

THE

CMTA Report

SPRING 2020

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TALKING TENDON TRANSFERS



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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.
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A MESSAGE FROM THE CEO



DEAR FRIENDS,

As I write this letter, the coronavirus has turned the world upside down. One thing that hasn't changed, though, is the CMTA's commitment to provide help and hope to our community.

Circumstances demand that we adapt, however, so the forms of help are going to change for a while. All CMTA branch meetings, walks and events are postponed until further notice. Check our website (www.cmtausa.org) to find out when they'll resume.

Until that happy day, we're moving operations online, including a live helpline for the CMT community, LiveLine. Staffed by volunteers who know their CMT, LiveLine is a way for community members to talk through their questions on CMT and COVID-19. The helpline will not provide medical advice but will direct people to resources and just be there for them during this time of uncertainty. The line will be staffed from 2–5 p.m. PT/Monday-Friday. The phone number is 877-4CMTFAQ (877-426-8327).

We're also launching some virtual programming for the community so that people can participate from the safety and comfort of their homes. In our first session, two leading CMT clinicians answered questions on COVID-19 and CMT. We'll be running weekly virtual programs in the areas of education, exercise and emotional well-being. Please make sure you are connected with the CMTA via Facebook to view the upcoming Facebook LIVE sessions. The link is www.facebook.com/CMTAssociation/.

Other things have not changed. Our research—and the hope for a cure—continues and you'll read in this issue about two exciting new projects we've just funded—a gene therapy project for CMT2E and a biomarkers project for CMT1B.

This issue also contains amazing stories from CMT experts explaining HNPP, tendon transfers and nerve conduction studies. And, continuing our ongoing efforts to provide tips for living with CMT, we have stories about help for hands and a newly launched Facebook Group called CMTActive. I'd like to leave you with a few words from CMTActive moderator and Houston Branch co-leader Benjy Hershorn, who says, "I truly believe the lessons learned in living with a chronic illness in general, and with CMT specifically, can help us cope with the uncertainty of the current coronavirus crisis."

All my best,

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

AMY GRAY, Chief Executive Officer

The Surgical Correction of the CMT Foot: IS SURGERY RIGHT FOR YOU?

PART 2 OF 4:

TENDON TRANSFERS

BY GLENN B. PFEFFER, MD



Dr. Pfeffer is an orthopedic foot and ankle surgeon and co-director of the CMTA's Center of Excellence at Cedars-Sinai Medical Center, Los Angeles. He is also a member of the CMTA's Advisory Board.

Welcome to the second part of our series on the surgical correction of the high-arched (cavovarus) CMT foot, focusing on tendon transfers. In part 1, I wrote about the boney surgical correction of the heel (calcaneus). Take a look at your heel. Does it twist inward? You were not born with a turned-in heel. So how did it happen? The underlying problem has to do with an imbalance of the muscles in your leg.

Some nerves are more affected than others, which is what causes some of the muscles in your leg to be relatively strong, while others are weak. The strong muscles overpower the weaker ones, which causes the foot and toes to take the abnormal twisted position so common with CMT. As a patient with CMT grows during childhood and adolescence, the uneven pull of the muscles on the developing bones can cause them to become misshapen. Hence the need to surgically correct the heel bone (calcaneus), as discussed in

part 1. Four main muscles contribute to the problem: the posterior tibial, tibialis anterior, peroneus longus and peroneus brevis. I think it is important to understand what they do normally, and what they do abnormally, with CMT. Videos on my Instagram account (@Charcotmarietoothsurgery) illustrate the difference.

First, some basic anatomy: Each muscle in the leg connects into the foot bones by a tendon, so when I talk about the pull of a tendon, I actually mean the pull of the muscle on the tendon. A tendon looks and feels like a big piece of al dente pasta. With every step, normal muscles function to balance the foot. In CMT patients, however, this balance does not exist. The imbalance that occurs between two important muscle groups causes most of the major problems. The first imbalance is between the tibialis anterior and the peroneus longus. The second is between the posterior tibial and the peroneus brevis.

The tibialis anterior is the main muscle that lifts up the foot



Figure 1:
THE TIBIALIS ANTERIOR

(figure #1). This muscle weakens early in the disease process. This is what causes foot drop, or at least diminished ability to dorsiflex at the ankle and lift the forefoot. The peroneus longus (figure #2) remains relatively strong. The peroneus longus tendon inserts on the bottom of the foot, at the base of the first metatarsal (the bone that extends from your big toe joint into the arch). The peroneus longus stabilizes the inside of your foot during weight bearing. The weak tibialis anterior and relatively strong peroneus longus cause the inside of the foot to twist downward. As the bone is pulled downward, the arch becomes higher, the foot becomes more imbalanced and a painful callus develops under the big toe joint. Look at the bottom of your foot at the base of the great toe. Many of you will have this callus, caused by the increased pressure from the abnormal position of the bone.

The second major muscle imbalance has to do with the posterior tibial tendon and the peroneus brevis (figure #3). The posterior tibial tendon connects to



Figure 2:
THE PERONEUS LONGUS



Figure 3:
THE PERONEUS BREVIS



Figure 4:
TOE EXTENSOR TENDONS

the inside of the arch and helps support it, much like a cable on a suspension bridge. Its pull is normally balanced out by the pull of the peroneus brevis tendon, which inserts on the opposite side of the middle of the foot. These two tendons are what allow the foot to move side to side and stay flat on the ground when walking. In a CMT patient, the posterior tibial stays strong compared to the peroneus brevis and causes the progressive inward turn of the foot. That's why many of you can turn your foot inward much better than you can turn it outward. The most important part of CMT cavovarus surgery is the balancing of these tendons, both to improve function and to minimize the use of braces.

If the posterior tibial tendon functions, it can be transferred from the leg to the top of the foot. This accomplishes two important things. First, it takes away the deforming force of the muscle that twists the foot inward. Second, it provides strength for the ankle to move up. This can make all the difference to someone who wants

to avoid braces or who has feet that are not sitting flat within braces. At the same surgery, if the peroneus longus is also strong enough (which is usually the case), it is transferred to the outside of the foot into the peroneus brevis. This is done by sewing the tendons together. This transfer takes away the deforming force of the peroneus longus that is pulling down the inside of the foot and creates a stabilizing force to prevent the foot from twisting inward. CMT surgery is all about taking away the strong tendons that are deforming the foot and transferring them to strengthen the weaker tendons.

A final key transfer has to do with the toe extensor tendons that run down the top of the foot (*Figure #4*). If sufficiently strong, I frequently transfer these tendons into the midfoot, at the top of the arch. The toes no longer deform

upward from over-pull of the tendon, and foot drop is minimized. Although not commonly done in the United States, I find that this transfer is often the key to a successful surgery. I am very proud that Max Michalski, MD,

my previous resident, and our CMT team at Cedars-Sinai recently won a national first place prize for our published research on this technique.

The longer the muscle imbalance is in place, the worse the deformity becomes and the harder it is to correct with surgery. Big problems start small.

The longer the muscle imbalance is in place, the worse the deformity becomes and the harder it is to correct with surgery. Big problems start small.

Even if your CMT progresses, it is important to balance the foot and minimize further deformity. Please see an orthopedic foot and ankle specialist early. ★

In Part 3 we will discuss the role of fusions.



CMTA BOARD AWARDS \$856,000 FOR CMT1B, 2E STUDIES

CMT2E GENE THERAPY COLLABORATION

The CMTA Board of Directors voted to fund a \$256,000 research project on CMT2E at its March meeting. The study is aimed at enabling development of CMT2E gene therapy by showing that it can be beneficial for this axonal form of CMT affecting motor neurons.

The project involves a new collaboration among the Ohio State University labs of Anthony Brown, PhD, Arthur Burghes, PhD, Kathrin Meyer, PhD, and W. David Arnold, MD. Several members of the team were involved in the development of gene therapy for spinal muscular atrophy from mouse models to patients.

The labs have complementary expertise in neurofilament biology, mouse genetics, gene therapy, viral vectors, neurodegenerative disease and electrophysiological assessments of neuromuscular function. CMTA Scientific Advisory Board (SAB) reviewers called the collaboration a strength of the proposal “that greatly enhances the likelihood of success.” The investigators have a history of productive collaboration and translation of preclinical studies to clinical trials.

CMT2E is caused by dominant mutations in the neurofilament protein L (*NEFL*) gene, but there are also some individuals with CMT who have recessive mutations in the same gene. According to the SAB review summary, the proposal addresses unresolved questions about the underlying mechanism for CMT2E, proposing as a unifying

hypothesis that both recessive and dominant forms of disease result from lost function of *NEFL*.

The study’s goal is to evaluate gene therapy strategies for restoring neurofilaments to diseased neurons in Type 2 mice. If the approach is successful, the preclinical studies will set the stage for obtaining approval for clinical trials.

CMT1B NATURAL HISTORY/BIOMARKERS STUDY

The Board also approved a new research project aimed at collecting natural history data and developing biomarkers for CMT1B at its March meeting.

CMT1B is caused by mutations in the myelin protein zero (*MPZ*) gene, the major protein in the myelin insulation that sheaths the nerve fiber, or axon. Over time CMT1B axons degenerate because of the abnormal *MPZ* in myelin, causing weakness, problems with balance and impaired ability to feel touch.

Multiple therapeutic strategies to treat Schwann cells—the cells that make the myelin—or to preserve axons are underway for CMT1B. These therapies are designed to slow the disease and include: Sephin1—a molecule that has been shown to help some *MPZ* mutant Schwann cells fold *MPZ* more efficiently—and inhibition of proteins called Sarm1 and HDAC6, which are both designed to minimize axonal degeneration.

Measuring disease progression, or natural history, is challenging in diseases like CMT that progress slowly, requiring clinical outcome assessments

(COA) that include neurological examinations, testing of patients’ functional ability to perform tasks, and evaluation of patient-reported questionnaires. Natural history data is lacking for CMT1B.

For clinical trials, natural history data also requires sensitive biomarkers that can show that a therapy is reaching its target and effecting change within a single year. The newly approved project aims to develop protein biomarkers, such as neurofilament L, which can be identified in blood samples, and RNA biomarkers, which can be identified in skin biopsies, that can be used to detect changes in myelinating Schwann cells using a minimally invasive technique. MRI imaging of patients’ legs will also be used because the accumulation of fat in muscles damaged by neuropathy can be measured very precisely as a measure of progression.

The National Institutes of Health recently funded a project to obtain skin and serum samples from 20 CMT1B patients for biomarker analysis, but the diversity of CMT1B presentations required additional samples. The new project will evaluate 60 patients with CMT1B over two years and recruit patients not just from Dr. Michael Shy’s clinic at the University of Iowa, but also from other sites in the Inherited Neuropathies Consortium, including leading CMT clinics in London, Milan, Rochester, New York, and at the University of Pennsylvania.

The CMTA recently secured commitments of \$600,000 from two families toward the \$601,280 cost of the project. ★

Members of the CMT2E collaboration developed gene therapy for spinal muscular atrophy.

HEREDITARY NEUROPATHY WITH LIABILITY TO PRESSURE PALSIES EXPLAINED

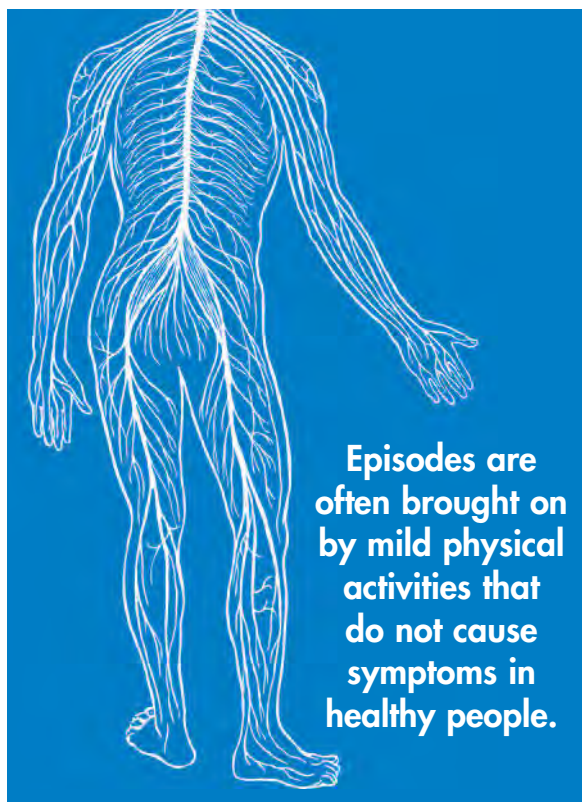
BY JUN LI, MD, PHD

Nerve tissues that reside in the skull and spinal canal make up the central nervous system (CNS). The nerve fibers outside of the CNS are collectively called peripheral nerves. When the peripheral nerves are damaged by a cause, it is called peripheral neuropathy. If the cause is a genetic mutation in a specific gene, it is called Charcot-Marie-Tooth disease (CMT). More than 100 gene mutations that cause CMT have been identified—hereditary neuropathy with liability to pressure palsies (HNPP) is one of them.

No one knows the true prevalence of HNPP patients. Genetically, it is a reciprocal disease of CMT1A, thus it should have a prevalence similar to CMT1A. However, due to the difficulties in diagnosing HNPP, the true HNPP prevalence has not been well documented.

HNPP is caused by a missing DNA segment on chromosome 17. The segment—c17p12—contains the *PMP22* gene, among others. Loss of one of the two copies of the *PMP22* gene (one from mother and one from father) is responsible for HNPP, which means that HNPP has a 50 percent chance of being passed to offspring. A small fraction of patients with HNPP may develop this mutation on their own, which is called de novo mutation, and thus would not have any family history of the disease.

While exceptions do occur, the majority of patients with HNPP develop initial symptoms around the first or second decade of life. Patients typically present with focal numbness, tingling (pins/needles) and muscular weakness in limbs. These episodes are often brought on by mild physical



Episodes are often brought on by mild physical activities that do not cause symptoms in healthy people.

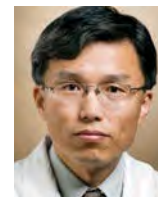
activities that do not cause symptoms in healthy people. The activities include compression from sitting with legs crossed, putting pressure on the peroneal nerve, or leaning on elbows against the ulnar nerve; repetitively doing the same movements (stereotypic movements) for a prolonged period; and over-stretching of the arms or legs. It can take anywhere from hours to months to recover from an episode. While most episodes are transient, some

patients with HNPP may experience permanent weakness. Some episodes may not have any identifiable triggers.

Peripheral nerves that go to muscles and sensory organs in the head are called cranial nerves and can also be impacted by HNPP. For instance, partial hearing loss and facial numbness have been reported by patients with HNPP. Many patients with HNPP also develop generalized symptoms such as intolerable fatigue and pain. There is a wide range in the severity of these symptoms. Life expectancy for people with HNPP is usually not affected by the disease.

Some patients may be asymptomatic, which can lead to severe limb paralysis when they participate in strenuous physical activities like running 10 miles a day with a 50-pound backpack. One asymptomatic woman developed leg paralysis after a nine-hour labor spent sitting in birthing position.

The diagnosis of HNPP can be quite challenging, due in part to many physicians' unfamiliarity with the disease. Upon physical examination, physicians may find sensation loss and muscle weakness in the hands and feet. Unlike other types of CMT, high arching feet or hammer toes are not common in patients with HNPP. An HNPP patient may be misdiagnosed with a lacunar stroke, multiple sclerosis, spinal muscular atrophy, chronic inflammatory



Dr. Li is a professor and chairman of the Department of Neurology at Wayne State University School of Medicine and Detroit Medical Center. He is a member of the CMTA's STAR Advisory Board.

(continued on page 12)



HALTS ACE-083 TRIALS

Acceleron Pharmaceuticals announced March 9 that it is discontinuing Phase 2 trials of ACE-083 in CMT patients. While the drug demonstrated an increase in muscle volume, those increases did not translate to statistically significant improvements in any of the functional or quality of life endpoints, such as muscle strength, the company said.

Habib Dable, Acceleron president and CEO, said in a statement, “Unfortunately, over the course of multiple clinical trials, our myostatin-plus hypothesis has not resulted in the functional outcomes necessary to provide clinically meaningful benefits for

patients with neuromuscular diseases.” Dable thanked all of the patients, families, caregivers and investigators for their support and participation. He also acknowledged the Acceleron team’s “hard work and commitment to executing robust Phase 2 trials that have provided us the data necessary to

Increases in muscle volume did not translate to functional improvements.

make the difficult but informed investment decision to discontinue the program.”

Acceleron plans to present results of the study at the next American Academy of Neurology Annual Meeting.

The two-part Phase 2 clinical trial was designed to evaluate ACE-083 in CMT patients with muscle weakness in the tibialis anterior (TA), a mus-

cle in the lower leg involved in ankle dorsiflexion (raising the foot at the ankle). Part 1 was an open-label, dose-escalation study, with ACE-083 administered by injection into the TA muscles of 18 patients once every three weeks to evaluate safety and increases in muscle volume over a three-month treatment period. Part 2 was a randomized, double-blind, placebo-controlled study using the optimal dose level selected in Part 1. A total of 44 patients were randomized and treated with either placebo or ACE-083 in Part 2 and were evaluated for changes in muscle volume, fat fraction, strength, function, quality of life and safety over a six-month primary treatment period, followed by a six-month open-label treatment period. ★

CMTA Advisory Board Member Clark Semmes, a participant in the ACE-083 trials, shares his feelings at their discontinuation.

I AM A LAB RAT NO MORE...



I began the clinical trial over a year ago when I received an invitation to participate from the Neurology Department at the University of Pennsylvania, where my neurologist practices. I received four injections into the lower front of each leg every three weeks for a year.

In addition to the injections, I also gave blood and urine samples, received MRIs and had my performance measured on various physical tests that included speed walking, running and my ability to maintain my balance. I will not lie, the travel was frequently grueling and the running and speed walking often left me sore and depleted, but the staff administering the clinical trial could not have been nicer or more accommodating.

While I was disappointed to hear the news that the drug was ineffectual and the clinical trial was ending, I have to admit I was not completely surprised. Neither I, nor a handful of friends with CMT who were also in the trial, felt as though the injections we received were making any life-changing impact. As my friend and fellow participant Angela Cretekos Dethloff said, “Kudos to all of us for trying: lab rats, doctors, staff and even partners. We have to continue our search and efforts on something else.”

As we texted one another following the announcement, there was one emotion that we all felt and expressed, and that was pride. I think I speak for all of us when I say I am proud to have taken part in this clinical trial. I am proud to have volunteered my bent, but not broken, body in the name of science. I am proud to have stepped forward in the effort to find a treatment for CMT. I am proud to have been a CMT lab rat. I would do it all again in a heartbeat.

I think it is important to remember that delay does not mean defeat. This was just one of the CMTA’s many research projects. While this effort may not have hit pay dirt, we will, one day, find the gold mine. In the words of the late Senator Edward Kennedy, “The work goes on, the cause endures, the hope still lives, and the dream shall never die.”



CMT Quilt Still Traveling

BY JOHN RAMOS, CO-LEADER OF CMTA'S LOS ANGELES BRANCH

Six years after Angela Beaumont conceived the idea, the CMT Traveling Quilt is still on the move, collecting signatures from CMTers and raising awareness about the disease around the world.

Angela, past leader of the Vidor, Texas, Branch started the project because she wanted a new quilt for her bed, but as she was finishing the top she ran across the idea of a signature quilt while watching TED Travels. She wondered what the response to a CMT quilt would be. She quickly found out—75 people joined the quilt’s Facebook group the day she started it. As one Facebook friend put it: “There are definitely some days where I just want to wrap myself up in a quilt and cover all the places that hurt. Then there are the days when my friends and family are the comfort I need. This project combines the two.”

In the five years since Angela finished the quilt, it has traveled more than 100,000 miles to 35 states, 300 cities and four different countries. It has been to many CMTA branch meetings, Walks 4 CMT nationwide, Patient/Family Conferences and even Camp Footprint. The seasoned traveler has visited cities and towns across the United States, including Houston, Philadelphia, Seattle, Denver, New York City, Miami, Chicago, Baltimore, Los Angeles and Las Vegas. It has also winged its way across oceans to places as far as Glasgow, Scotland; London, England; and Sydney, Brisbane and Melbourne, Australia. Its picture has been taken in front of landmarks as varied as the Sydney Opera House, the Liberty Bell and the battleship New Jersey.

In the last few years, the quilt’s travels have been limited to branch meetings and CMTA walks. The quilt currently has 621



CMTA Quilt visits the Liberty Bell.

signatures out of a total of 1,500 triangles. Some of the triangles have as many as three signatures, leaving lots of open spaces. If your CMTA branch would like the quilt at an event, please contact john.cmtalabbranch@gmail.com or join My CMT Traveling Quilt Project/Facebook. Once the top is fully signed, it will be auctioned off, with all proceeds going to benefit the CMTA. ★

QA ASK AN EXPERT

I'm confused about the difference between electromyograms (EMG) and nerve conduction studies (NCS)—can you please explain?



Dr. Lewis is the co-director of the Inherited Neuropathy Clinic and the director of the EMG Laboratory and of the Clinical Specialty Clinic at Cedars-Sinai Medical Center in Los Angeles. He is currently on the Steering Committee of the Inflammatory Neuropathy Consortium.

Dr. Richard A. Lewis answers:

EMG, which stands for electromyogram (“myo” = muscle), is the term used for electrodiagnostic tests (EDX) for neuromuscular disorders. The total EDX includes both nerve conduction studies (NCS) and needle EMG. Depending on the clinical question, one or both parts of the test may be conducted.

For CMTers, the most important component is the NCS, which determines whether a person has a neuropathy and whether it involves sensory nerves, motor nerves or both. If the disorder just involves motor nerves, it's Hereditary Motor Neuropathy (HMN); if sensory, Hereditary Sensory Neuropathy (HSN); and if both Hereditary Motor/Sensory Neuropathy (HMSN). HMSN is the primary disorder that comprises CMT.

Sensory nerves usually only require one stimulation point—the wrist (sometimes the finger) or ankle and recording over the nerve a short distance away. The sensory velocity is determined by the time it takes for the signal to reach the recording electrode (latency) divided into the distance between stimulating and recording site (see box, item A).



EMG Test (above) and NCS Testing (below)



To determine motor nerve conduction velocity, it is necessary to stimulate the nerve at two locations: In the arm, the two stimulation sites are the wrist and the elbow. In the leg, they are the ankle and knee. The motor nerve velocity in the arm is determined by subtracting the latency of wrist stimulation from the latency on elbow stimulation. Dividing that nerve latency into the distance from wrist to elbow determines the motor nerve conduction velocity (see box, item B).

The amplitude of the response indicates whether the nerve fibers are functioning; a low amplitude

suggests that many have stopped. The velocity determines whether the disorder primarily affects the myelin and Schwann cells or the axon. The disorders that comprise CMT1 are characterized by very slow velocities and are due to mutations of genes that form myelin. CMT2 has more normal velocities but very low amplitudes and are disorders of the axon. Normal nerves conduct at ~ 50 meters/second (m/sec). CMT1A usually has nerve velocities around 20 m/sec. There is a somewhat arbitrary cut-off of 38 m/sec for motor nerve conduction in the median or ulnar nerve of the forearm that determines CMT1 or CMT2. CMTX is considered intermediate with velocities between 30 and 40 m/sec.

The EMG portion of the test, which involves the insertion of fine needles in the muscle, can determine if there is nerve damage to the muscle not identified by the nerve conduction tests. This can

A FEW SAMPLE CALCULATIONS:

A) MEDIAN SENSORY VELOCITY:

15 cm from wrist to finger divided by 3 millisecond (msec) latency = 50 meters/second velocity

B) MEDIAN MOTOR NERVE CONDUCTION VELOCITY

Latency from elbow (e.g. 8 msec) minus latency from wrist (3 msec) divided into the distance from elbow to wrist (30 cm) = 60 meters/second

be particularly helpful in HMN and can determine if there is any muscle involvement in HSN. EMG can evaluate muscles that are more proximal—above the knees and elbows—which are not easily tested with NCS. This can be helpful, but rarely allows a diagnosis of CMT. Because it is not always necessary for the EMG portion of the EDX to be done, the decision should be discussed with the treating doctor and electromyographer.

Electrodiagnostic studies are not risky or dangerous and do not cause problems afterward, but they can be uncomfortable. The NCS requires electrical stimulation, which is very brief but can be painful. Some CMTers have nerves that are difficult to stimulate, which can require higher amounts of stimulation. This may be painful, but the pain lasts a

fraction of a second. It's best if the patient can allow testing of at least one motor and one sensory nerve even if it's uncomfortable. Sensory nerves need less stimulation than motor nerves and are less painful. For CMTers, studies of the arms may provide more information than the legs, but each case is different. Relaxation techniques can help reduce anxiety and pain.

The needles used in EMG are very thin and sharp. They are disposable, so there is virtually no risk of infection. They are thinner than the needles used for drawing blood and there is minimal risk of bleeding even if one is on aspirin. Anyone on a blood thinner should bring it to the electromyographer's attention, but most muscles can be tested even if the patient is taking Coumadin or other major blood thinners. For most patients, the needle examination is only

mildly uncomfortable, but for some, particularly patients with aversion to any needles, the needle examination can be painful. The good news is that if needle studies are done, there shouldn't be the need to study many muscles.

NCS and EMG can be performed at any age, including infancy, but with children, the examination has to be modified to account for their size and inability to fully cooperate during the study. The 38 m/sec velocity that distinguishes CMT 1 and 2 cannot be used under the age of 2. The examination in young children is usually brief and sedation is not normally necessary. If a child is from a family with known CMT that has been diagnosed genetically, then EDX may not be needed. If the child is symptomatic, there may not be a need for any testing. ★

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- Wendy, Oregon.



HNPP

(continued from page 7)

demyelinating polyneuropathy (CIDP) or idiopathic axonal polyneuropathy, among others. A high index of suspicion is often needed to reach the diagnosis in patients with episodes of focal sensory loss or weakness.

An electromyogram/nerve conduction study (EMG/NCS) is an important diagnostic tool for HNPP (*see related article p. 10*). It shows changes in areas where peripheral nerves are exposed to mechanical pressure, such as the ulnar nerve at the elbow or median nerve at the wrist. This finding should prompt physicians to perform DNA testing.

DNA testing allows physicians to reach a definitive diagnosis. It should be noted that unlike the majority of lab tests, which use blood samples from a red-top tube, blood samples for DNA testing should be collected in a purple-top tube that contains a chemical to prevent the blood from clotting. This is necessary for DNA extraction. If a red-top tube is mistakenly used, clotted samples will be rejected by the lab and the patient may have to return to the clinic for another blood draw.

The HNPP mutation is usually tested using a technique called multiplex PCR. In rare cases, this technique may not detect the mutation. If the clinical suspicion is strong, alternative techniques would have to be used to clarify the diagnosis. In a few reported cases, the patient's HNPP was not caused by a missing copy of the *PMP22* gene, but by an altered DNA sequence in the *PMP22* gene that multiplex PCR cannot detect, but DNA sequencing can.

There is currently no cure for HNPP and clinical management mainly aims to alleviate symptoms

and optimize quality of life. We advise HNPP patients to avoid the physical activities (compression, prolonged stereotypic movements and over-stretching) that may bring on symptoms. However, we do not advocate a sedentary lifestyle since this may lead to obesity and metabolic problems. Thus, activities should be tailored for individuals to have adequate exercise without triggering nerve symptoms.

Many patients with HNPP complain of pain, whether focal symptoms are present or not. Those with true neuropathic pain (sharp, burning, tingling, highly sensitive to touch) tend to be responsive to treatments. Others may not exhibit features of neuropathic pain and the pain may be difficult to control. Physicians may have to seek additional factors contributing to the pain, such as inadequate ankle braces causing overuse of leg muscles, etc.

On the medication front, severe side-effects have been reported in patients with CMT1A who took Vincristine and developed limb paralysis. This is a difficult subject to study in patients with HNPP due to ethical issues. However, an HNPP animal model shows slower recovery from nerve damage. We believe that patients with HNPP should be carefully monitored for side-effects when they receive any new medications.

We are not aware of any specific dietary restrictions for HNPP patients. A high dose of vitamin C has been shown to reduce PMP22 levels. We recommend that HNPP patients avoid consuming high doses of vitamin C. However, we do not see any problems with a regular dose (75-90mg daily) of vitamin C. This issue needs to be further investigated in carefully designed studies. ★

This past January, the CMTA rolled out CMTActive™, a new Facebook group aimed at encouraging, inspiring and cheering members on to fight CMT through movement.

As moderator Benjy Hershorn explains, "Being CMTActive is a lifestyle and a mindset. CMTActive means taking small steps each day to better your physical health. CMTActive means finding and adapting the sports and activities that you love, cherishing your body and giving it the support and care it deserves to take control over CMT." Other moderators include Julie Glover Barnett, Julie Stone, Leslie Nagel, Elizabeth Ouellette and contributor Bethany Noelle Meloche.

The group welcomes participation, tips and guidance from a wide range of participants, from beginners to experienced fitness enthusiasts, with one common goal—to keep moving. CMTActive content includes a growing library of videos that demonstrate movement and exercise that can be done at home! In just over a month, CMTActive exploded to 800+ members.

Technology and the social network allow CMTActive to engage with group members who live all over the world, something that's much needed at a time when everyone has to stay at home and practice social distancing.

Benjy said he truly believes that "The lessons learned in living with a chronic illness in general, and with CMT specifically, can help us cope with the uncertainty of the current coronavirus crisis." He says he is "clear-eyed AND concerned," and that he remains optimistic and ready to give support and encouragement to those who are in need.

CMT **ACTIVE** ON THE MOVE

FROM THE NEW FACEBOOK PAGE:

Here is a sample of group member's comments and answers to moderators' questions:

How do you motivate yourself to be active and exercise regularly?

- I think CMT IS my motivator. If I didn't have CMT I don't know if I'd be as active as I am. Because of CMT I'm hyper aware of what's happening to my body and what will happen over time. As a result, I'm super motivated to stay active and make sure my body is as strong as it can be. In many ways being active and exercising has become a personal passion because of my CMT.
- Just ran a short mile race. Running is becoming a big part of my fitness and CMTActive journey while I still can! Second-to-last in my age group, so not last! Regardless, it's important to me to keep pushing myself.
- I am a professional horse trainer and a PATH International Certified Therapeutic Riding Instructor. I started my own self study of CMT and I'm trying to develop a program using horsemanship to exercise/strengthen the muscles affected by CMT."
- By "listening" to others we learn so much—support and encouragement is powerful medicine—keep MOVING!
- This group helps me keep my positive attitude! Seeing other people coping with CMT shows me that I am not alone! I know I have to wear AFOs, and carry a walking stick, but there are things I can still do!
- CMT = Courage, Motivation & Tenacity. I believe you have to have the courage, motivation and tenacity to keep moving forward and not let the challenges in life, including those of CMT, stop you from your passion.

By "listening" to others we learn so much—support and encouragement is powerful medicine—keep MOVING!

Who has a routine to walk their dog (or pet) to stay CMTActive?

- I have not walked my dogs on my feet for years. I now walk my service dog using my power wheelchair. Every day, twice a day—morning and evening—she insists!

What activities do you enjoy the most? Trying to see what everyone does to stay healthy and strong.

- "G'day! At 69 many of my activities have been reduced but I still continue with regular trail horse riding in the bush (which requires daily ground activity to keep my horse fed, clean and healthy).
- Lots of distance wheeling in my manual wheelchair, which provides 90 percent of my mobility—100 percent when working, shopping, etc.
- Can still crawl around a campsite to put up my tent, cook a meal, etc.
- Playing physical games with my ten grandchildren (ages 2 to 19).
- I do go to the gym and use non-weight-bearing machines to maintain strength in arms and legs but find it boring (weight and strength resistance, no aerobic).
- Hands/fingers strength loss and reduced fine motor skills present many barriers that continually require lots of individual and changing solutions to maintain activities.

Anyone here into gardening? What tactics/tools do you use to make it more comfortable to use your green thumb?

- Great question! I now container garden almost entirely. I love daylilies and they are in the ground. I have a beautiful raised bed my wife gave me. I grow vegetables and flowers in it. I grow annuals in pots of various sizes.



All CMTers are invited to join the conversation at www.facebook.com/groups/cmtactive/

ADAPTING TO CHANGE: From Weight Training to Yoga

BY JEFF SEITZER



Jeff Seitzer, 61, teaches at Roosevelt University in Chicago and is author of a memoir, *The Fun Master* (forthcoming), among many other works.

People say that the one constant in life is change. For me, the one constant is and always has been cycling. My love of the sport never wanes. But when a major muscle imbalance caused by overtraining left me not just in pain, but almost unable to stand, I knew I would have to adapt.

I use a sturdy older bike for errands and for getting around my Chicago neighborhood. When I ride longer distances, down the lakefront trail or across town, I am pedaling a newer, sleeker hybrid bike. I even have a nifty foldable bike I throw in the trunk and use on trips, for example, while visiting the CMT Clinic in hilly Iowa City.

This is good, right, all this exercise? The adverse health consequences of a sedentary lifestyle are well-established. For a CMT sufferer like me, though, it comes with a big asterisk. Cycling primarily uses the large muscles of the upper thighs—the quadriceps and hamstrings—while CMT works its dark magic on the muscles of my feet and ankles. I have

CMTX, which tends to be more severe in males, but I am fortunate to have very mild symptoms and decent muscle mass and tone in my calves, feet and ankles. I am highly motivated to keep those muscles as strong and flexible as possible.

I made a painful discovery when a freak Halloween blizzard finally forced me off my bike. Walking to the train and around the neighborhood made it clear that I had a major muscle imbalance. Walking uses a wider range of muscles than biking. Besides the calf muscles, walking also works the muscles of the buttocks and stomach, as well as the pelvic stabilizer muscles, such as the adductors and the muscles of the abdomen and the back.

Finally, and here is the kicker for CMT sufferers, it uses the symmetrical tibialis anterior muscles in the front of the calves essential for lifting the feet.

I resumed my troubled relationship with weight training to correct the imbalance. Very quickly I was reminded why lower body weight work is the one form of exercise I don't do regularly. For me, calf exercises in any



Jeff Seitzer practices yoga at home.

form—against a wall, on a machine, in a bridge position, or even with a Pilates ring—always produce muscle strain. This time around was worse, though. I also hyperextended the fascia on my insteps, making it hard to stand without shoes, a startling change for me.

In despair, I thought of just giving up. Since this problem came on rather suddenly, however, I thought it must be correctible. I experimented with two changes in my conditioning program. First, I tried a new approach to calf exercises. I use two yoga blocks, one cork and one foam. The cork block is very firm and a bit smaller than the foam one (Photo A). With the balls of my feet on the cork block, I rest my heels on the foam one positioned just behind it (Photo B). I raise my heels a little (Photo C) and lower them very slowly onto the foam block, which gives a little as the heels come to rest on it. Coming down onto the foam block corrects the big flaw in calf exercises for me—the lack of

WE'RE LOOKING FOR A FEW GOOD MEN!

The CMTA needs male counselors for Camp Footprint this summer.

Calling all caring and spirited men to spend a week leading our amazing campers.

For more information contact National Youth Programs Manager Jonah Berger. jonah@cmtausa.org

CAMP FOOTPRINT

Dates: August 8-15, 2020

Location: YMCA camp Kon-O-Kwee Spencer Fombell, PA

See what Camp Footprint is all about at cmtacamp.org



control in returning my feet to the starting point.

The other change involved my daily stretching regimen. The twisting and turning of my feet throws my whole body out of alignment. Yoga generally—and the triangle and half-moon poses in particular—helps me coax everything from my feet to my hips and buttocks back into proper position. In this weakened state, though, my yoga practice was accentuating the hyperextension of the fascia in my ankles. So, I stopped going to classes and began a full yoga practice at home in my SMOs (supra-malleolar orthoses), which support the leg just above the ankle bones. Stretching while wearing the SMOs enables me to do the full poses without further aggravating the hyperextension of the fascia.

The program is working. I am pain free and standing well after only a month. My annual visit to the CMT clinic in Iowa City in February confirmed that my ankles are stronger than they were at my previous visit last May. ★

CosySoles Heated Slippers Warm Feet and Hearts

BY AMANDA KOTACK

My dad, Allan Kotack, had no intention of starting a business 25 years ago. His only concern was finding a solution to the problem closest to his heart—my mother's CMT.

Back then, their only solution was to immerse her feet in hot water, which restricted her in many ways. Determined to develop a product that was warm and comfortable and allowed for mobility, Dad single-handedly stitched the very first pair of CosySoles. The microwave-heated, grain-filled booties provide a direct heat source and enclose the entire surface of the foot, providing a more efficient heat distribution. The slippers are designed to allow the freedom to walk around without losing the heat source.

The slippers were life-changing for my mom, Patricia Kotack, and before long our parents realized that CosySoles could help others. The discovery of a wide array of disorders that caused cold feet led to the decision to share the warmth of CosySoles with the rest of the world.

In 2009, my whole family appeared on Canadian Broadcasting Company's *Dragon's Den*, which led to further exposure and an investment deal with Brett Wilson. The response from the episode was amazing and we were grateful, humbled and thrilled with the resulting increase in demand.

Our parents kept the business going strong for years. It became a true passion into which they poured their hearts and souls. My siblings and I witnessed their tireless dedication to manufacture and market a high-quality therapeutic product that would have a major impact on many lives.

Sadly, Dad passed away in 2013 after battling and eventually losing to cancer. This unimaginable loss left our family in despair. There is no recovering from this loss, but after some time, it is the moments of light and the memories of our Dad that help us stay strong.

The torch has now been passed along to us "kids." After years of pursuing our own careers and experiencing the ups and downs of life, we're ready to spread the warmth a little further. We hold with us the lessons and qualities of our Dad and remain humble to where we began. We remain true to creating a quality Canadian-made product that helps warm the soles and the soul. ★



CosySoles is a proud supporter of CMTA and donates 50 cents for every pair of CosySoles sold to the organization. In addition, the company is offering 10 percent off to readers of *The CMTA Report* (enter code CMTA at checkout on www.cosysoles.com).

The Kotack family—Jordan, Amanda, Patricia and Melissa



TEE OFF FOR CMT

2nd Annual CMTA
Golf Tournament
SEPTEMBER 28, 2020

The Elkridge Club,
6100 N Charles St., Baltimore, MD 21212



*Hosted by Steve O'Connell,
SVP & Treasurer, Navient
and Steve O'Donnell, CMTA
Board Member*

Join us for a fun-filled day of golf, fun and laughs while contributing to research for the Charcot-Marie-Tooth Organization.

Cocktail and Heavy Hors d'Oeuvres Reception, Auction & Awards immediately following golf

*For more information, contact:
Steve O'Connell at steve.connell@navient.com or
Steve O'Donnell at steve@stevenfodonnellinc.com*

SIGN UP NOW AT: www.cmtausa.org/tee4cmt

LET'S HAVE SOME FUN.

WHILE RAISING CRITICAL FUNDS FOR CMT RESEARCH.



SWIMBIKEWALK

JUNE 6, 2020

The 6th Annual FUNATHLON consists of a **one-mile swim** across the Tred Avon River, and/or a **20-mile bike ride** and/or a **walk in beautiful downtown Oxford, MD**, followed by **lunch at Capsize** for their award-winning crab cakes.

Please join us for any or all of the events!

WHEN: Saturday, June 6, 2020, 7:30 am start.

CHECK IN: Oxford Ferry Parking Lot - (Next to the Robert Morris Inn, 314 N Morris St, Oxford, MD 21654).

WHY: To raise money for research to help cure Charcot-Marie-Tooth disease.

REGISTER/DONATE AT: cmtausa.org/funathlon

MAIL DONATIONS TO: CMTA, PO Box 105, Glenolden, PA 19036

Your continued support in helping find a cure for CMT is greatly appreciated!

Steve O'Donnell & Clark Semmes



BRANCH LEADER PROFILE: Jeannie Zibrida, Atlanta

In conversation, Atlanta Branch Leader Jeannie Zibrida seems more like a bright and lively teenager than a retiree with CMT who had a recent ankle fusion. She speaks in excited bursts and seems to know everyone and everything going on in the CMT community.

Jeannie grew up on the south side of Chicago and is convinced this makes her a “southern girl.”

At 15 she moved with her family to Saint Petersburg, Florida, cementing her claim to a southern heritage. She went to grad school at Emory where she studied nutrition and then became a registered dietitian. Later she went into medical sales.

When Jeannie was first diagnosed in 1985, technicians actually stuck a needle into your big toe when doing an EMG/NCS. She recalls it being quite painful. She wasn't surprised by her diagnosis because her father had recently been diagnosed. Genetic testing confirmed

her CMT1A in 1986. Looking back, she now realizes her CMT was the reason she couldn't ride a bicycle until the fourth grade. Jeannie also has an aunt and a brother with CMT1A. She was a participant in the Vitamin C trial, one of the first studies to investigate a drug treatment for CMT.

A member of the Atlanta Branch since its first meeting, Jeannie took the helm in 2018.

Jeannie grew up on the south side of Chicago and is convinced this makes her a “southern girl.”

The branch currently has an email list of 150 people, 113 people on its Facebook page, and 15 to 20 people regularly attend meetings.

At one memorable meeting, noted foot surgeon Dr. Glenn Pfeiffer (*see related article p. 4*) spoke

for an hour and then spent two hours evaluating attendees. The branch meets at Saint Martin's Episcopal Church in Atlanta because of its central location.

Jeannie began wearing orthotics in her 30s, then 12 years ago she started wearing an AFO on one foot. She had an ankle fusion in November 2019

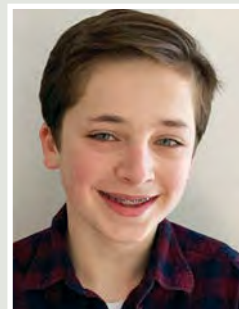


and is currently wearing a boot, which she admits slows her down a bit. Knee replacement also may be coming soon. But despite these setbacks, Jeannie remains incredibly upbeat and positive. She is proud that Atlanta hosted a Parent/Family Conference recently, and she looks forward to the branch's next Walk 4 CMT.

Jeannie and her husband, Alan Segrave, live on Lake Lanier and love to travel. Jeannie also loves to walk and hike with her golden retriever Dash, who takes part in all Walks 4 CMT. She is passionate about helping the CMTA in finding a cure and creating a world without CMT. ★

YOUNGEST-EVER ADVISORY BOARD MEMBER APPOINTED

Evan Zeltsar, 14, became the youngest-ever member of the CMTA's Advisory Board in January. Evan, a student at Masconomet High School in Boxford, Massachusetts, is a CMTA Youth Council member, four-time CMTA Camp Footprint attendee and Boston Walk 4 CMT Ambassador. Evan, who has CMT1A, is an enthusiastic advocate for youth, aiming to show them how to “live with CMT rather than have CMT.” He hopes to bring the unique perspective of the CMT youth community to the Advisory Board. In his free time, Evan enjoys skiing, playing the clarinet and saxophone in his school band and annoying his older brother.



Community Members Offer HELPING HANDS

CMTers all have tips. They are gained through hard-won experience and passed along like family treasures. They are shared at branch meetings, patient/family conferences and fundraising events. Some are merely helpful; others are life-changing. These nuggets of wisdom help those of us with CMT get through our lives and accomplish our goals with as little unnecessary friction as possible.

In 2016, the CMTA published *101 Tips for Living with CMT*. Community members kept sending the CMTA tips, even after publication. Here we share a few hand-related tips:

TIP: Take Care of Your Hands

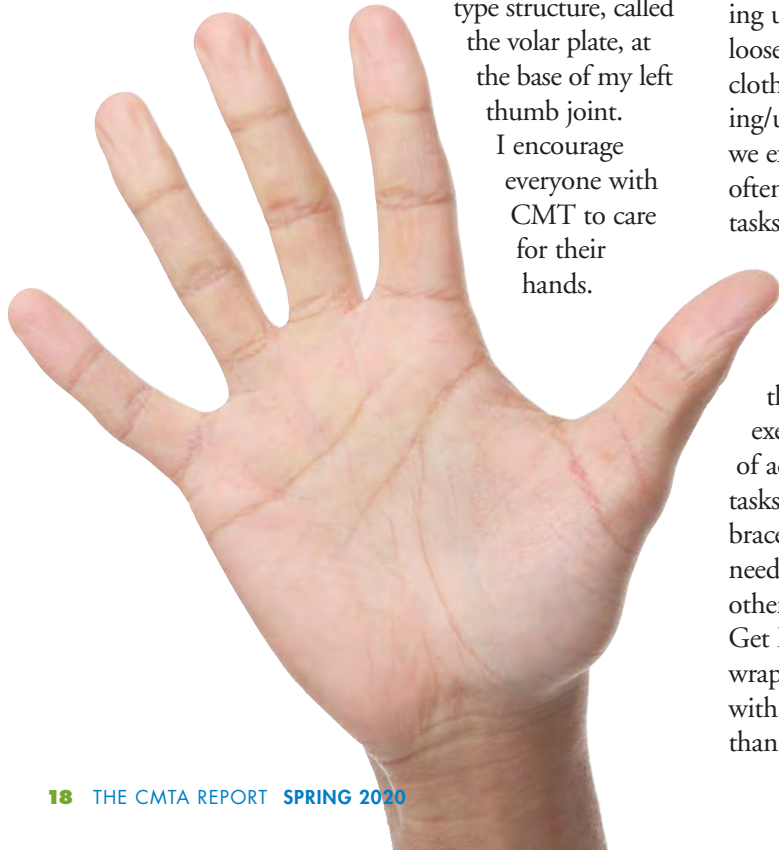
By Lisa Weiner

Hand pain, weakness and fine motor deficiencies progressively worsen with CMT.

After experiencing sharp thumb pain while doing my regular Theraband exercises, I consulted with a Stanford orthopedic hand surgeon. She diagnosed a ruptured ligament

type structure, called the volar plate, at the base of my left thumb joint.

I encourage everyone with CMT to care for their hands.



Work with a physical therapist, occupational therapist or athletic trainer for proper form when exercising/working out. This can include how you hold/grip hand weights and proper hand/finger/thumb placement when using sports/strength training equipment like Therabands, Pilates straps or lateral pull down bars. Participate in yoga classes by a certified yoga instructor who can teach proper hand placement during various yoga poses. Common yoga postures, like downward facing dog, place intense pressure on hand flexion.

Yes, most of us struggle with fine motor tasks, including picking up/holding credit cards or loose change, buttoning or zipping clothes, handwriting, and holding/using eating utensils. And yes, we experience hand weakness, often utilizing adaptive aids for tasks like opening jars and bottles.

Occupational hand therapists not only possess expertise in recommending specific adaptive equipment, they teach hand strengthening exercises and alternate methods of accomplishing daily living tasks. Employ hand and wrist braces or custom splints, if needed, when doing chores or other excessive hand use activities. Get hand massages and paraffin wraps, and keep hands hydrated with lotion or oil. Your hands will thank you for it.



TIP: Try Liftware

By Brian Bourgault

I survived the first 33 years of life without ever knowing that I had CMT. In 2003, I began losing strength in my hands and when I finally went to see a neurologist in 2005, I was diagnosed with CMT. The progression from 2005 to present has been rapid and severe. I have lost use of my left hand completely, and can move only the ring and middle fingers on my right hand. I also have extreme weakness in both arms and shoulders. Preparing and eating meals has become the most difficult task in my daily life. Unable to grip utensils and barely strong enough to move food from the plate to my mouth, I developed a technique of standing up to eat so I can bend over the plate, moving my mouth to the food.

As you can imagine, this made eating out rather impossible until I discovered Liftware (www.liftware.com) in November 2016 and quickly ordered the Level starter kit. My Liftware

THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS...

straps onto my hand and the utensil, fork or spoon, stays level no matter how my hand twists on its journey from plate to mouth. How is this possible? The rechargeable handle has sensors and a motor that quickly adjust the utensil to your hand movements. It is a very high-quality piece of equipment with a user-friendly design that takes no time to get used to. If you struggle with gripping utensils, I give Liftware my highest recommendation and hope you find it as useful as I have.

TIP: Empty Nail Polish Bottle Makes a Great Pencil Holder

By Madison Waters

I am 15 years old. I live in Nova Scotia and have CMT1X. I have trouble holding a regular pencil so I decided to create something to make it easier. I looked around my bedroom at everyday materials and decided that my nail polish bottle had a shape easy to hold. I put some glue in the bottom of the empty bottle and inserted a short pencil. I kept my pencil short for easier writing. The opening of the bottle is a perfect width for a pencil and the container has a nice weight! I let it dry and the finished product was an easy-to-hold pencil grip. Since making my first one, I have made others in different colors and shapes. ★



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Ms. Jeannie Reed

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Ms. Dawn Mehanna

KEN TROUT
Ms. Susan Wingate

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THE WONDERFUL VOLUNTEERS AND EMPLOYEES OF THE CMTA
Mr. Steven Khosrova



CMTA BRANCH NEWS

ANTELOPE VALLEY, CA

The Antelope Valley Branch, led by Donna Murphy and Danielle Metzger, welcomed the CMT Traveling Quilt to its first meeting of the year. Created by former Branch Leader Angela Beaumont from Texas, the quilt has traveled to many CMTA branch meetings and events in the last five years (see related story p. 9). Branch leaders who would like a visit from the quilt can email Los Angeles Branch Leader John Ramos at john.cmtalabbranch@gmail.com. The Los Angeles and Antelope Valley branches are looking into the possibility of a joint meeting in August.



Antelope Valley

TAMPA BAY AREA, FL

The Tampa Bay Area Branch, led by Sarah Gentry and Ed Linde, had its first meeting of 2020 on February 15 with 15 attendees, both new and familiar. The group worked on branch plans for the year, including the group's 6th Annual Tampa Bay Walk 4 CMT, set for November 14. The group also discussed future meeting topics and speakers,

including: filing for disability/ADA rights, mobility adaptations/hand controls/Florida licensing requirements, Medicare and health insurance, staying active with seated yoga and a family fun bowling day.

BOSTON, MA

The Boston Branch, led by Jill Ricci and Mimi Works, had its first meeting of the year on January 8 with 15 people in attendance. Members viewed the STAR research webinar, which explains the CMTA's incredible research projects. The webinar is available on the CMTA's website. The Findlay family presented a donation check to the Boston CMTA Branch for their 2019 fundraiser held



Boston

during September Awareness Month with the hashtag #FightForAubriElla.

LAS VEGAS, NV

Ten people came out for the Las Vegas Branch's first meeting of the year on January 18, led by Martha Boadt. Guest speaker Dave Kovach, the owner of Evolve Prosthetics, talked about the best orthotic and bracing options. His knowledge of CMT is amazing, and he goes way beyond in making and ordering braces that are just right for each individual.

NEW MEXICO

The New Mexico CMTA Branch, led by Gary Shepard, met on February 8, with 15 in attendance. They welcomed guest speaker Kevin Matthews, an orthotist and brace designer from San Antonio with 37 years of experience working with clients who have CMT, and watched a video he made about gaits and how they affect brace design (www.youtube.com/watch?v=kzQJDHoHVJo). After the video Kevin answered questions via Skype from the audience. The group then discussed the successes and failures of various types of braces. The bottom line was that each person with CMT is different and these differences can affect what type of brace is appropriate. Some members have different types of braces for different activities. In New Mexico, members particularly like the Orthotics Department at Carrie Tingley Hospital and Advanced Prosthetics and Orthotics, both in Albuquerque.

ALBANY, NY

The newly named and revived Albany CMTA Branch gathered on February 22 for its first meeting of the year with 18 members in attendance. Branch leader Cara Leath welcomed everyone, shared her CMT story and talked about why she wanted to start the branch. Many original members from the Upstate NY Branch attended. Group members brainstormed ideas for events and meetings, including an orthotics show-and-tell and watching CMTA webinars as a group.

WESTCHESTER, NY

The Westchester, NY Branch, led by Beverly and Frank Wurzel, held its first meeting their 2020 on March 7 with 16 very enthusiastic people sharing stories about the challenges of living with CMT. An anesthesiologist in attendance stressed that "Anyone with CMT expecting to have surgery must let their anesthesiologist know that they have a neuromuscular disease." Group members also had a discussion on how food affects health and discussed plans for their 2020 CMTA fundraiser, which will be held on October 25 at the Tarrytown Hilton, Tarrytown, NY.



Westchester

ALL WE NEED IS YOU!

Led by CMTA volunteers, the CMTA's national Walk 4 CMT campaign provides multiple opportunities to raise awareness and funds to improve the lives of those living with CMT. Join thousands of people across the country by visiting Walk4CMT.org to find an event near you.

If there is no walk near you, consider starting your own—we'll help.

Funds raised by the Walk 4 CMT campaign help to support the CMTA's mission of finding treatments and, ultimately, a cure for CMT.





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

Dear David,

I am a 64-year-old woman and have been married to my husband for almost 40 years. Although we have our problems, like everyone else, it's a good marriage in many ways. My CMT has progressed but I still try to lead a full life with help from my braces and a cane when necessary. My husband has always been sensitive to my physical issues and does more than his share around the house. My problem is that I find myself increasingly scared that something will happen to him and I will be lost without him, both physically and emotionally. Every time he has a cold I imagine him dying, when in truth he is in good shape for a man his age. I know that I'm overreacting, but my fears about his health are beginning to annoy him. I just can't imagine getting along without him and I find myself in a constant state of anxiety.

David replies:

While it is true that a long-term marriage can create a natural feeling of dependency on one's spouse, having a condition like CMT or any other chronic illness can exacerbate feelings of vulnera-

bility, especially as we age. There is a difference between the occasional fear of one's spouse dying and being left alone, and being totally obsessed and panicked every time he sneezes. Feelings of healthy dependency are a part of loving someone and are something we all experience, but overwhelming fear can come from a lifetime of living with some limitations that can lead to feelings of fragility and helplessness. Being able to share these feelings with your husband or a therapist may help you gain perspective. Many people have fears of abandonment even under normal circumstances.

You are not as helpless as you might feel, and it's important to find a balance between allowing help from your husband and doing things without his help. Our self-esteem grows when we can accomplish things on our own. I know I have been guilty of allowing my spouse to do things for me when I have been very capable but lazy. I might do things more slowly, but I can still get them done.

When we feel vulnerable it can touch very powerful feelings

of abandonment from childhood. It's helpful to be aware of these old fears, which can easily be triggered by present-day events. While it's not necessary to probe these old fears with a therapist, be aware that they exist, especially when you have an overreaction like freaking out when your husband has a cold. Being able to put a name to what you're feeling, like anxiety or fear, helps put a little distance between you and what you are feeling. In other words, you can have a feeling instead of becoming the feeling.

In addition, it's always a good idea not to isolate yourself and to stay connected to others outside your marriage. It takes a little extra work to stay connected to people other than your husband, but it will help you feel less dependent on him. Loving someone always entails some fears of loss and dependency, but try not to lose your identity in your marriage simply because of challenges with CMT. We are whole regardless of our physical limitations and have much to offer others as well. Stay strong and stay involved with life. ★



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. "My CMT has been my greatest challenge and my best teacher in life," says David.

Donate and support the CMTA in the fight against the progressive and devastating effects of CMT

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Check enclosed, payable to the Charcot-Marie-Tooth Association. Donate online at www.cmtausa.org/donate

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City _____ State _____ Zip _____ Phone _____

I am making this donation in honor or in memory of (name): _____

Please send me CMTA updates via email at: _____

To give a gift of stock or learn about leaving a legacy gift to the CMTA, please call or email Jeana Sweeney, 800-606-2682 x106 / jeana@cmtausa.org.



NEW CMTA CENTER OF EXCELLENCE AT UCSF

Pediatric neurologist Alex Fay, MD, PhD, heads the CMTA's newest Center of Excellence at the University of California San Francisco. Jonathan Strober started the multidisciplinary pediatric neuromuscular clinic at UCSF in 1999, and it includes pulmonology, cardiology, physical and occupational therapy, respiratory therapy and social work in one location, as well as collaboration with experienced colleagues in orthopedics, neurosurgery and physiatry.

The neuromuscular clinic at UCSF-Mission Bay is pediatrics focused, and staffed by Drs. Strober and Fay, while adults are seen by Drs. Ralph, Poncelet, Lomen-Hoerth, Rosow and Greene primarily at the Parnassus campus of UCSF. UCSF is a site for several clinical trials in neuromuscular diseases, and its clinics provide an opportunity for medical students, residents and neuromuscular fellows to learn about the diagnosis and treatment of neuromuscular diseases across the age spectrum.

Dr. Fay obtained his PhD in Biophysics and MD from UCSF, and completed his child neurology residency and neuromuscular fellowship at Washington University in St. Louis. Since joining the faculty at UCSF, he has devoted his time to identifying a novel form of CMT in a large family from South America, developing CRISPR-based therapeutics for CMT2, serving as an investigator on several clinical trials for childhood neuromuscular diseases, and expanding his neuromuscular practice to include UCSF Benioff Children's Hospitals in both San Francisco and Oakland. He is a native of the Bay Area and is proud to be serving this community.



Pediatric neurologist Alex Fay, MD, PhD, heads the CMTA's Center for Excellence at University of California San Francisco.

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
Kane Hall Barry Neurology (Dallas/Fort Worth)*	Dr. Sharique Ansari
Lucile Packard Children's Hospital at Stanford (Palo Alto)	Drs. John Day and Ana Tesi Rocha
Massachusetts General Hospital (Boston)	Dr. Reza Seyedsadjadi
Nationwide Children's Hospital (Columbus)*	Dr. Zarife Sahenk
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
Rush University (Chicago)*	Dr. Ryan D. Jacobson
Stanford Neuroscience Health Center (Palo Alto)	Dr. John Day
University of California (San Francisco)*	Dr. Alex Fay
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 Michigan (Ann Arbor)*	Dr. Dustin Nowacek
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



CMTA Branches

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

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Anchorage Area
Lisa Hubert
907-223-4566

ARKANSAS

Little Rock
Lisa Jones
501-776-5364

ARIZONA

Phoenix Area
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
John Ramos
951-318-5669

San Diego Area

Annette Van Veen
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Kendall Trout
760-632-5654

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Dick Kutz
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Michael Driedger
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Interested in starting a branch in your area?

Contact CMTA Director of Community Outreach
Laurel Richardson at laurel@cmtausa.org.



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



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WHAT IS CMT?

- ▶ More than 3 million people worldwide have CMT, which is one of the most commonly inherited nerve disorders and affects the motor and sensory nerves.
- ▶ CMT is slowly progressive, causing the loss of muscle function and/or sensation in the lower legs and feet, as well as hands and arms.
- ▶ Men and women in all ethnic groups may be affected by CMT.
- ▶ CMT is genetic, but it can also develop as a new, spontaneous mutation.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT causes structural deformities such as high-arched or very flat feet, hammertoes, hand contractures, scoliosis (spinal curvature) and kyphosis (rounded back).
- ▶ CMT can also cause foot drop, poor balance, cold extremities, cramps, nerve, muscle and joint pain, altered reflexes, fatigue, tremor, sleep apnea, hearing loss and breathing difficulties.
- ▶ CMT rarely affects life expectancy.
- ▶ Some medications are neurotoxic and pose a high risk to people with CMT, notably Vincristine and Taxols. See full list (at left) of medications that may pose a risk.
- ▶ More than 100 different genetic causes of CMT have been identified.
- ▶ Many types of CMT can be determined by genetic testing. Please consult with a genetic counselor (www.nsgc.org) or your physician for more information.
- ▶ Although there are no drug treatments for CMT, a healthy diet, moderate exercise, physical and/or occupational therapy, leg braces or orthopedic surgery may help maintain mobility and function.
- ▶ The CMTA'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.