

SUMMER 2016

THE CMTA Report

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An extraordinary 4th grader brings CMT awareness to the classroom and raises funds for research
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THE **CMTA** Report

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CMTer Jenny Decker Becomes First Person to Kayak Solo Around Big Island of Hawaii

BY CLARK SEMMES

TWELVE-FOOT SWELLS pounded Jenny Decker's 16-foot kayak as she approached tiny Punalu'u beach

on the Big Island of Hawaii in her attempt to become the first person to kayak solo around it. Whitecaps engulfed her and despite her best efforts, she could not move forward against the

oncoming current. Hours passed and Jenny grew exhausted from battling the current and the waves, but hazardous lava walls and coral reefs blocked her from going ashore. Increasingly desperate, Jenny longed for an eject button. Her ground crew furiously worked the phones, looking for one. Miraculously, her crew contacted the lifeguard stand at Punalu'u beach, where a brave guard offered to launch a rescue. Paddling a surfboard, the guard found her kayak almost impossible to locate in the churning waters. When he

finally spotted Jenny, he declared her a "beast," then guided her through a narrow pathway along a lava wall to shore. On reaching dry land, Jenny found she could barely stand and began shaking uncontrollably, but she eventually regained her composure and even gave autographs to a group of admiring guards. Seven days later, she paddled triumphantly into Kamakahonu Bay to a hero's welcome.

For Jenny, being the first person to kayak solo around the Big

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New Cause of CMT1 Discovered By University of Pennsylvania Team

CMTA Scientific Board Member Dr. Steven Scherer has done it again. As detailed in the March 2016 edition of the journal *Brain*, Dr. Scherer led an international consortium of CMT researchers that recently uncovered a new genetic cause for Charcot-Marie-Tooth disease type I (CMT1). This discovery significantly expands the body of genetic knowledge on CMT Type 1, CMT's most common iteration.

"This has been a highly fulfilling effort. We were able to track down the cause of this family's CMT, help another family, and find a new genetic cause of CMT

in the process," said Dr. Scherer, the senior author of the article in *Brain*, "De novo *PMP2* mutations in families with type 1 Charcot-Marie-Tooth disease." He added, "The participation of the family, the clinicians and the scientists, from Penn and around the world, makes this success even sweeter."

The breakthrough occurred when Dr. Scherer collaborated with Dr. Sabrina Yum of Children's Hospital of Philadelphia to evaluate a father and son with CMT1. The father and son did not carry a mutation in any of the five genes known to cause CMT1. The father's parents did not have the disease, suggesting that a new random mutation had occurred, not shared by either parent, which the father then passed on to one of his three sons.

Using an amazing technology that sequenced all of the father's 20,000 genes, Dr. Stephan Züchner at the University of Miami and Dr. William Motley at the University of Pennsylvania were able to identify 49 mutations that could be the cause of the pair's CMT. One mutation, a change in the peripheral myelin protein 2 gene (*PMP2*), emerged as the most likely culprit. *PMP2* encodes a protein that transports fatty acids, which are the building blocks of the myelin sheath and known to be one of the most abundant proteins in peripheral nervous system myelin. Further testing of the father's living siblings, parents and two other sons showed that he and his one affected son were the only family members to carry this mutation. This was strong evidence that mutations in *PMP2* cause CMT1,

slowing nerve conduction and resulting in weakness and numbness in the hands and feet.

"Next-generation sequencing technology has allowed us to find new causes of genetic diseases in much smaller families," explained the study's lead author, William Motley, MD, PhD, now a neurology resident at Johns Hopkins University. "The fact that his parents did not have the disease allowed us to narrow the number of possible mutations, as so few arise between generations. We are fortunate to have these tools to help us provide genetic diagnoses to our patients, sometimes even in cases where the patients have no mutations in known causes of their disease. Traditional genetic techniques would never have allowed us to find the cause of this family's CMT."

To provide further evidence of an association between *PMP2* mutation and CMT1, the Penn team reached out to an international consortium of CMT researchers to find patients with mutations in the same gene. Working with collaborators at the University of Antwerp, an additional 136 European families with CMT1 were screened for mutations in *PMP2*. These identified an Austrian family with several affected members who share a mutation in *PMP2*. Interestingly, the mutation was adjacent to the mutation in the family seen at Penn.

Congratulations to Drs. Scherer and Motley and the entire international team of researchers on this most recent scientific discovery. We are certain it will not be the last. ★

CLARIFICATION ON FLUOROQUINOLONES

In the Spring 2016 issue of *The CMTA Report*, we told you that the U.S. Food and Drug Administration (FDA) has required that the drug labels and medication guides for all fluoroquinolone antibacterial drugs be updated to better describe the serious side-effect of peripheral neuropathy. This serious nerve damage potentially caused by fluoroquinolones may occur soon after these drugs are taken and may be permanent. The risk of peripheral neuropathy occurs only with fluoroquinolones that are taken by mouth or by injection.

To be clear, the **FDA-approved** fluoroquinolone drugs that fall in this category include levofloxacin (Levaquin), ciprofloxacin (Cipro), moxifloxacin (Avelox), norfloxacin (Noroxin), ofloxacin (Floxin) and gemifloxacin (Factive). The topical formulations of fluoroquinolones, applied to the ears or eyes, are not known to be associated with this risk.



KAYAK

(continued from page 3)

Island was just the most recent in a series of challenges that began in her early 20s, when she underwent her first nerve conduction study. Even at the highest setting, her feet barely moved. The tech moved the needle higher and higher, increasing the current but not the movement. Knowing that the doctor would look at the results and think the machine was broken, the technician made sure to indicate that the scores were indeed correct. The diagnosis was Charcot-Marie-Tooth disease.

While Jenny wasn't diagnosed until her early 20s, her parents knew something was wrong early on when she couldn't walk. They took her to several doctors, and she was misdiagnosed with cerebral palsy. She underwent surgeries on her legs at the age of 3 and learned to walk with leg braces after physical therapy. She struggled with balance issues, muscle atrophy, foot drop, clubbed toes and many injuries.



An intrepid spirit with a yearning for travel, Jenny decided to ignore her CMT and get on with her life. She went to nursing school and eventually became a traveling nurse, taking short-time jobs anywhere that sounded interesting. At the age of 30, she began working at the Kona Community

Hospital in Kealahou, Hawaii, where she worked 12-hour shifts in the emergency room and ICU. Jenny found that she loved Hawaii, and in particular the Big Island. The ocean was always nearby and the weather was always warm. She swam in the ocean

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CMTA CENTERS OF EXCELLENCE

Centers of Excellence (COEs) like the one where Dr. Steven Scherer conducts research and treats patients are critical to the CMT community, not only because of their multidisciplinary focus on the disease, but also because they are an easy way for community members to get into the INC (Inherited Neuropathies Consortium) database.

The INC database, which is the largest CMT patient database in the world, is critical as the CMTA's STAR initiative gets closer to clinical trials. Reflecting that importance, the CMTA recently doubled its financial commitment to INC, which is responsible for the both COEs and the database, and renamed the COEs the CMTA Centers of Excellence.

Commenting on their importance, CMTA CEO Patrick Livney said: "The community should draw comfort from the fact that members have access to experts who are intimately familiar with CMT. You go from your family doctor who doesn't know anything about CMT to a COE that is a one-stop shop from point of diagnosis to genetic counseling to physical therapy to orthotics to orthopedic surgery if necessary. This avoids the years of trials and tribulations of being tossed around to different clinicians who don't understand the disease." (See related story on misdiagnoses on p. 9.)

Livney also stressed the importance of continuing to build the database, which demonstrates to pharmaceutical companies that the CMTA can provide access to the patients needed for clinical trials.

Tiptoes and Dancing at 84!

BY SHERI L. COOPER

When I first met John Stadler, a bright-eyed, retired physician, he walked with a slow, heavy gait, even though his legs seemed light and thin.

Both feet seemed attached to the floor as he took each unsteady step forward. Four years of training later, John, now 84, can stand on his tiptoes for the first time in 44 years. He can also jump, balance on one leg and slowly dance around—all without braces.

I met John while training his domestic partner, Emily. He chuckled when I suggested that he, too, could benefit from training and exercise, explaining that his Charcot-Marie-Tooth disease forced him to wear rigid foot-drop braces for stability and compromised his agility and

strength. I admit I was unfamiliar with the term.

John's CMT did not affect him until he was about 40. He first realized something was wrong with his legs and feet during a family vacation when he tried skiing for the first time. He had graduated from the bunny slope to an intermediate slope, which he came straight down at high speed,



Balance exercises are an important part of John's twice-a-week training routine.

unable to slow, turn or stop. The ski instructor was shouting at him, "Remember your snow plow!" He remembered it perfectly, but wasn't able to execute the maneuver because it required applying pressure with his big toes, which were paralyzed.

A neurologist diagnosed John—and eventually his two older brothers—with CMT. None of them were ever able to stand on tiptoes, and all eventually needed foot-drop braces.

In his 50s and 60s, John was able to



Body weight exercises help strengthen multiple muscle groups simultaneously.



enjoy bicycle riding without wearing braces, but he broke his neck in a serious bicycle accident at the age of 71 and gave up cycling.

When John told me his story, I was even more convinced that a fitness program could improve his strength and balance. Not only does exercise retard the rate of atrophy in muscles, but it increases strength, promotes better balance and enhances flexibility. Skeptical and a bit apprehensive, John agreed to begin an exercise program.

At first, John did most activities sitting in a sturdy chair with his braces on. We started with exercises to strengthen his upper body, abdominals, quadriceps, adductor and abductor muscles. Then, for five minutes at a time, he removed his braces to work on strengthening his toes, feet and calves. We worked on flexion, extension and rotation of toes, feet and ankles. Little by little, he decreased his reliance on his braces. After about



John and Emily

six months of training, he was able to stand and walk without them. We then either added more weight to his upper body routine or adjusted each particular exercise. It was amazing how quickly, even at his age, he was able to increase his upper and lower body strength.

One day, about a year after beginning training, John sat in his chair, looked down at his feet and wiggled his toes! It was then that I knew that he could, with a lot of persistence and determination, someday achieve his longtime goal of standing on his tiptoes. He also began walking around the house for a few minutes a day without braces, keeping his cane by his side.

From there, we worked on improving John's balance since that is a key component to exercise and safety for anyone in their 80s. We constructed obstacles on the floor for him to step over, around and through. Emily and I both spotted him as he walked forward and backward, sometimes with weights in his hands. In another set of exercises, he repeatedly stood up and sat down from a chair to strengthen his quadriceps and calves, and improve his foot stability and directional change. When I introduced a new activity he'd joke, "You think so, huh?" as if I were crazy for even suggesting he could do it. I reassured him that if he couldn't do it, or it didn't feel right, we could change it, modify it or give him extra support.

Much of John's regular, twice-weekly routine consists of strength training, balance, abdominal work

and stretching. Some basic upper-body exercises include bicep curls with many variations, tricep extensions and dips, push-ups against the wall, on the stairs or bent-kneed on the floor and rowing motions with resistance bands. Because CMT makes it difficult to use the legs and feet, strong abdominal muscles can really help stabilize movements. The center of our bodies, the abdominals require control and awareness for ALL exercises. When exhaling to perform a movement, abdominals come in towards the spine. Lower body work will vary greatly for people with CMT, and any work must be done with a general comfort level and proper support. Stretches are gentle, and done while lying down, so the leg muscles can fully relax and elongate. A stretch should be held for at least 10 to 20 seconds to increase agility and flexibility. Anyone beginning this or any type of exercise program should first consult a physician for individual recommendations and guidelines.

Today, John is delighted to be able to stand on his tiptoes. Most of his daily activities are easier than they have been in years, but he still takes his cane as a precaution when he leaves the house. John continues to work hard to expand his range of mobility as he develops new goals such as hopping, skipping, and an occasional do-si-do. Sometimes now, even in the middle of a training session, he smiles, takes Emily by the hand and begins slowly dancing around the room with her. ★



Sheri L. Cooper is a group fitness instructor and personal trainer through Aerobics & Fitness Association of America (AFAA).

She has 25 years' experience in the fitness industry with specialties in senior and prenatal exercise training and lives in Briarcliff Manor, New York.



FIRST PERSON SINGULAR: The Long Journey to My CMT Diagnosis

BY SY AHMED

Philosopher Lao Tzu said that the journey of a thousand miles begins with a single step. The long journey to my CMT diagnosis began with a single misstep when I began third grade and for the first time had to climb a flight of stairs to get to my classroom. A teacher noticed that I was having trouble with the stairs and informed my parents, setting off the search. It would be 25 years between that misstep and my diagnosis.

First, my parents and I met with an orthopedic doctor who was very well versed in neurological disease. He told us that it was either muscular dystrophy, Charcot-Marie-Tooth or Guillain-Barré syndrome. I spent the summer following my third-grade year being tested for all types of diseases. I had an MRI, X-rays, a gait analysis and an EMG. When all the results were in, I was told I had scoliosis (an S-curvature of the spine) and Guillain-Barré syndrome, or GBS.

I began living my life thinking I had Guillain-Barré. I was always a curious child and I read everything I could get my hands

on about it. I never felt that my symptoms matched up with GBS, but I ignored my feelings of doubt and told myself that maybe my version was different than the typical one.

My life went on this way for 25 years. Then I started noticing a dramatic change in my energy levels, my ability to work and my ability to do normal daily activities.

I started to have injuries, pains and problems doing things that I had always been able to do. So, I visited my doctor again and he said I should see a neurologist. I took the same tests that I had taken as a child, but this time the results and the diagnosis were different: Charcot-Marie-Tooth. I was shocked but not surprised, if that makes sense, because I had never truly believed I had GBS.

After reading about CMT and its symptoms, I was almost

sure this was what had plagued me for my entire life. I was upset because I'd had so many bad days and so many issues that could

have been explained and treated with the right diagnosis. The next step was to find out more information about CMT, so I joined the CMTA. I also became Co-Leader of the Chicago North CMTA Branch. This was one of the best decisions I have ever made. The CMTA helped me find the resources I needed to better understand and manage my CMT. Also, the CMTA is funding research that gets closer every day to finding a treatment

for those of us who have it.

While I had all of this new information and the best resources from the CMTA, I was still not 100 percent convinced that I had CMT. So I decided, in my role as a CMTA branch leader, to bring in



I am a firm believer that if something does not feel or seem correct, always question it.

STAR LAUNCHES RESEARCH FOR CMT4C

The CMTA is pleased to announce a new STAR research project on CMT4C. Completely funded by the CMTA, the 18-month project headed by Dr. Kleopas A. Kleopa of the Cyprus Institute of Neurology and Genetics will explore the possibility of using gene editing to treat CMT4C.

This is the first time that the CMTA has funded research on a recessive type of CMT, exciting news for everyone with any type of the disease! Through STAR (Strategy to Accelerate Research), we are now attacking CMT1A, CMT1B, CMT2A, CMT2E and CMT4C. We truly believe that research for any type of CMT helps all types of CMT.

We will keep you posted on Dr. Kleopa's progress. Thanks for supporting STAR!

Julie Hedrick of GeneDx to speak at a branch meeting. Like many people, I was concerned about the expense of genetic testing, but Julie and the team at GeneDx helped me through the process of getting genetic testing done with my insurance. After a few months, it was confirmed that I have CMT4C.

According to the CMTA, CMT4C is caused by mutations in SH3TC2 and has a wide range of severity. This type of CMT involves childhood onset of sensory and motor neuropathy in the lower limbs and high-arched or flat feet. Patients often have mild difficulty walking and some may need a wheelchair. Scoliosis is almost always present, usually onset in the first two decades. The onset of neuropathy symptoms varies. Some begin in the first decade of life and others in adulthood. Lower limb and upper limb weakness is common, beginning in the hands and feet and sometimes extending above the elbows and knees. Hearing loss, vocal cord involvement and facial paresis have been reported.

Being involved with the CMTA lets me keep up with the latest research, and I was happy to learn that the CMTA's STAR research team has recently begun a project on CMT4C.

I am a firm believer that if something does not feel or seem correct, always question it. For years, I felt that my diagnosis did not fit me but I accepted it, either because I was too trusting, misinformed, in denial or just putting a Band-Aid on the real issues I was having. Don't do what I did: Get the right diagnosis for yourself and get the help you need to deal with your CMT. ★

Survey Finds Patients Face Significant Obstacles In Getting Rare Diseases Diagnosed

Genetic testing company Invitae Corp., a CMTA partner, presented a paper at the American College of Medical Genetics and Genomics in March showing that both patients and clinicians in the rare disease community face significant obstacles in navigating the diagnosis of rare disease. Those obstacles include lack of information, time to diagnosis and cost.

The paper, "Rare Disease Diagnosis Obstacles: Patient Perspectives and Physician Findings," was based on an online survey of 101 clinicians and 150 patients/caregivers in the rare disease community. While the survey didn't specifically mention CMT, its findings are broadly relevant to any rare disease, including CMT.

Patients reported receiving an average of three preliminary diagnoses and seven diagnostic tests and/or procedures during their diagnostic journeys, which lasted an average of 3.9 years. During this time, 39 percent of patients felt they had paid for ineffective treatments or interventions that were based in part on an incorrect diagnosis. Approximately 23 percent of patients received multiple genetic tests. Obstacles for patients in the diagnostic journey included lack of information (76 percent) and inadequate insurance coverage (21 percent), resulting in 60 percent of patients incurring an unexpected financial burden and 29 percent going into debt.

Clinician findings supported those patient perceptions. Clinicians observed that rare disease patients receive on average four to five diagnoses and 14 diagnostic

tests and/or procedures during their diagnostic journey. Physicians reported lack of information about genetic testing (54 percent) as an obstacle, even though 83 percent agreed that genetic testing is useful and 69 percent observed that it shortens the time to diagnosis. Lack of information about cost of testing (49 percent) and about indications for referral to a clinical geneticist (31 percent) were also considered obstacles. Approximately 45 percent of physicians indicated that more resources are needed to effectively diagnose members of the rare disease community and some 67 percent of clinicians indicated the lack of a proper diagnosis for rare disease patients hinders their ability to effectively care for these patients.

Invitae said the observations suggest a need for increased education resources for patients and clinicians regarding the role of diagnostic genetic testing, earlier implementation of appropriate genetic testing and mechanisms to make genetic testing financially more accessible. "At Invitae, we strive to make genetic testing more affordable and accessible. A diagnosis is especially important to the rare disease community, not just for the treatment of a rare disease, but also for the emotional aspects of living with a rare disease," said Stephanie Gandomi, MS, LCGC, genetic counselor at Invitae and lead investigator of the study. "Genetic testing can help these patients and their families find answers and transform the way rare diseases are diagnosed and managed in the clinical setting." ★



Tai Chi for CMT

BY FRANK WOLEK

“NO PAIN, NO GAIN”
is exactly the wrong
advice for anyone with
a disability like CMT.

While Western culture encourages denying disabilities and pushing beyond them, Tai Chi encourages listening to your body and responding appropriately. The Tai Chi approach is valid for both injuries and permanent disabilities like CMT.

This article is based on my personal experience of doing Tai Chi with Charcot-Marie-Tooth disease (CMT). I’ve found that CMT is indeed progressive and incurable, but my message for anyone with a disability is: “My CMT is part of who I am. It has enhanced my individuality, presented valuable challenges, brought new friends and filled my life with insight. I do more than accept my CMT; I treasure it!”

Tai Chi is the rhythmic alternation of taking energy (chi) in and expressing it. In one sense this is simple. Indeed, the Chinese philosophy of life is based on the functionality and interaction of two phenomena: Yin (energy in) and Yang (energy out). The philosophy is expressed in the familiar symbol seen above.

The Mayo Clinic is one of many respected sources that encourages doing Tai Chi to improve your health. While Tai

Chi was originally developed as a martial art, this graceful form of exercise is also useful for stress reduction and health conditions. Often described as meditation in motion, Tai Chi’s gentle, flowing movements promote serenity, social cohesion, and healthier bodies.

My own experience shows that while reduced capabilities can alter Tai Chi’s benefits, those with CMT will still improve their strength, range of motion, balance and spatial sense by incorporating Tai Chi into their lives.

Many of the benefits of Tai Chi come about without conscious awareness of change. For example, double-blind studies prove that Tai Chi improves balance and reduces falls. But improving

what the Chinese call rootedness is not always apparent and includes such changes as:

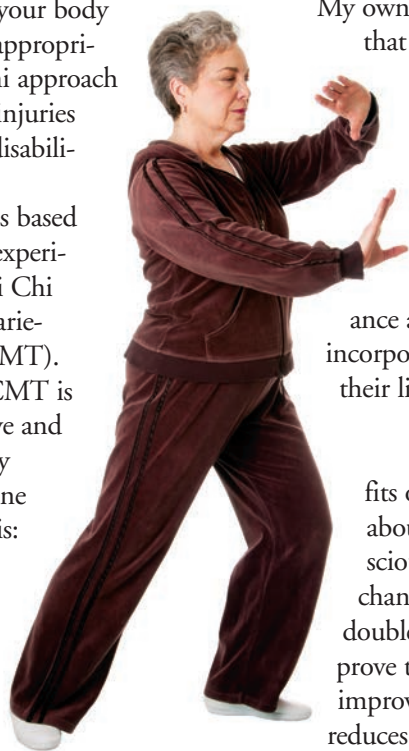
- Unconsciously sensing a more solid base for your foot before moving
- Integrating non-atrophied feet, leg, core muscles into a support system
- Subconsciously sensing energy availability before transferring weight
- Sinking, which refers to gradually increasing the weight on your lead foot before turning
- Developing a better grip with your toes and arch (vacuum cup effect)

The gains from Tai Chi come from the following basics:

- *Core Rotation*—Rotating the core of the body benefits health through such mechanisms as organ massage, stimulating movement of healthy and waste fluids, and loosening tissues.
- *Circulation*—Rhythmically alternating the Yin and Yang increases your oxygen capacity and strengthens your “second heart” to pulse blood, oxygen and fluids through the body.
- *Weight Transfer*—Transferring power from side to side and front to back benefits health, loosening and stretching tissues and connective joints that control movement.
- *Loading*—Challenging the body with added weight, deeper stance and slower tempo benefits health through such mechanisms as tension and release, coordination of body and spirit and mental focus.

The most basic approach to coping with a disability such as CMT is learning and then doing what your body allows. The practice of Tai Chi will not restore lost nerves or atrophied tissue. The keys to effectively doing what you can are the basics of spirit-guided rotation, Yin and Yang alternation, weight transfer, and loading to the extent that your body allows. The key question is how much your body allows. The answer is to adapt the key principles:

- *Strength*—What if you can’t stand on one leg, put considerable weight on the “full” leg and, or even raise an empty leg? How do you know how much



AWARENESS MONTH LOOMING: GET PROCLAMATIONS NOW!

Hey All,

So the CMTA is preparing for Awareness Month. I know crazy, right! But, September is just around the corner...!

In years past, we have asked our CMTA Branch Leaders to contact their governors to request that they declare September as Charcot-Marie-Tooth Awareness Month. Well this year, we are asking EVERYONE to do the same! The more state proclamations we get, the more awareness we can receive.

For more information on the proclamation request please visit www.cmtausa.org/proclamation-request. If you have any questions please contact me at jeana@cmtausa.org.

If and when you receive a proclamation, be sure to scan and email me a copy so I can share it with the CMTA community!

Thanks and I look forward to Awareness Month 2016!

Jeana Sweeney, Director of Community Services
814-269-1319



Doug Sutherland from Southern Connecticut Branch and proclamation from Governor Daniel P. Malloy

weight to put on the full leg or whether and how high to take your foot off the ground? Experiment and find the point where balance is consistently lost or pain is consistently felt; then back off to 90 percent.

- *Range of Motion*—What if you can't rotate your waist 90 or even 45 degrees? Rotate it as much as you can. How do you know how much that rotation is? Experiment and find the rotation that consistently results in pain or tilting; then back off to 90 percent.
- *Smoothness*—What if you can't make a 180 or 90 degree change of direction in one continuous movement. Do it in two or even more steps. How do you know how many or how wide those steps should be? Experiment and find the sequence that allows you to stay balanced and smoothly flowing.

The key in all movement, whether you have a disability or not, is to maintain as smooth and as continuous a flow of energy, weight transfer, and rotation as

your body allows. Any flow, even minimal, will yield a Tai Chi benefit. Health-enhancing Tai Chi can be done in a wheelchair, standing in one place or in a swimming pool. But when you wobble, stumble or wince, the flow of energy will be less effective. This means you must listen to your body, do what it allows and pay no attention to what others think you can do!

Learning to experiment is a valuable talent. At first, this seems easy; just move until it hurts and then back off. But our bodies are more complex than that. Some pains emerge a short time after movement rather than during. Some emerge after hours and some the next morning. Some body signals (aches, warmth, tics, etc.) signal damage and some signal healthy improvement. Some signals of damage are controllable with aids such as ice, heating pads, or wraps. Distinguishing the signals and managing them requires clinical experience, patience, humility and knowledge. That means listening to your body, to

each other, to health professionals, and to expert sources.

A basic lesson of Tai Chi is that we will not perform as well as we can unless we extend ourselves. The key to the apparent conflict between doing what we can and extending ourselves is found in the fundamentals of Tai Chi: Practice slowly, listen to your body and work with a sympathetic and knowledgeable coach.

Each of us with CMT has already learned to accept what we can and cannot do. It is OK if kicks are low, steps are small, sinking is minimal and loading is light. It is also OK if we must use a wheelchair, cane, orthotic or wall. None of these blocks internal energy or invalidates Tai Chi. As long as you keep at it, energy will flow and you will feel and be better. ★



Frank Wolek was diagnosed with CMT over 20 years ago. He has been doing Tai Chi for 30 years and is an accredited Tai Chi Master. He is also an Emeritus Professor at Villanova University and co-owns the Siu Lum Academy in Havertown, Pennsylvania.

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

Dear David,

I was diagnosed with CMT three years ago and went on disability in 2015. I had to give up a job that I loved and some days I have a hard time getting out of bed. I have no motivation to do anything. I find that if I do some activity, it takes several days to recover. I know I need help with my depression. Because of my CMT, I really miss my "happy place" that used to be part of my life. What can help with my depression?

David replies:

While depression can often accompany CMT, it's important to state that CMT in itself does not cause depression. A true clinical depression has specific symptoms like lethargy, difficulty sleeping, isolation, and a feeling of hopelessness that generally lasts more than two to three weeks. Loss of appetite and thoughts of suicide are also symptoms. Clinical depression also includes a biological component that might require a course of anti-depressant medication. This can often be highly successful. There is absolutely no shame in needing medication to help overcome depression. I have taken medication at certain periods in my life and it has helped me greatly, along with talk therapy. The medication helped lift the cloud that was hanging over me and gave me back some energy to put things in perspective. As we all know, fear plays a major role in our struggle with CMT and when our fears become overwhelming, we just want to pull the covers over our heads and retreat from life. I have often described depression as putting on a pair of glasses with green lenses so that everything we see is tinted green. We don't see the many other

colors in the world. As I mentioned before, talking to a counselor who can give you some tools to help when you go to those dark places is invaluable. Simply having someone who can listen to you in an empathetic way—and not judge you for what you are experiencing—helps enormously with feelings of isolation.

I understand that you miss your "happy place." When we are in midst of one of those fearful periods and our thoughts are out of control, it's almost impossible to imagine that we will one day feel joy again. Learning to breathe and do simple relaxation exercises at those moments can help you feel what is underneath the frightening scenarios that we create in our mind and can help quiet your thoughts. Allowing yourself to grieve for what you are unable to do is part of the path we all must take. If you allow yourself to truly feel these painful feelings, they will inevitably pass. Being gentle with yourself during these times and



Write to David at info@cmtausa.org.

having compassion for what you are going through helps in accepting your life for what it is. This is a form of self-love that is crucial in order to accept our reality and begin to see other possibilities. A fortune cookie message I carry around in my wal-

let says: "The darker the night, the brighter the stars." I tend to believe that what we resist seems to persist, so allowing yourself to feel it all helps you to experience life again with all its ups and downs. To be fully alive—even with the challenge of CMT—is the goal. It is only then that happiness can be a byproduct of the gratitude and we can feel all the small moments of pleasure that have never really gone away. ★

David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized 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.

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FIRST ANNUAL FREE CMTA YOUTH SUMMER CAMP
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RAISING FUNDS FOR A CURE

4TH-GRADER TIMOTHY LAURIAULT RAISES \$650 FOR RESEARCH

Last November, my 10-year-old son Timothy asked his fourth-grade teacher if he could have a fundraiser to raise money for the CMTA. His teacher, Mrs. Ann Rowland, immediately said “Yes!” and guided him through the process of creating and writing up his own flyer to give to the students. This is what he wrote in the flyer. I couldn’t have said it any better.

HELP PEOPLE LIKE ME WALK!
Hi, my name is Timothy and I have CMT. It's a disease that affects the way I do things. For example, it makes it so I can't play a lot of sports, my feet burn like they are on fire if I walk a lot. I have bad balance and trip and fall so I wear leg braces. My hands shake when I write. So if you donate money to the CMT association; you can help kids like me. For more information visit www.cmtausa.org

The Friday before the fundraiser Timothy gave a presentation to each fourth-grade class telling them about CMT and why he wanted to have the fundraiser. He gave each class a blue shoebox to collect money in. His teacher came up with his new logo “The Big Blue Box” to make it fun for the kids. For the week Timothy was known as “Big Blue.”

I am so proud of my son for speaking up and putting together his own fundraiser for the CMTA and the STAR initiative! He loved every minute of this fundraiser and raised an astounding \$646.68 between classroom and online donations! —Rebecca Lauriault



Timothy Lauriault and his teacher, Mrs. Ann Rowland

“GREAT BEARD OFF” RAISES \$1,500 FOR RESEARCH

The Great Beard Off wasn’t the first time Zack Smith had grown a beard. In fact, it was an annual occurrence for the U.S. history teacher at Fossil Ridge High School in Keller, Texas. Every year, he started a beard around Halloween (in honor of No-Shave November, which raises awareness for cancer patients) and then shaved it off in time for Christmas. This year, however, Zack, who has CMT1A, started growing his beard early and then shot right past his usual clean-shaven date. Then his wife had an idea: Why not keep growing the beard throughout the spring and then ask his students to vote (through donations to the CMTA) on how he should shave it off? Zack mentioned the idea to a few co-workers who liked the idea and wanted to join in. Soon the Great Beard Off was underway.

Four generations of Zack’s family have been touched by CMT. His great-grandfather had it, his grandmother had it, his mom and his aunt have it, and now Zack and his brother are also affected. Zack was diagnosed when he was just 9 years old. Embarrassed by the disease well into his mid-20s, Zack is

no longer ashamed and has decided to spread the word about CMT and raise money to help find a cure. His wife and his students are fully supportive.

The ground rules for the Great Beard Off fundraiser were simple. If his students donated a grand total of \$20, Zach’s beard would come off in a single clean shave. If they donated \$50, he would leave just a pair of muttonchops; \$75 would secure a Fu Manchu mustache; \$100 would yield a Fu Manchu with sideburns; \$200 would lead to muttonchops connected to a mustache (like Lenny from the band Motorhead), and \$500 would result in a “Jack Sparrow” (two long braids). Voter turnout was heavy.

In the end, Zack and his coworkers ended up raising over

BEFORE AND AFTER—Beard Off participants left to right: Chris Brown, Brad Harmon, Zach Smith, James Jones, Adam Webb



\$1,500 for the CMTA and CMT research and Zack ended up with a Jack Sparrow. Many thanks to Zach Smith, Chris Brown, Brad Harmon, James Jones, Adam Webb, Jeremy Manginell and Deron Fontenot, to their wives who put up with all their excess facial hair, and to all the students and faculty at Fossil Ridge High School in Keller, Texas. Go Panthers! ★

The CMTA Gratefully Acknowledges Gifts:

IN MEMORY OF:

ROBERT ALBRECHT
Ms. Deborah Reed

JAMES R. BLANKENSHIP
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Ms. Peggy Rios

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Mr. and Mrs. Bruce Rose

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MARIANNE KREYCIK
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CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

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Occasion (if desired):

- Birthday
- Holiday
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Amount Enclosed: _____ Check Enclosed

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Name: _____

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Take Advantage of the National Park Service Access Pass

Summer's the time when many of us pack up our cars and head to one or more of the United States' great national parks. Cleveland Branch Co-Leader Heather Hawk Frank looked into the National Park Service's Access Pass, which allows U.S. citizens or permanent residents with permanent disabilities like CMT to enter the parks free of charge. Here's what she found out:

Passes may be obtained in person at a federal recreation site or through the mail. Although the access pass is free, the cost of obtaining it through the mail is \$10 for processing the application. Applicants must provide documentation of permanent dis-

ability and residency or citizenship.

Passes may provide a 50 percent discount on some amenity fees charged for facilities and services such as camping, swimming, boat launching, and specialized interpretive services.

A pass generally does NOT cover or reduce special recreation permit fees or fees charged by concessioners.

The Access Pass admits pass owners and passengers in a non-commercial vehicle at per-vehicle fee areas and pass owner and three adults, not to exceed four adults, where per-person fees are charged. (Children under 16 are always admitted free.) Photo identification will be requested to

verify pass ownership.

If you have more than four people in your car, one pass covers the vehicle at sites that charge "per vehicle." At "per person" sites, the applicable fee will be charged for each additional person.

At federal recreation sites that don't have entrance stations, you need to display your pass either on your rearview mirror using a free hangtag or on your dashboard with the signature side showing. Remember, the hangtag itself is only a way to display your pass and is not valid for entry unless it holds a valid pass. ★

For more information, visit: www.nps.gov/planyourvisit/passes.htm.



The Forest Service, National Park Service, Fish and Wildlife Service, Bureau of Land Management, USACE, and Bureau of Reclamation all honor the Access Pass at sites where Entrance or Standard Amenity Fees (day use fees) are charged.

All of the major view points in Bryce Canyon National Park are accessible with easy-to-roll pathways along the rim.



BRANCH LEADER SPOTLIGHT: Vicki Pollyea, Tampa Bay, FL

Vicki Pollyea is no stranger to adversity. Born into a family with CMT1A, Vicki and her mother (who was thought to have polio as a child) were both wrongly diagnosed with Friedrich's ataxia when Vicki was young. Growing up in Tampa Bay, Florida, she couldn't run or ride a bike, and she got terrible grades in physical education. But she could swim and catch needlefish to sell for bait to tarpon fishermen and she and her sister, who also has CMT, "lived in their bathing suits." She also kept her sense of humor, telling people that "My mother and sister and I would always say we were the ones who would always find money on the ground, because we always had to look down when we were walking."

After undergoing a lot of physical therapy in her youth, Vicki got a degree in occupational therapy from the University of Florida. She worked as a therapist at the county Community Mental Health Center, the Mendez Exceptional Center and finally for the school system, but as her disease progressed, work became more and more difficult. She eventually had to quit because of the strain of carrying therapy equipment around with her. "I told them if they just gave me a closet I could keep working," she said, but in the days before the Americans with Disabilities Act there was no legal requirement, and she had to quit.

Undaunted by this setback, and soon on full disability, Vicki became a CMTA branch leader and neighborhood activist. She was part of a former Mayor's Neighborhood Task Force and helped draft Tampa Bay's tree-protection



Vicki Pollyea

code. Vicki is also president and one of the founders of Bayshore Gardens Neighborhood Association, where she and her husband, Archie Giannella, live in a 1921 bungalow they restored. She has also spent more time fishing, a passion she and Archie share.

Since 1985, Vicki has had more than two dozen orthopedic operations. Over time she became more homebound, sometimes going weeks without leaving her house. She discovered that she could surprise people with how much she got done with her computer and phone—last year Vicki got three proclamations for CMT Awareness Month without once leaving the house. Every day she tries to live by her mantra: "I cannot control the things that happen in life, but I can control my attitude about the things that happen."

Today, Vicki is facing a new challenge following a diagnosis of

lung cancer. After a frustrating delay between her diagnosis and her surgery, as of May 21 she was six weeks post-op and all reports remained good. While she has very little energy and some pain, she is surrounded by "lovely cards and many caring messages" for which she is grateful. She is also thankful for her lovely back-porch where she likes to sit to take in the birds, butterflies, and flowers, especially the orchids. For company when Archie is working, Vicki has always had at least one dog, all of them "mutts." Right now they have Dylan, a Craigslist find who is protective of Vicki and sensitive to her needs.

Vicki's father was an Army Air Corps (later U.S. Air Force) officer who piloted a B-17 as part of a segregated, Jewish flight crew in World War II and eventually became a Strategic Air Command commander. Her mother was a

(continued on page 19)

The Science of Happiness

BY ELIZABETH K. MISENER, PHD, LMSW

“What we appreciate, appreciates.” — Dr. Ben Sahar

As you read Dr. Sahar’s words, focus on each one: “What we appreciate, appreciates.” What does this mean to you? To me it means that what we put our attention on will grow. CMT is not a choice. The choice is where we focus our attention. When my 11-year-old son is upset because his

braces hurt, I lean into the pain with him for a few minutes. Then we move out of the negative emotions by talking about Mindcraft, which he loves and can spend hours discussing.

This article will highlight a few key findings from the science of happiness. Are you aware there is a science of happiness called “Positive Psychology?” Positive Psychology studies the strengths and tools that enable individuals and communities to thrive. So while we are waiting for research to find therapies to help our bodies, we can spend some time on tools to support our minds and help us thrive with CMT.

Positive Psychology does not deny negative events, emotions or struggles, but recognizes that balance is required. In 1998, Dr. Martin Seligman pushed for a shift in research from how to fix what isn’t working to how to build on what is working. Research found that leaning on our strengths (building on what we are good at) by focusing on such notions as mindfulness and gratitude leads to overall well-being.

I want to share a few techniques for working with our brains instead of letting our brains control us. A few years ago, I took a course called “How to wire your brain for more happiness” by Drs. Sandy Buczynski and Bobbi Hanson. They acknowledge that there is suffering in life. (I am sure I don’t need to tell you that!) If we

try to run from our negative thoughts, they can overtake us and consume us. But if we can sit with the suffering, witness it and feel it, we can move through it. We can also cultivate positive thoughts. Our minds are like gardens. If we pull out the weeds when we see them, we can replace them with seeds for beautiful flowers to grow. The seeds need to be watered and we need to be patient until they are ready to bloom. In my garden, weeds grow very well and very fast: That is the natural tendency. But I spend a little time each day pulling one or two weeds and planting my seeds and I am so grateful when I see one beautiful flower. It is our natural tendency to scan our environment for all that can go wrong (weeds), but this no longer serves us like it did when we lived in caves. We can build in gratitude (flowers) and cultivate our strengths to help us feel more content and less anxious or depressed.

Let me give you an example. Each day we have experiences that can make us feel crappy and get us stuck there. It sucks when you try to walk and you trip because of a drop foot or when you can’t run as fast as others or play sports! If you find you spend most of your day in a bad place in your head—because of how debilitating your CMT is or how alone or just plain miserable you feel—you can make a choice to rewire your brain for a slightly more positive mindset. You can cultivate more positive experiences and purposefully focus on them.

To start, you need to be aware of how you are thinking. If you are not sure what your automatic

Smiling Meditation *By Dr. Itai Ivzan.*

Slowly allow a smile to spread on your face. Feel the muscles around your mouth move as the smile grows and grows. Keep on smiling while bringing your awareness to your heart. How does your body or heart feel when you smile?

Gradually let go of the smile and allow the muscles around the mouth to move back to neutral position. Once they are in neutral position move your awareness back to your heart: How does the heart feel now?

Slowly allow a smile to spread on your face. Feel the muscles around your mouth move as the smile grows and grows. Keep on smiling while bringing your awareness to your heart. How does your heart feel now that you are back to the smile? Do you notice anything?



thoughts are, then it might be time to get mindful and pay attention to that voice in your head. Is it your friend or your enemy? Take a moment and tune in to your voice. What is it saying? When you first wake up in the morning what does your voice say?

I rewired my brain to be grateful for another day, but I had to work hard at it. The Smiling Meditation (see box) is one way to shift your mind. When you smile, hormones are released that make you feel better. Over time, you can actually re-wire your brain by doing this meditation. Try doing it three times a day for the next three days: when you wake up, at lunch and at bedtime. Start small and be very specific as you move toward taking in more good each day. Focus on the connection you have with a

I rewired my brain to be grateful for another day, but I had to work hard at it.

community that understands you—the CMTA! Each morning before you get out of bed think of three things for which you are grateful. Today, mine were air conditioning, as it is so hot; a

good cup of coffee; and the birds singing. What are you thankful for? This can set the tone for your day.

Try these tools for a week and see if you notice any shifts. If you want to be scientific about it, take one of the questionnaires

on the websites below. (I like the Gratitude one.) Then see if your score changes in a few weeks. You can be your own research study of one! There is a lot of great research out there on tools that work to help us flourish. See the resource list for just a few and please email me at emisener@gmail.com if you have questions or need more information! ★

RESOURCES

Gratitude:

Robert A. Emmons, PhD, is the world's leading scientific expert on gratitude. He is a professor of psychology at the University of California, Davis, and the founding editor-in-chief of *The Journal of Positive Psychology*. He is also the author of the books *Gratitude Works!: A 21-Day Program for Creating Emotional Prosperity* and *Thanks! How the New Science of Gratitude Can Make You Happier*.

Benefits of Gratitude (10min): www.youtube.com/watch?v=RRrnfGf5aWE

Cultivating Gratitude (5min): www.youtube.com/watch?v=8964envYh58

Mindfulness:

Dr. Ellen Langer, PhD, is a social psychologist and the first female professor to gain tenure in the psychology department at Harvard University. Dr. Langer has been described as the “mother of mindfulness” and has written extensively on the illusion of control, mindful aging, stress, decision-making, and health. Among other honors, she is the recipient of a Guggenheim Fellowship and three Distinguished Scientist Awards, the World Congress Award, the NYU Alumni Achievement Award, and the Staats award for Unifying Psychology. She has written 11 books and more than 200 research articles on mindfulness in the last 35 years. Her best-selling books include *Mindfulness*, *The Power of Mindful Learning*, *On Becoming an Artist: Reinventing Yourself Through Mindful Creativity*, and *Counterclockwise: Mindful Health and the Power of Possibility*.

Podcast with Ellen Langer: www.onbeing.org/program/ellen-langer-science-of-mindfulness-and-mindfulness/6332/audio?embed=1

Video of Ellen Langer: youtube.com/watch?v=4XQUJR4uIGM

Authentic Happiness:

University of Pennsylvania Authentic Happiness: www.authentichappiness.sas.upenn.edu/

VICKI POLLYEA

(continued from page 17)

British girl he met while stationed in Oxford after the war. Her mother's father was one of the first casualties of the Blitz in London, and her mother may have been saved because she was among thousands of children shipped out of the city during the bombing.

In addition to her sister, Vicki has two cousins, both teenagers, who live in New Zealand and also have CMT. She hopes all the research currently underway will make a difference in their lives. Vicki believes that “the most important thing is awareness. We can't imagine a world without CMT until people know what it is.”

Vicki and Archie do not have any children. “We made that decision,” she said. “It's a bit of a sadness, but it was the right decision. I didn't want to risk not having the energy to raise a disabled child. But we're blessed with lots of nieces, nephews, and godchildren.” The couple also likes to have neighborhood children in their home, and they keep two cupboards of toys in their den. “I want kids to be comfortable when they come here,” she said. “We have a liquor cabinet for adults, so we should have a toy cabinet for the kids.”

No one in the previous generation of Vicki's family lived past the age of 50, but she'll turn 59 in October. “It's hard to know what my outlook is,” she said. “I don't have longevity in my frame of reference. I don't know how much longer I'll live, but Archie will be by my side. It teaches you to live in the moment, to tell the people around you that you love them. You don't know what's going to happen.” ★



CMTA BRANCH NEWS

SOUTHERN CONNECTICUT

The Southern Connecticut branch welcomed guest speaker Lindi Campbell, a certified orthotist from the North Haven Hanger Clinic, to its March 9 meeting. Lindi provided valuable information about the different types of AFOs and shoe orthotics available at Hanger Clinics. She brought samples of AFOs and shoe inserts, including the new silicone AFO, explaining how they are made and who benefits from each type.

NAPLES, FL

The Naples Branch met at Naples Community Hospital on March 10, with 10 members and family in attendance. Members brought aids for dealing with CMT, including a clamp for opening jars from Bed, Bath & Beyond, a cane with a built-in flashlight and light weight carbon fiber AFO's. The Bellaveaus family talked about their recent trip to the CMTA Center of Excellence at the University of Miami. Mother Lynne and daughter Juliette were among the five children and five adults invited to attend a conference on measuring the severity of CMT to establish scales for physical therapy and occupational therapy capability.

INDIANAPOLIS, IN

Five people, including one new member, attended the Indianapolis Branch meeting on May 21. Group member Jim Matthews shared his CMT journey with the group, leading into a discussion about grief, depression and anxiety related to chronic illnesses. The group also talked about the 2nd Annual Walk and Roll, which will take place on September 17, in Anderson, Indiana, at Shadyside Park (www.firstgiving.com/CMTA/indy). Lunch, beverages and baked items were available for sale during the event as well. The branch aims to raise \$8,000 this year.

★

NORTH IOWA

Three people, all of them related, attended the May 21 meeting. Branch Leader Michael Groesbeck shared new CMTA publications and information from the Branch Leaders Conference in Tampa.

★

BOSTON, MA

Five new members joined the Boston Branch at its March 6 meeting to discuss fitness and CMT. Personal trainer Robert Corrigan, who works at Boston Sports Club, shared information on specific movements to stay strong and fight fatigue. He recommended stretching and limiting weights to every other day for optimal health. The Boston Branch Facebook page has some new additions, including its entry in the "Silly Dance Challenge" and an overview of Turbomed Orthotics by Vittorio Ricci. At a special session the Saturday before the Boston Marathon, Boston Branch members enjoyed pizza and getting to know two world class Athletes: James Cuizon from Hawaii and Santi Sanz, a three-time Paralympian, from Spain. The group had a great time getting to know both athletes and how they became involved raising awareness for CMT.

BALTIMORE, MD

The Baltimore Branch heard from Johns Hopkins Neurologist Dr. David Cornblath and GeneDx Representative Alex Davis at its March 7 meeting. Dr. Cornblath advised anyone with CMT to join (and donate to) a national group like the CMTA in order to have a bigger voice. He also urged group members to identify their specific genetic mutation through genetic testing, to follow research on PubMed (www.ncbi.nlm.nih.gov/pubmed) and www.clinicaltrials.gov, and to join a study. Finally, he stressed the importance of members writing their congressional representatives. Letters or emails should say: *"I have Charcot-Marie-Tooth disease, the most common inherited peripheral neuropathy occurring in about one in 2,500 Americans. It affects my daily life. I would like you to support more research into CMT and other neuropathies that affect millions of Americans. Please ask the NIH how much money they are spending on research into peripheral neuropathy and CMT and send me that information."* Finally, GeneDx representative Alex Davis explained the reasons behind the recent dramatic reduction in the cost of genetic testing.

★

CENTRAL NEW JERSEY

One new member and several occasional or not-in-a-long-time members joined the Central New Jersey Branch on March 12 for a far-ranging discussion that included braces, wound care, and vegetarianism. The highlight was Alexandra Winant's recounting of her experience in becoming a vegetarian. Alexandra, who is a high school junior, adopted the diet with animal rights in mind, but discovered that it was also amazingly beneficial for her CMT, allowing her to sleep all night with no cramping or leg pains! The diet also allowed her to get off all the pain meds she had been taking. Aukje and Alexandra shared a lot of shopping tips and recipe sources, including Pinterest. Aukje also suggested that people look at the allergen statements on ingredient lists first: Lists that include eggs or milk immediately show that a product is not vegan.

★

BUFFALO, NY

More than 20 people, including half a dozen new ones, came out on March 10 to hear Dr. Lawrence Wrabetz from the Hunter James Kelly Research Institute at the University at Buffalo Jacobs School of Medicine and Biomedical Sciences.

★

WESTCHESTER, NY

CMTA Advisory Board Member David Tanenbaum was the guest speaker at the Westchester Branch's meeting on April 2. Some 22 people attended, making it one of the largest turnouts ever. David spoke about the emotional and physical challenges of living with CMT. He spoke to many people individually after the meeting ended, sharing his keen insights and positive attitude and inspiring everyone. The branch held a pot luck brunch on May 14,

(continued on page 23)

WALK 4 CMT!

We all want a treatment for CMT. You can bring us one step closer by holding a Walk 4 CMT in your community!

Holding a walk is a great way to bring your community together, make new friends and create a lasting impact for everyone with CMT. Whether your walk is big or small, you will have 100 percent support from the CMTA and tons of fun in the process!

If you are ready to make a difference and want more information about holding a Walk 4 CMT, please email me at jeana@cmtausa.org.

I can't wait to talk to you!

—Jeana Sweeney, Director of Community Services



2016 CMT SPARTAN RACE ONE FOR THE RECORD BOOKS



Editors Note: On April 9, CMTA CEO Patrick Livney and 8-year-old Lily Sander braved the wind and the cold and the mud to complete their respective Spartan races. Patrick's sister, Charlotte Branch Leader Tricia Hirsch, tells us what the experience was like. Donations are still coming in; we'll report on the total in the next issue.

It's been said that it takes strength and courage to admit the truth and the truth is that we all have personal challenges. Events like the Spartan Race not only bring out the physical ones, but also allow for personal emotional confrontation and growth. As many CMTAthletes realize in their daily training, it takes more than physical fitness to accomplish an athletic goal. Participating and crossing the finish line with my brother Patrick was so meaningful to his friends and family. Most of us also learned a little something about ourselves: Stephanie and Becca overcame their fear of heights to climb course obstacles, and Tommy and LaTrone will never look at training clients the same way again. The rest of us now understand that wading through freezing cold muddy water is over in 10 minutes, but living with CMT includes a lifetime of obstacles and challenges that make us all appreciate how one wild and crazy event can expose individual determination.



Thank you to all who supported Patrick and Lily in making this event truly special.

—Tricia Hirsch

SADDLE UP: REGISTRATION OPEN FOR THE THIRD ANNUAL CYCLE 4 CMT

Register now for the Third Annual Cycle 4 CMT to be held on August 28, 2016, at the Old Lantern in Charlotte, Vermont. Help find a cure for CMT while you enjoy incredible cycling and breathtaking views of Vermont's Lake Champlain and the Green Mountains.

Riders can choose from one of four beautiful cycling routes that travel through the scenic Vermont towns of Shelburne, Charlotte and Hinesburg. All routes start and end at the Old Lantern in Charlotte and take cyclists over a covered bridge offering beautiful views of the mountains, rolling hills and farm country around Charlotte.

We are looking forward to another great day of riding, spreading CMT awareness and fundraising in support of the research required to find a cure for CMT.



Questions? Please visit www.cycle4cmt.com or contact Chris Ouellette: cycle4cmt@gmail.com



CMTA ON PINTEREST

Be sure to check out the CMTA's Pinterest account with online pin boards dedicated to helpful products for people with CMT. (We have 100s of great tools, and add more every day!) There are also inspirational images and poems, links to resources and educational information (including our favorite exercises for CMT) and tons more. Visit our Pinterest at www.pinterest.com/CMTAssociation. Be warned though, your afternoon may suddenly fly by! Make sure to "Follow" us on Pinterest to be notified when we add new pins!



Wanchik's Writer



KAYAK

(continued from page 5)

every day, went scuba diving regularly and hung out on Kona pier. Soon she began daydreaming of kayaking around the entire island.

In time, Jenny's daydreams turned into action, and she began studying maps of the island and its history. As much as she researched and read, Jenny could find only one record of anyone circumnavigating the island by kayak. In 2002, two men named Kelly Harrison and Mickey Sarraille accomplished the feat. Jenny set out to find them. Eventually, Jenny learned that Kelly had passed away in a hang-gliding accident. Mickey, however, was still alive and living in California. Jenny found his number and called him. They talked for hours and her plan slowly took form. The trip would cover 300 miles and would take approximately 20 days.

As she planned her adventure, Jenny received some sage advice from her partner Krystal: "Do this for a cause." Jenny decided to use the adventure as a fundraising tool to fund CMT research. She set up

a GoFundMe site and began raising money.

After months of planning and pouring over maps, Jenny finally set out on her adventure on March 25. While long days of paddling and pedaling her kayak were exhausting, Jenny found the ocean exhilarating and the island's coastline filled with great beauty. Life quickly fell into a routine of kayaking by day and then coming ashore each evening where she met different members of her 10-person support team to receive fresh supplies and camp under the stars.

Jenny frequently encountered humpback whales as she kayaked and could clearly make out their eyes studying her as they came close for a better look at her and her kayak. One mother and calf accompanied her for many hours, the mother swimming underneath the very young calf and lifting it to the surface to breathe. Jenny says she always knew humpback whales had souls, but these

encounters made that even clearer to her.

When planning her trip, Jenny identified beaches and landing sites at irregular intervals along the coastline where she would be able to beach her kayak. However the coast of the Big Island did not

always offer a convenient landing site, and on four occasions Jenny had to anchor her kayak offshore, pack a dry-bag and swim to shore. In the morning Jenny would wait until daybreak, then strap on her dry bag (loaded with fresh supplies and often weighing

as much as 25 pounds), swim out to her kayak and scramble onboard.

Today, Jenny and Krystal are back on the mainland and planning their next adventure, joining a crew to participate in a three-ocean crossing by sailboat, starting in Italy and ending in the United States. Her GoFundMe campaign surpassed her goal of raising \$10,000 for CMT research. ★

An intrepid spirit with a yearning for travel, Jenny decided to ignore her CMT and get on with her life.



CMTA MEMBERSHIP, PUBLICATIONS & ACCESSORIES ORDER FORM

BRANCH NEWS

(continued from page 20)

2016, and exchanged ideas for its annual fundraiser, which will be held in November at a new and very beautiful venue.

★ WILMINGTON, NC

Eight members (including one new one) met for chair yoga and coffee on Saturday, February 20. The chair yoga session, a first for everyone, was enjoyable and challenging. Members also had a great dialogue with the regular class attendees, using the opportunity to educate them about CMT. Post yoga, members talked about their goals for the year—the biggest one being the first-ever Wilmington Branch fundraiser in September!

★ CLEVELAND, OH

The Cleveland Branch celebrated meeting its fundraising goal with dinner at Panera on May 25. After dinner, Branch Leader Heather Hawk Frank talked about the National Parks Access Pass (see related story, p. 15). The group also voted on the Walk for CMT Cleveland logo for its September 24 walk. Finally, Heather discussed the first annual Ohio picnic, a joint event for Cleveland, Columbus, and Cincinnati, to be held July 30 in Columbus. After the business portion of the meeting, Don Wheldon from Hanger discussed bracing and the role of an orthotist with the group.

★ BUCKS COUNTY, PA

Meeting on March 12, members discussed the new CMTA app, which is available in the app store and is useful for keeping track of individual fundraising. They also discussed other ways to raise funds individually such as bake sales, Igive.com, Amazon Smile, and the upcoming buffet dinner and basket raffle in September.

★ HARRISBURG, PA

The Harrisburg, PA branch raised \$6,017 for STAR research at the 1st Annual Fishing for a Fix youth trout derby April 17! More than 100 people cheered on the 55 kids competing for prizes for the first fish caught, smallest fish, first palomino trout caught, and the top three largest trout by length. Silent auction items included a Japanese fly rod, fly gear and more. Raffle items were up for grabs too, with packages assembled for Mother's Day and Father's Day, summer fun, and sports and outdoor packages! The branch showed its appreciation for the borrowed derby location and several hundred donated fish by splitting the proceeds of a 50/50 drawing with the Dauphin County Anglers and Conservationist group. Get Smok'd BBQ had their smoker rolling and grilled up hamburgers, hotdogs and pulled pork sandwiches for lunch.

★ PHILADELPHIA, PA

Seventeen people came out for the Philadelphia's inaugural meeting on April 23, discussing the CMTA, the STAR Initiative and the CMTA Centers of Excellence. They also took the time to get to know each other, exchange stories and advice and talk about future goals for the group. The group talked about using hand-controls for driving, and noted that in some cases the Pennsylvania Department of Vocational Rehabilitation can subsidize the cost of driving lessons.

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Subscription Membership Benefits: <ul style="list-style-type: none"> • Online access to valuable information about living with CMT • An information kit and a 10% discount at the CMTA store • Quarterly delivery of <i>The CMTA Report</i>, (electronic and/or hard copy) 	STAR Membership Benefits: <ul style="list-style-type: none"> • All of the benefits of Subscription Membership <p>PLUS</p> <ul style="list-style-type: none"> • One free pair of Aetrex Shoes in the style of their choice (new STAR members only) • 50% off all Aetrex shoes (new and renewing STAR members) • An expanded and updated copy of the CMT Survivor's Guide • A 20% discount at the CMTA Store • One <i>You're a STAR</i> auto decal
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CMTA Brochure & Neurotoxic Drug Card			FREE	
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Check payable to the CMTA (US residents only; non-US residents, please use credit card or international money order.)

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Mail to: CMTA, P.O. Box 105, Glenolden, PA 19036; or fax to 610-499-9267

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

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):

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

Moderate to significant risk:

Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Eribulin (Halaven)
Fluoroquinolones
Gold salts
Ixabepilone (Ixempra)
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
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)
a-Interferon

Negligible or doubtful risk:

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

THE CMTA Report

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WHAT IS CMT?

- ▶ CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- ▶ CMT may become worse if certain neurotoxic drugs are taken.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT can, in rare instances, cause severe disability.
- ▶ CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ▶ CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ▶ CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ▶ CMT does not affect life expectancy.
- ▶ CMT is sometimes surgically treated.
- ▶ CMT causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- ▶ CMT has no effective treatment, although 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.