar to prove it.) My confidence was definitely shaken and I was embarrassed, but I still finished 8th in that 1000. I then placed 5th in the country in the mile. This was probably the best race of my life, and felt great hours after falling off the blocks. This time I was smart enough to ask for help getting up!

I used to wish that I was never born with CMT, but honestly, it has made me the man I am today. It's given me a sense of appreciation, determination, fearlessness, and most of all, strength. ★

MASSACHUSETTS GENERAL CENTER OF EXCELLENCE LAUNCHES NEW WEBSITE

Bringing together physicians, physical therapists, orthotists and researchers, the Massachusetts General Hospital Charcot-Marie-Tooth Center of Excellence is committed to patient care and research specific to inherited neuropathies. The MGH CMT Center offers a comprehensive experience aimed at improving symptoms, providing educational resources and advancing research into potential therapies. Its staff provides complex specialized services focused on improving symptoms and increasing mobility, balance and muscle strength.

In collaboration with the other members of the Inherited Neuropathies Consortium, the center aims to advance the understanding, diagnosis, and treatment of inherited neuropathies. Patients at the CMT Center have the opportunity to participate in the most current research endeavors.

Because foot drop and leg weakness are major components of disability in patients with hereditary neuropathies, physical therapy and orthotics are often prescribed together to help improve efficiency, function, and safety with ambulation and other activities. The center's neuromuscular physical therapists focus on maximizing function, with emphasis on balance training and exercise, not only to improve function and enhance independent ambulation, but also to help minimize pain and more chronic complications from neuropathy. Bracing/orthotics in conjunction can offer additional support to further normalize gait pattern and increase walking speed.

Learn more about the MGH CMT Center at www.massgeneral.org/neurology/services/treatment-programs.aspx?id=1987.

The clinic phone number is 617.726.3642.



Mass General COE Staff

Christina's World of CMT

Many people with CMT wait years for a diagnosis, going from doctor to doctor until they finally find one who knows something about the rare disease. But no one waited longer than Christina Olson, subject of Andrew Wyeth's famous 1948 painting "Christina's World." Born in 1893, she wasn't diagnosed until long after her death in 1968.

"Christina's World" depicts Olson lying on the ground at the bottom of a hill, looking up at a farmhouse. She is shown from the back, in a posture of yearning. To most viewers, she is simply reclining lazily on the ground. Few people know that she was the painter's friend and neighbor, and that she was not reclining but dragging herself along the ground because she was crippled by CMT.

For many years, it was thought that Christina had polio, but the theory that it was CMT has gained increasing acceptance in recent years. In March 2017, neurologist Dr. Marc C. Patterson from the Mayo Clinic published an article in *The Journal of Child Neurology* laying out his case that

Olson had CMT. According to Patterson and his coauthors, unlike polio, which usually causes symptoms relatively rapidly but then doesn't worsen, Olson's weakness developed slowly and spread through her body over the course of her life. At age 3, she walked on the outer edges of her soles, an asymmetric symptom seen in CMT but not polio. Further, Patterson noted, Olson was also born several years before the major polio outbreaks, making polio unlikely.

Olson walked unassisted until she was in her 20s, although she stumbled frequently. It was around this time that her hands also began to show signs of muscular weakness, Patterson learned. In her 50s, Olson was burned while sleeping near a stove, a finding leading Patterson to conclude that she had difficulties with pain sensation. Olson's combination of motor and sensory problems, typical of CMT, let the neurologist rule out muscular dystrophy.

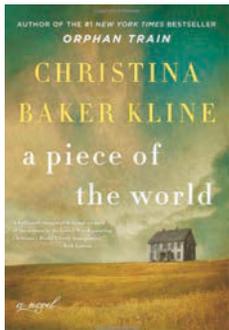
Christina never used a wheelchair, instead crawling around her 16-room farmhouse in Cushing, Maine. Wyeth described her



"crawling like a crab over the New England shore," using the remaining strength in her shoulders and hips to pitch herself forward. She is captured in this pose in Wyeth's painting.

"As a neurologist," Patterson said, "it is always fascinating to me that there seems to be a limited number of alternatives that people think of when patients have neurologic symptoms, and I guess that's because we haven't done a good enough job at educating the public about these things."

Patterson was presented with Olson's case history as a clinical challenge by Dr. Philip Mackowiak, a professor emeritus at the University of Maryland School of Medicine, who organizes the annual Historical Clinicopathological Conference in which a physician receives the clinical history of an unnamed historical figure and then makes and presents a diagnosis in the style of medical grand rounds and guesses who the historical figure is. ★



Best-selling author Christina Baker Kline, who published a fictionalized account of Christina's life titled "A Piece of the World" in January 2017, will be a speaker at the CMTA's Eighth Annual New York City Gala on October 24. Tickets are \$500 each and can be purchased at www.cmtausa.org/gala.

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The CMTA Legacy Society for Planned Gifts

For people who like to make plans, the CMTA's Legacy Society for planned giving offers a neat way to tie up their estates and make sure their wishes are honored. Planned giving is just what it sounds like: The donor makes a plan, usually in the form of a will or an estate plan, to give to the CMTA at some point in the future. Planned giving often takes the form of bequests in a will: A donor can make a specific bequest to the CMTA, or leave it a percentage of the proceeds. A donor can also make gifts of stock, real estate or insurance policies, among other assets.

Robin Ryan is one of the CMTA's Legacy Society members. The retired professional photographer left Ohio after college for an exciting career in San Francisco. She photographed rock stars, fashion models and even the Dalai Lama. Everything was great until she began falling off her high heels and her toes started curling under. A bad hand injury "jogged my wellness," she says, and she had a rough few years in which she "went from being almost invincible to

having something wrong." She saw "lots of docs" before finding a neurologist at the University of California San Francisco who said it was a genetic disease. A blood test confirmed her CMT1A in 1995. She says she struggled with self-image for a while, fighting the idea that she was no longer fabulous. She resisted wearing braces until she broke a leg and her doctor told her that she needed them to walk. Looking back, she sees that "the whole thing with my CMT is: developing what I can do well and adjusting to a new self-image," which she finally did at 60.

Robin, now 68, lives in a retirement community with an Olympic-size pool in San Diego, California. She swims a half mile four times or five times a week and teaches swimming to adults, many recovering from illness or injury, a couple of times a week. She highly recommends the silicone AFOs she wears today, which help her maintain some agility while correcting foot drop.

In a bit of kismet, Robin got the idea of putting the CMTA in her will from the estate of the

woman from whom she bought her house. That generous soul left everything she had to her two favorite charities. Robin and her husband thought that was a great idea. They don't have children so when it was time for them to write their own wills, they looked around at their family members, saw that no one was in real need and decided to make a couple of personal bequests, then split the remainder between the Big Brothers of America, which her husband holds dear, and the CMTA, which is close to Robin's heart. "The CMTA is dear to me because I am witnessing progress in diagnosing and healing the disease that has made my life difficult," she says, adding, "If you have feelings for a charity, make your wishes known now."

The CMTA is happy to have the chance to express its deep gratitude to Robin for all the good her gift will do for the CMT community. We think she's more fabulous than ever! ★



Retired photographer Robin Ryan is proud to be a member of the CMTA Legacy Society.

For more information about planned giving, contact CMTA Director of Development Susan Ruediger at sruediger@cmtausa.org or 800-606-2682, x108.

CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
- Thank You Anniversary Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

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Allard AFOs Explained: Finding the Right Fit

Individuals with CMT often find themselves stumbling, tripping, dragging their feet, feeling unstable or lacking good balance. They often accept this as just another symptom of the disease and compensate by walking with a gait pattern that can damage other joints, muscles and ligaments.

If you have any of these symptoms, bring them to the attention of your physician and physical therapist. Tell them you've read on the CMTA's website about other people who found AFOs helpful and ask if they might work for you. You might also want to take to your appointment either the Allard "What Is Foot Drop?" or the "Pediatric Patient Options for Foot Drop" brochure (<http://getbackuptoday.com/brochures/>).

Finding the right AFO can be life-changing, improving gait and balance, leading to greater confidence, a more active lifestyle and a more positive outlook.

Allard foot drop AFOs are recognized worldwide for providing dynamic response without limiting function. Each brace is a technologically advanced, carbon composite foot drop orthosis that flexes in reaction to your weight and then releases kinetic energy to propel the leg forward, much like the spring you get when jumping

off a diving board. With varying sizes, degrees of stability, strength and surface area support, these dynamic AFOs help wearers walk with a more natural gait pattern.

All Allard AFOs require a prescription from a physician and fitting by a certified orthotist or prosthetist. Each has its own unique list of applications. On the low end of the stability scale is the Ypsilon® Flow, designed for individuals who are relatively stable and don't need much orthotic stabilization. This would be good for a CMter who has good ankle stability, but stumbles or trips occasionally as the day progresses when walking becomes more and more tiring. The BlueROCKER® is on the other end of the spectrum. It is designed for patients who require significant orthotic stabilization, but without immobilization. The BlueROCKER® could be good for an individual whose CMT has progressed to the point that the ankles are very unstable and the knees and/or hips show signs of instability as well.

Your orthotist will do an assessment of your walking pattern to determine which AFO will offer the support you need without "over-bracing," or restricting the movement of your leg more than necessary to meet the treatment

goals. Many factors are considered: the degree of your deficits (from toe to head and head to toe), your level of physical fitness, symptoms, your gait pattern when walking without an AFO, leg length discrepancy, fixed deformities, your lifestyle and your mobility goals, your body style (thin, stocky, etc.) and your activity level. The orthotist may have samples of each style of Allard AFO to help assess which functions best for you. The orthotist will likely need to make some modifications to your AFO to assure the best alignment and foot position to achieve as close to a normal gait as possible. All Allard AFOs should be fitted with a soft interface that goes between the carbon composite anterior support and the tibia, and a foot orthotic (semi-rigid insole) on top of the footplate. There are certain contraindications for Allard AFOs, including leg ulcers, moderate to severe edema, moderate to severe foot deformities and severe spasticity.

In an article recently published in the journal *Muscle & Nerve*, Ohio State University researchers found that the "overwhelming majority of ambulatory neuromuscular patients with distal leg weakness will benefit from off-the-shelf ToeOFF® or BlueROCKER® CFAFOs (Carbon Fiber Ankle Foot Orthoses)." The study went on to conclude that, "Overall, 89% (109 of 123) of the patients were satisfied or extremely satisfied. This included 38 individuals who previously had been prescribed custom-made, solid ankle posterior AFOs." No one AFO works for all individuals with CMT, but Allard continues to add new designs to meet individual needs. ★



STUDY FINDS EXERCISE THE BEST MEDICINE FOR KIDS WITH CMT

Progressive resistance exercise significantly reduces the muscle weakness experienced by kids with CMT, according to a paper presented at the Peripheral Nerve Society's annual meeting in Barcelona, Spain, and published in *The Lancet Child & Adolescent Health* on July 10.

Led by Professor Joshua Burns, Director of the Paediatric Gait Analysis Service at The Children's Hospital at Westmead and Professor at the University of Sydney, the study found that six months of moderate-intensity progressive resistance exercise helped slow the progression of muscle weakness in kids with CMT by up to 30 percent. The exercise program also strengthened their muscles over a two-year period.

"For patients with CMT, the results of the trial are life-changing, helping to not only improve their chronic pain and reduce the degree of disability but also greatly helping to improve their quality of life," Burns said. "In partnership with clinicians, scientists and patients all over the world, we are also working on medications to ultimately cure CMT, but exercise is an important bridging therapy for children and adults in the meantime."

Burns is working closely with the CMTA on a PT/OT conference to be held in Arizona in November.

The full paper is available at [www.thelancet.com/journals/lanchil/article/PIIS2352-4642\(17\)30013-5/fulltext](http://www.thelancet.com/journals/lanchil/article/PIIS2352-4642(17)30013-5/fulltext).



The Adventures of Rui Rui and Tango

Lia Bleifus, known to her friends and family as Rui Rui, wanted a dog. Her parents, Sherry and Ethan, wanted a dog too. Because Rui Rui, 13, has CMT, they also wanted a companion to help her with her balance and leg strength issues. The answer turned out to be Tango, a lovable black Goldador (Golden/Labrador Retriever cross) mobility assistance dog.

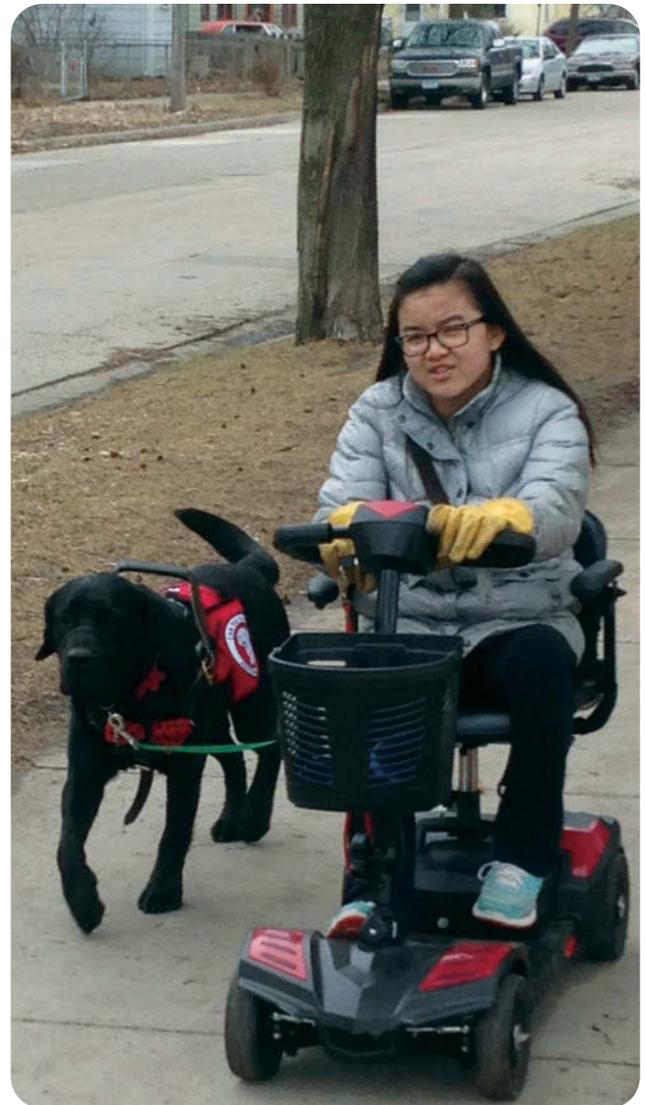
Tango came from Can Do Canines, an amazing organization in New Hope, Minnesota, that provides mobility assistance dogs at no cost to clients with mobility challenges, hearing loss or deafness, seizure disorders, diabetes complicated by hypoglycemia unawareness or childhood autism.

Can Do Canines trains 50 to 60 dogs a year, many adopted from local animal shelters. The dogs' initial training is done by federal prison inmates, who live with the dogs 24/7. The dogs are then handed over to volunteer trainers who slowly introduce the dogs to their new owners.

For Rui Rui, Tango is not just a beloved pet, but also an invaluable companion whose harness provides her with balance assistance and who can pick up things that she drops, although often with an added layer of slobber. Tango also helps Rui Rui make new friends and provides an introduction to discussing her CMT. With a big head and a semi-goofy disposition, Tango keeps Rui Rui and her family amused and entertained. Rui Rui reports that Tango likes to cuddle with her rabbits, gets along well with the family cat and enjoys eating snow. He doesn't seem to mind the cold weather in Minnesota and will happily walk with Rui Rui in 10 degree weather.

In addition to swimming and hanging out with Tango, Rui Rui loves acting and recently performed in a production entitled *Aphrodite Loveletters* in which she played a sassy nymph. ★

For more information on Can Do Canines, visit www.can-do-canines.org.



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

Write to David at
info@cmtausa.org.



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.

Dear David,
Last week I was fortunate to be invited to a family reunion at a relative's beach house. Although I am mobile with a cane, it is difficult for me to circulate around a room and mingle. Watching the teenagers run and jump on the beach pushed some buttons about that part of my life being long over. I sat in one spot overlooking the Pacific Ocean and tried to control feelings of jealousy. I do not think anyone in the crowd actually knows what I have, nor do they seem particularly interested. Even my brother-in-law, who is a neurologist, barely asks me how I am. Am I foolish to expect people to take more of an interest in me?

David replies:

Personally I try to avoid large parties, which can often make me feel isolated. I realize that having CMT all my life has contributed to a certain shyness or lack of confidence. I have compensated by developing other qualities. Having

your heart broken also means that it is opened, and this can contribute to a strengthening of empathy and compassion. I have learned how to listen and focus, an important quality for success in many aspects of life.

I find that many adults and nearly all adolescents have the attention span of a fly. Call me old fashioned, but I was brought up to address older relatives and at least pretend to care. Of course, with so many kids addicted to their electronic devices, trying to get them to focus is nearly impossible.

I realize that some people are simply uncomfortable with disability and will avoid you. I have also come to realize that many people have really awful listening skills so conversations only go one way. I try not to dwell on negative thoughts and just enjoy being part

of a community, however unskilled its members are at conversing. When I actually observe others, there is not much communicating going on between them either.

For some reason, we have come to expect our families to be more sensitive than others. I suspect they feel they shouldn't have to make the effort. If you really want to connect with someone, go ahead and make the effort. Don't allow yourself to get increasingly annoyed while you wait for them to approach you. I have always believed that listening is a form of love, and we all need love. It doesn't take a lot of people or long conversations to make a real connection. Making even one connection in an evening can be truly satisfying and is worth the effort. It's their loss if they avoid us because I think we all have a lot to say! ★

My Allard ToeOFF
makes me...



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Interested in starting a branch in your area?

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



CMTA BRANCH NEWS

SOUTHERN CONNECTICUT

The branch welcomed CMTA Advisory Board member David Tannenbaum to its June 3 meeting, a reward for raising more than \$10,000 in 2016. The majority of the 17 people in attendance were new participants, some traveling from as far as from Providence, Rhode Island. It was an emotional meeting as David and others shared their struggles of living with CMT or having a loved one with CMT. David's own experiences and expertise provided a meaningful discussion about how to cope and grow emotionally as we face the challenges of CMT. Participants were encouraging, offering suggestions and helpful information to each other, especially those with recent diagnoses.

ST. LOUIS, MO

The CMTA's own Jeana Sweeney and Michelle Hayes kicked off their Great Midwest Road Trip with the St. Louis Branch meeting on April 29. They walked members through some of the many resources available on the CMTA website, including free webinars with CMT experts, information about medical professionals, Camp Footprint, and patient/family conferences. The pair also gave updates on CMT research. Lastly, Michelle and Jeana talked about staying updated and connected with the CMT community through social media. The CMTA posts research updates, news about upcoming events, ways to get involved, and more at www.facebook.com/CMTAssociation/.

KANSAS CITY, KS

Jeana Sweeney and Michelle Hayes joined the Kansas City Branch on April 30 for the last stop on their Great Midwest Road Trip. They updated the group on upcoming clinical trials and stressed the importance of signing up for the CMT Patient Registry at www.rarediseasesnetwork.org/cms/inc/registry. Not only does it allow researchers to gather data, but it informs people about clinical trials for which they may be eligible. A person does not have to know his or her CMT type to participate.

NEW MEXICO

Jeana Sweeney joined eight branch members via Skype on May 6 to discuss fundraising ideas for New Mexico. After going over the definition of fundraising and how to become a dynamo at it, she presented five fundraising ideas and the group agreed to pursue several of them. The branch also heard a presentation on genetic testing by an Invitae representative.

PITTSBURGH, PA

A record 25 people came out to hear special guest speaker Jeana Sweeney, CMTA Director of Community Services, at the May 6 meeting. Jeana covered the history of the CMTA and the importance of genetic testing. She also talked about fundraising for STAR, the CMTA's research initiative, which was created to find treatments to slow, stop or reverse the progression of CMT. Members also talked about visiting Camp Footprint, which is held just 40 miles north of Pittsburgh.

MOUNTAINEER, WV

Eighteen people turned out for the branch's inaugural meeting on June 1. They shared their reasons for attending, which included wanting to meet others, learn coping mechanisms, increase quality of life, learn more about CMT and help create awareness. They briefly discussed braces, including Turbomeds, and decided that they would like to have health care professionals speak to the group. They also talked about possible weekend activities for the group, including day camp, family camp, swimming and a fitness day.

SEATTLE, WA

Thirteen people attended the branch's May 20 meeting, including one new member. They discussed two Awareness Month events coming up in September, a wine tasting and one member's participation in a marathon. At the September meeting, Dr. Michael D. Weiss from the University of Washington Medical Center will be asking for volunteers for a CMT Natural History Study. Volunteers will answer questions and undergo a nerve test. They should bring their genetic testing information, if they have it.

TORONTO, CANADA

Fifteen people attended this branch's inaugural meeting on May 13, including three spouses and one mom. Branch leader Linda Scott Barber shared that the group's purpose is to help members find resources to help them with challenges and to create a positive atmosphere to discuss those challenges. Members brainstormed on future guest speakers they would like to hear and fundraising ideas. The group also agreed to begin compiling a list of resources, including good shoe stores, professionals who help with CMT, etc.

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
Connecticut Children's Medical Center (Farmington).....	Dr. Gyula Acsadi
Massachusetts General Hospital (Boston).....	Dr. Reza Seyedasadjadi
Johns Hopkins University (Baltimore).....	Dr. Thomas Lloyd
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My Child Has CMT		\$5	\$5	
CMTA T-Shirts <input type="checkbox"/> Navy Blue with white logo) <input type="checkbox"/> White with blue logo) Quantity and Size: S__ M__ L__ XL__ 2XL__ 3XL__		\$15	\$12	
CMTA Shark-0 T-Shirts Quantity and Size: S__ M__ L__ XL__ 2XL__ 3XL__		\$20		
CMTA Sweatpants Quantity and Size: Youth XL__ Adult S__ M__ L__ XL__ 2XL__ 3XL__		\$20		
Be a STAR Wristbands		\$1.50 each*		
Be a STAR Necklaces (Includes battery)		\$5 each*		
Washable CMTA Tattoo (Pack of 5)		\$1 per pack		
CMTA Pin		\$3 each		
CMTA Brochure & Neurotoxic Drug Card		FREE		
Donation to the CMTA (100% Tax-deductible)				
Shipping & Handling (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)				
*Quantity discounts for these items available online				ORDER TOTAL

Check payable to the CMTA (US residents only; non-US residents, please use credit card or international money order.)

Money Order American Express MasterCard VISA

Card Number: _____ Expiration Date: _____

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.



THE CMTA ANNOUNCES 7TH ANNUAL CONTEST:

I'M A STAR! / I'M A SHOOTING STAR!

Do you know an extraordinary person living with CMT? Please share that person's story with us and he or she may be selected as the recipient of the Seventh Annual "I'm a Star!" award (ages 18 and up) or the "I'm a Shooting Star!" award (ages 10-17).

In 500 words or less, please tell us about your extraordinary individual. How old was he or she when first diagnosed? What type of CMT does the person have? How does living with CMT affect his or her ability to have a full and rewarding life? What does that person do to rise above disability and prove his or her abilities on a daily basis? What is your nominee's special expertise or quality?

Family life, community involvement, mentoring, sports, hobbies and interests will all be considered in the selection of our winners.

You can email your submission to: info@cmtausa.org or mail your entry to:

CMTA Extraordinary Person
c/o CMTA, PO Box 105,
Glenolden, PA 19036

All entries must be submitted or postmarked by midnight, September 22. Winners will be announced on the final day of Charcot-Marie-Tooth Awareness Month, September 30, and featured in the fall issue of *The CMTA Report*. This contest is sponsored by the CMTA.



CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):

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

Moderate to significant risk:

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

Uncertain or minor risk:

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

- ▶ 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 genetic research, bringing us closer to solving the CMT enigma.