

WINTER 2017

THE CMTA Report

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WINTER
HOT &
COLD



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OUR MISSION: To support the development of drugs to treat CMT, to improve the quality of life for people with CMT and, ultimately, to find a cure.
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A MESSAGE FROM CMTA BOARD CHAIRMAN AND INTERIM CEO GILLES BOUCHARD

DEAR CMTA FRIENDS:

As interim CEO of the CMTA, I start this New Year with a profound sense of hope and excitement. The CMTA continues to make great progress on all fronts, and across the majority of CMT types.

Now that the goal line is in sight, though, we must double down and accelerate our efforts. In this context, I am excited to share a few announcements about developments that will strengthen our organization as we go forward:

Clinical Expert Board: Since the inception of the STAR program, we have moved from basic scientific research to partnering with top pharmaceutical companies on a promising pipeline of potential drug candidates. As we continue to fill and extend this pipeline to more types of CMT, we are also preparing for clinical trials, always the riskiest and most expensive phase of drug development. To assist in that effort, we have created a Clinical Expert Board, with top clinicians from around the world, whose role is to provide guidance and support to the CMTA's alliance partners, helping to assure the success of clinical trials. (See all our scientific and clinical advisors at www.cmtausa.org/research/star-advisory-board.)

New Board Members and Advisors: I am delighted to announce that Bruce Chizen, one of the most recognized and respected business leaders in the tech industry has agreed to help us as an advisor. Additionally, Tom Dubensky just joined our Board of Directors, bringing with him over 25 years of experience in biotechnology and in advancing novel drugs to clinical trials. Please join me in welcoming Bruce and Tom to the CMTA family (see related story p. 5).

New CEO Search: Following Patrick Livney's December 2016 departure, the Board formed a search committee, retained one of the most respected search firms in the field (Kittleman and Associates), and published the job at CMTA CEO Position (www.cmtausa.org/news/cmta-hiring-for-ceo). If you are interested in learning more about the position or would like to recommend a professional for this opportunity, please contact Alicia Yamada, senior associate at Kittleman (ayamada@kittlemansearch.com).

Because the CMTA prides itself on providing help for today as its research provides hope for tomorrow, we also have a full slate of activities and events planned for members in 2017. Details are still being worked out for most, but you can add to your calendar the second annual Camp Footprint on August 14 to 18 and a national Patient/Family Conference in Miami on March 18, in addition to your local branch activities.

As you can see, we are off to a busy start for this year. I want to thank every one of you for your support, and promise you that everybody at the CMTA will be working very hard to make 2017 another banner year in our fight against CMT!

Sincerely,

Gilles



Ski-Bike Lets CMTer Return to Slopes

Benjy Hershorn thought his skiing days were over

after a 2011 accident that left him with a traumatic spinal cord injury and late-onset CMT that took years to diagnose. But in January 2017, Benjy returned to the slopes on a ski bike, a specially engineered bicycle-like device with skis instead of wheels.

The slopes were located at Winter Park Resort in Winter Park, Colorado, where the National Sports Center for the Disabled (NSCD) operates one of the largest outdoor therapeutic recreation and adaptive sports agencies in the world.

The NSCD began providing ski lessons for children with amputations in 1970. Today more than 3,000 children and adults with disabilities participate in its programs, which are designed to enable the human spirit through therapeutic sports and recreation. With specially trained staff and volunteers and its own adaptive equipment lab, the NSCD teaches a variety of year-round sports and activities to individuals with almost any physical, cognitive, emotional or behavioral diagnosis.

During his time in Winter Park, Benjy trained and successfully moved from the bunny slope to well up the mountain, untethered from the safety of a bungee cord. He had help on the chair lifts because of his balance issues, and his petite instructor carried the heavy and awkward ski bike up the chair lift in her lap. As Benjy, co-leader of the Houston, TX CMTA Branch, says: "If you see a tortoise on a fence post, you know it had help getting there."

Likewise, he says, he did not get to the NSCD without the support and encouragement of loyal friends, family, the CMTA



Benjy getting briefed by his NSCD instructor

community, and many skilled, dedicated and compassionate medical professionals and research scientists.

Benjy left Winter Park “enthused, energized and inspired” by the other participants—including a brave child with a brain tumor, an accomplished sit skier fighting post-polio issues and a terrific skier with cerebral palsy. He says that the challenges of his CMT Type 2D and incomplete traumatic cervical spinal cord injury with a three-level fusion allow him to relate to the challenges of the NSCD community.

He stresses that his own personal successes were “really not that extraordinary,” but rather the result of following the NSCD’s mantra: Participate while gaining access to the beauty of the outdoors, some level of mastery over fear and physical limitations and self-confidence. “I am NOT one of the extraordinary ones,” Benjy says, adding, “If I can do it—so can you!” ★



Benjy and his NSCD instructor well up the mountain

PREPARATION FOR CLINICAL TRIALS RAMPS UP

Because clinical trials are always the riskiest and most expensive phase of drug development, the CMTA recently created a Clinical Expert Board (CEB), engaging top clinicians from around the world to guide and support to the CMTA’s alliance partners.

The CEB will help to assure the success of clinical trials by:

- Providing the natural history and clinical expertise to design, develop and enable clinical trials.
- Collaborating with scientists in the development of clinical biomarkers.
- Ensuring the adequate recruitment of carefully evaluated patients and experienced investigators to conduct these trials.

The CEB is co-chaired by Dr. Michael Shy, head of the CMTA Center of Excellence at the University of Iowa, and Dr. Mary Reilly of the National Hospital in London, England.

Human clinical trials for promising therapies will take place at the CMTA-sponsored Centers of Excellence. We need to build our database of people with CMT to have successful clinical trials, so it is critical that everyone in the CMT community join the CMT Patient Contact Registry (www.rarediseasesnetwork.org/cms/inc/registry).

The connections made with patients and families through the Patient Contact Registry and the CMTA, together with the use of outcome measures and biomarkers, will provide the Inherited Neuropathies Consortium with access to an adequate number of patients and the means to measure changes in them over time, two key elements essential for the success of any clinical trial.

CMTA WELCOMES NEW BOARD MEMBER AND NEW BOARD ADVISOR

The CMTA is delighted to welcome two new leaders to its Board of Directors and the board's newly established Advisory Board. Tom Dubensky brings to the Board of Directors more than 25 years of experience in biotechnology and in advancing novel drugs to clinical trials. Bruce Chizen, one of the most recognized and respected business leaders in the tech industry, has agreed to serve as an advisor to the board. Their bios follow:

DR. THOMAS W. DUBENSKY JR, PHD, is the chief scientific officer of Aduro, a publicly traded biotechnology company engaged in the clinical development of immunotherapeutic approaches to treat advanced cancers. His background is in virology, immunology, molecular biology and tumor biology, and his expertise is in advancing basic science discoveries to early phase clinical trial evaluation of immunotherapy drug candidates. He has been personally affected by CMT and is strongly committed to helping the CMTA advance compelling clinical candidates to clinical testing.



BRUCE CHIZEN, a technology executive and the former CEO of Adobe Systems, sits on a number of private and public boards including those of Oracle Corporation and Synopsys Inc. After many years of living with undiagnosed CMT, Bruce finally learned the cause of his symptoms. He was referred to the CMTA for a better understanding of the disease and has relied on the organization ever since. "The help that the CMTA provided and the potential of finding a cure for the next generation gives me reason to assist the organization in any way I can," he says.

CMTA ADVISORY BOARD MEMBER PROFILE: DR. GREG STILWELL, DPM

Dr. Greg Stilwell's family tree is rooted in Durango, Colorado, where it continues to spread its branches. His grandparents were homesteaders who settled and then ranched much of the land where he still lives. Greg's son Daniel followed in his professional footsteps, becoming a board-qualified podiatric surgeon who specializes in conservative and holistic care of foot and ankle problems.

Greg recently retired after 30 years of practicing foot and ankle surgery and podiatric medicine, and he now dedicates himself to the self-healing of CMT and scoliosis. Together he and his son are "The Sole Brothers," with a website (drsolebrothers2.wordpress.com) that offers advice and support on topics like pole walking, water exercise, eating right and hydration.



(continued on page 9)



CMTA PATIENT/FAMILY CONFERENCE HEATING UP MIAMI IN MARCH

In collaboration with the CMTA Center of Excellence at the University of Miami, the CMTA is pleased to announce a Patient/Family Conference at the Miami Marriott Biscayne Bay from 9 a.m.–4 p.m. on Saturday, March 18.

Join us for this educational and inspirational conference where you and your family members will have the rare opportunity to interact with CMT experts and meet and chat with many others with CMT. The special guest speaker will be world-renowned clinician and researcher Dr. Michael Shy, head of the CMTA's new Clinical Expert Board.

Topics will include bracing, foot care, physical therapy, CMT research updates and our famous lunch with the CMT Experts! Seating is limited, so don't wait to register. Reserve your space at www.cmtausa.org/miami. The conference is being sponsored by Invitae and Fillauer.

*Hablantes de Español son
¡Bienvenido! Materiales estarán
disponibles en español.*

While adults are attending the Miami Patient/Family Conference, CMTeens ages 10-18 will embark on the journey of a lifetime—the Dolphin Odyssey and Teen Luau made possible by a generous grant from the Dralla Foundation.

At the Miami Seaquarium, participants will hug, kiss, shake hands and play with the dolphins as they frolic in deep and shallow water. They will also have a chance to visit other animal shows and exhibits at the Seaquarium and enjoy lunch at a beachside park. That night, there's a Teen Luau. The experience is

limited to the first 28 CMTeens, ages 10-18, who register (www.cmtausa.org/dolphin).

A waiver and details regarding the event, including times and pick up/drop off information, will be emailed to you shortly after you complete the registration form. In order to complete your registration, you must complete, sign and return the waiver to Jonah Berger at jonah@cmtausa.org.

Also, if this day sounds irresistible to siblings ages 10-18 without CMT, tickets for both events can be purchased for \$170 per child. Please contact Susan Ruediger at sruediger@cmtausa.org to buy sibling tickets or ask questions. ★

Head of Miami Center of Excellence Optimistic About CMT Research

Mario Saporta, MD, PhD, MBA, FAAN and head of the CMTA Center of Excellence at the University of Miami Miller School of Medicine, says that in general he is a pragmatist who sometimes veers

over the line into pessimism. But when he looks to the future of CMT, he's a full-on optimist and says those who have it should be as well.

The genetics field is “on the verge of a revolution,” Saporta says, and a treatment “is likely to happen sooner than we think.”

Saporta's road to Miami took him all over the world before he settled in the Magic City. A clinical neurologist specializing in neurogenetic and neuromuscular conditions, he trained at major clinical and research centers around the world. He did his medical training and residency in Brazil, then went on to the National Hospital in London for a general course in neurology. That's where he encountered Dr. Mary Reilly, now co-chair of the CMTA's Clinical Expert Board (CEB), who imparted her long-standing interest in inherited neuropathies to him. What grabbed him about CMT, he says, was the variety of genes involved, as well as the compelling research model it presented. He says he also found the patients very interesting and he connected with them on a personal level.

Saporta went back to Brazil to finish his clinical training, got



married, then joined Dr. Michael Shy, CMTA Board Member and CEB Co-Chair, in Detroit to continue work in his specialty. He says the city was a bit of a culture shock for him and his wife, but Detroit's sports and music, along with the collegial atmosphere at the Detroit lab, soon

won them over.

After spending three years in Detroit, Mario received the first-ever INC (Inherited Neuropathies Consortium) grant, which funded a two-year stint in San Francisco, working for a biotech company that pioneered stem cell research. After that, it was back to Brazil for the birth of his daughter.

Three years later, neurologists Michael Benatar, MD, PhD, and Stephan Züchner, MD, PhD, invited Saporta to join them at the University of Miami to set up a CMT clinic and research lab. He arrived in Miami in September 2015, but it took a few months to organize the clinic and get funding for the specialists he wanted to include.

The clinic became fully operational in April 2016 and today offers patients a wide range of services—a physical therapist, an orthotist, a social worker and a nurse coordinator. Saporta says the multidisciplinary approach is really the best way to take care of patients, who are then also directly connected with the research.

The clinic is held two Mondays a month. Two-thirds of patients are local, and Saporta credits local CMTA branches,

including Tampa, Sarasota, and Boca Raton for the steady stream of patients making their way to Miami.

Patients who come from afar, including many from South America, are accommodated with Friday afternoon “new-patient” appointments, followed by a multidisciplinary day at the clinic the next Monday. New patients can call (305)243-7400 to make appointments, which will be available starting at the end of March.

Saporta spends about half his time in clinic and half engaged in research. On the research side, Saporta works on developing stem cell lines, which start out as skin scrapings. From there, the cells are induced to become adult stem cells, which can then be differentiated into nerve cells and Schwann cells. The Miami Center of Excellence has developed 14 different CMT lines thus far.

Saporta has a particular interest in CMT2E, which is caused by mutations in the neurofilament light gene (NEFL), the “scaffolding” on the nerve. The mutations prevent the NEFL from assembling properly, resulting in the formation of abnormal filaments.

Saporta praised the CMTA's “very clear drive toward therapy” and said the Miami Center of Excellence is gearing up to be ready for clinical trials in the not-too-distant future. In the meantime, he encourages CMTers to keep engaged, support the research and “be proactive.” There's always a fight over funding dollars for rare diseases, he points out, and patients need to advocate for scientists, just like scientists advocate for patients. ★

DR. GREG STILWELL, DPM*(continued from page 6)*

Dr. Stilwell's own workout regime involves Gyrotonic® related exercises three times a week, water-based movement therapy virtually every day, and Pilates-style pole walking multiple times a week. He is both a proponent and teacher of pole walking and pole dancing, finding them tremendously helpful in strengthening and supporting his upper body while also increasing flexibility and body awareness. He is also a great proponent of yoga and Pilates for people with CMT.

Greg's interest in podiatry grew from watching his mother undergo foot surgery while still in her 40s. He underwent his first

surgery while he was in podiatry school in Chicago, and the chairman of the department straightened his toes. He met his future wife when they both served as volunteers, teaching injured military veterans to dance and enjoy life despite having missing arms or legs.

Dr. Stilwell holds a patent on the Hozhoni Balance Rail (formerly known as the Barefoot Orthotic), an innovative self-adherent orthotic that sticks to the foot, providing support in all kinds of shoes. Named for the Navajo word meaning "to walk in beauty," the Hozhoni (www.hozhonibalancerail.com) can be reused thousands of times. A percentage of all profits from

sales goes directly to the CMTA to help patients with CMT neuropathies have therapies available to them to manage or modify their disease.

While Dr. Stilwell can no longer perform surgery because of his CMT, he lectures internationally on foot and ankle topics, including CMT. His fluency in Spanish has led to speaking invitations from seven Latin American countries, including Mexico, Argentina, Brazil and Uruguay. He is a published author on MRI results of calf muscle atrophy in CMT and is dedicated to helping podiatrists in the United States and Latin America recognize CMT and become current on various diagnostic and treatment options. ★

BOOK REVIEW: "HOW SHOULD A BODY BE?"

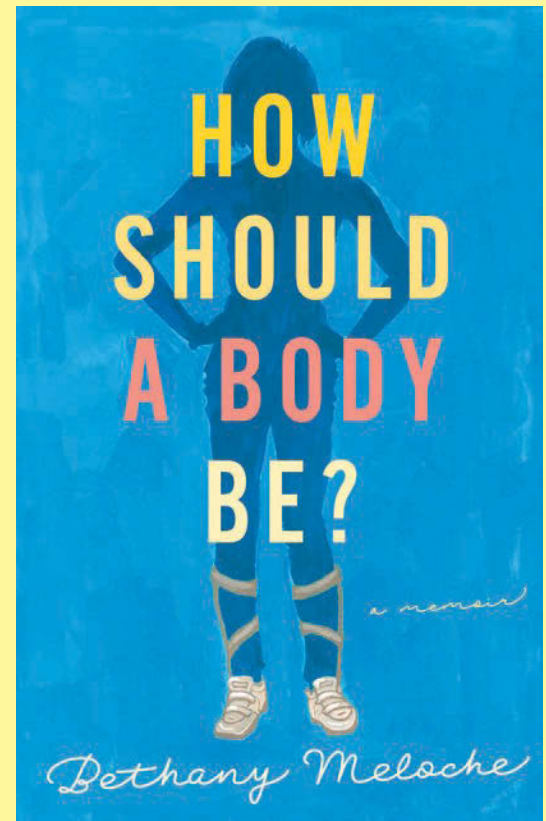
Bethany Meloche's thoughtful memoir—"How Should a Body Be?"—recounts the life story of a strong-willed young woman with a never-give-up, never-look-back stance to being alive in this world. In a culture that places so much emphasis on physical perfection, many are dissatisfied with their appearance and obsess over achieving unrealistic standards of beauty and fitness. Compound these everyday societal pressures with a progressive neuromuscular disease like Charcot-Marie-Tooth—which causes foot deformities, muscle weakness, tremor and breathing difficulties—and growing up with confidence and assurance becomes that much more arduous.

With wit and humor, Bethany relates the challenges of living in a world where people's well-intentioned, but short-sighted commentary and feedback inadvertently amplify her feelings of self-doubt, uncertainty and isolation.

Driven by a lust for knowledge and unquenchable curiosity, Bethany lives each day to the fullest, making her story both unique and inspirational. It would have been easy for Bethany to surrender, to lose hope, to fall into the depths of despair and depression, but by turning her anger outward she discovers strength, willpower, connection and success.

"How Should a Body Be?" is a personal journey toward self-acceptance, healing and living life to its fullest, despite apparent limitations. Mature beyond her years, Bethany offers nuggets of wisdom to be shared, pondered and cherished. Honest, truthful and profoundly insightful, this book is for people with CMT, their families, their friends and anyone who struggles with self-image, confidence and the fear of being seen. This is the best book to date on growing up with physical differences, obvious or not. —*Elizabeth Ouellette*

Visit www.bethanymeloche.com to order "How Should a Body Be?"



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WORKING OUT FOR CMT

When Brian Prochaska, a longtime coach at CrossFit Augusta, turned 40, his wife Ashley and several members and coaches orchestrated a surprise party and workout for him.

Brian was the birthday boy, but the CMTA got the gifts. Some \$450 in proceeds from special commemorative T-shirts and additional gifts went to the CMTA in honor of Brian's sister Cheryl, who has CMT.

The party also raised CMT awareness, bringing people together who had never heard about CMT to help eradicate the disease.



SONIA & ME

BY BETHANY MELOCHE

“Bethany. Bethany, wake up!” I groaned and looked up at my mom, my eyes still half closed. “What?”

“The hotel just called and said someone is here to see you.”

“That doesn’t make sense,” I said, rolling over. “We’re in a hotel in the middle of Peru. No one is here to see me.”

And besides, I thought, I wasn’t getting out of bed and walking downstairs for anyone.

We were in Cuzco, Peru, because my mom was writing a book about two married doctors who’d started a mission hospital in the mountains. I tagged along because... Vacation! Adventure! Fun!

Or at least it would have been if I hadn’t caught a cold on the plane ride there. By the end of the trip, it would turn into a chest infection.

Now, there are a lot of things I don’t complain about—the daily challenges of CMT being a big one. Because those are just that—daily. They are a part of my life, and I have become more-or-less accustomed to them.

But a cold? I respond to colds like they are the greatest injustice that has ever happened to me.

“I think I’m dying,” I said, as dramatically as possible.

“I’ll go find out who it is,” my mom said, heading toward the stairs. “And you’re not dying.”

My mom bounded back up the stairs a few minutes later. She told me the following, as I lay in bed like a zombie—surrounded by tissues and self-indulgent despair:

There was someone at our hotel, in the middle of South America, who wanted to see me. Her name was Sonia—and those doctors I mentioned? They’d given her the name of our hotel, because Sonia also has CMT. And she’d come.

This was enough to get me out of bed. And slowly, my gloomy disposition softened as my mom came back with more updates.

Sonia could barely walk.

Sonia couldn’t get up the four long, rickety flights of stairs up to our hotel room (I’d barely been able to, myself).

The taxi driver and the staff were carrying her up the stairs.

She had traveled a long way. She didn’t speak any English. But she had heard I was here, and she had come.

Despite the fact that Sonia didn’t speak English, and my Spanish is limited, we spoke for four hours. When we very quickly reached the limits of my Spanish vocabulary, Google translate graciously filled in the gaps. (Gracias, Google!)

Sonia asked all the questions that someone with CMT always wants to know: How will it

progress? What can I do to get rid of the pain? What if I have children?

As an English-speaker, all of this information is literally at my fingertips. But that information wasn’t at her fingertips. Outside of her own family, she had never met anyone with CMT before. In contrast, through my involvement with the CMTA, I’ve met thousands of people with my disease. I’ve been able to talk with them (without needing Google translate) and to hear their stories and share my own. Often, they share a lot of similarities. It’s made me feel like part of a community.

These were opportunities that were so easy for me to take for granted until I met a woman—otherwise like me—who didn’t have them.

We lived in different countries, were from different cultures, and didn’t speak the same language. And yet, her hands looked like mine. Her body moved like mine. Despite all of our differences, we shared part of the same world.

At the end of our time together, I knew the last words I wanted to say to her. I think that they are the ones she had come so far to hear—from a stranger who was like her.

“No estas solo.”

You are not alone. ★

From the Mouths of Babes: Working Around the Weakness

BY DIANE WITTENBERG

Part of me feels guilty for passing along the CMT1A gene to my son. But the other part of me sees that it's made him who he is today—an amazing, strong (mentally, if not physically) and confident young man.

Daniel is now 22. When he was in middle school, he was bullied relentlessly. I know how that feels, because so was I. When he came to me at the end of eighth grade and stated, in no uncertain terms, that he was going to play football in high school, my first thought was, “NO! They’ll kill you!” But then he explained: “Mom,” he said, “they won’t and here’s why: 1) it’s a no-cut sport so I don’t need to worry about try-outs; 2) I’ll learn how to work out

and lift weights the right way; 3) you don’t have to worry about me getting hurt because I won’t really be good enough to get much play time and I’ll be on the bench during games, and 4) I’ll never get picked on again because I’ll be hanging out with the football players.”

I was impressed.

This was from a 13 year old! He had some very good points. Although I was still nervous, I was never the kind of mom to stop my kids from making their own choices, as long as the thought process was right. So off he went!



Daniel in uniform

And his plan worked perfectly. From the first day of school, he had friends that he’d made during summer practices. Sure, the football players still gave him a hard time, but in a friendly, teammate kind of way, not a bullying kind of way. Even today, his best friend is someone he met freshman year on the football team.

Another thing that might be worth mentioning ... at that time he didn’t know he had CMT. He just thought he was weak, uncoordinated and un-athletic. I knew, but I didn’t think he was mature enough to approach it the right way back then. I waited to tell him until his junior year of high school so he could address it with confidence and strength, and never use it as a crutch or an excuse.

I’m writing this article instead of Daniel because he doesn’t like to even acknowledge that there’s anything different about him. I think his attitude is that everyone has something, and you just deal with it and live your life. Don’t dwell on the negative. Figure out how to best work around whatever “weaknesses” you have and move on. This doesn’t define who you are. For every ounce of physical strength that CMT takes away, you can gain mental strength to move your life forward in whatever direction you choose. You choose what to do with your life. ★

Diane is a partner at a CPA Firm in Orange County, California. She’s married and has three kids, one of whom inherited her CMT.

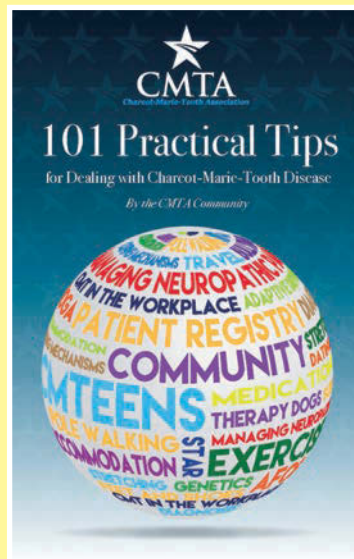
“101 PRACTICAL TIPS” OFFERS DISTILLED WISDOM FROM SCORES OF CMTERS

Written by, for and about the CMT community, “101 Practical Tips for Dealing with CMT” is a must-have book for anyone who lives with the daily challenges of Charcot-Marie-Tooth disease (and anyone who lives with them).

With one-page “tips” and pictures of most of the authors, this portable little book offers practical advice on everything from the importance of stretching to how to adaptive driving to foot care.

As one grateful reader said, “If I were new to CMT and someone gave me this book, I would think I hit a pot of gold because it completely busts through the issues related to isolation, gives so many coping skills, and is so positive in its approach.” This reader went on: “For the newly diagnosed ... the book gives an understandable and empathetic practical explanation of what they have, what they face, what they can do, and what it all means for everyday life.”

To order, visit www.cmtausa.org/101tips or use the order form on page 23.



Yoga + CMT = Compassion

BY REEVE WASHBURN

I was never an exercise fanatic, but I definitely like to stay in shape. I used to think I needed to do more intense conditioning workouts to stay fit—running, kickboxing and high-impact aerobics. After I was diagnosed with CMT, I tried to maintain that exercise regime. I soon realized, though, that my body was getting more fragile and wasn't very happy with my pounding, pumping and fast movements.

CMT1B runs in my family. For my mother, my aunt, their mother (and probably hers as well), it was later onset, with milder symptoms of muscle and sensation loss. I was in my late 40s when I was diagnosed, with plenty of years to deny or rationalize my symptoms. I chose not to reveal my condition to many, which made it an unusual, private burden to bear. Enter yoga.

I abandoned exercise during a very stressful time at work that resulted in the loss of a long-term job. At the time, I didn't realize how much I needed to keep my foot, leg and core muscles strong for balance and mobility. I lost a lot of strength in just a few months and was embarrassed to be part of the GroupX classes I attended since I couldn't participate as I might have been able to in years past. I decided to try a very small yoga class taught by a friend since I felt safe and thought it would be a good place to heal many things from my challenging time at work.

The last time I had taken yoga regularly was prenatal classes with both kids. I enjoyed it and remembered how respectful we needed to be of our growing, changing bodies. I was a little



Reeve Washburn at her home in Seattle, Washington

more goal-oriented at that time, seeing yoga as a way to succeed at natural childbirth. I didn't see it as a regular practice, but more as a physical means to an end.

My new yoga class became a mini-therapy session for me. I had to face so many things that were uncomfortable for me at one time. I had time to take a class in the middle of the day because I was between jobs. I couldn't do many of the standing poses without going to the wall to support myself. I had to be public with my physical weaknesses and be different from the other students throughout class. But then so

much of the practice felt so good: all the stretching, strengthening my upper body with downward facing dog and other floor-based poses or ones where I could use blocks. My wise teacher, addressing the entire class of five, spoke about how yoga is all about compassion: being kind to yourself, listening to your body, wherever you are that day, however you are feeling. The 70-year old classmate heard that comment one way for her body, the 40-plus year old former male ballet dancer heard that comment another way for his. The 49-year-old me heard that it was

(continued on page 23)

The Magic of RPGC

BY CLARK SEMMES

Four-time Super Bowl MVP Tom Brady swears by them and wears them both during practice and while sleeping. CMTAthletes organizer Donna DeWick wears one set during athletic events and another during recovery periods. Iron Man triathlete (and CMTA Hawaii Branch Co-Leader) James Cuizon also wears them on the advice of his coach and trainer. I recently started wearing them, and my leg muscles have never felt stronger. My grandmother wore them, but called them support hose. What is this miracle product? Recovery and Performance Compression Garments (RPGC) are being adopted by athletes everywhere to gain a critical edge.

I first became aware of compression garments while trying to solve a problem common to many CMTers. I noticed that after going to the theater to see a movie, or sitting down for a nice meal, I would have a lot of trouble standing up and regaining the use of my legs. I had to lean on a chair or a handy wall and wait for my legs to decide they wanted to work again.

The reason for this problem is simple: Blood is pumped down to the legs by the heart but relies on muscle contractions and one-way valves to work its way back up again. This system does not work well for those of us with CMT after sitting for long periods of time. Our leg muscles just do not work well enough to push the blood back to the heart. Insufficient blood circulation leads to poorly fed muscles, which refuse to perform when the movie or the meal suddenly end and we try to stand up.

All of this changed for me when I read an article about Tom Brady and discovered compression leggings. The theory is simple: Compression leggings gently squeeze the legs like a ketchup bottle, assisting the muscles in pushing blood back up to the heart. They are tightest at the ankles and slightly looser as they move towards the upper thigh. Compression leggings improve circulation, which in turn means better blood flow to the leg muscles, less cramping and faster recovery from exertion. Plus they come in all kinds of snazzy colors and designs and look really cool!

I enthusiastically ordered my compression leggings, but soon begin to have doubts. Tom Brady

is a professional athlete looking for even the tiniest edge over his opponents. Would something that helped him really have the same impact on me? By the time my leggings arrived I was dubious of their value, but I nonetheless put them on and wore them throughout the day. That evening I went to a friend's house for dinner. To my amazement, I was able to get up from the table gracefully after the meal, without the usual two-minute delay before my leg muscles began working.

That night I wore the leggings to bed, and the next morning I woke up feeling great and went for an eight-mile bike ride, despite the fact that I had just ridden the day before. Now I am a believer. I may never date Gisele Bundchen or become the Super Bowl MVP, but Tom Brady and I now have one thing in common—our super cool compression underwear!

Podiatrist and CMTA Advisory Board Member Dr. Greg Stilwell offers some suggestions for wearing compression garments:

- Fabric content should be breathable and wickable—like hollow fibers either natural or synthetic—and cotton should be limited to less than 50 percent.
- Below-the-knee length compression hosiery is easier to get on and off, but can potentially cause a tourniquet effect around the calf if it is not a quality brand or if swelling exists.
- Several recent papers tout the benefits of sleeping “in the buff,” allowing body temperature to fall at night. Wearing compression stockings to bed might make temperature regulation more difficult. ★



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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: _____

Address: _____

Occasion (if desired):

- Birthday
- Holiday
- Wedding
- Thank You
- Anniversary
- Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

Name: _____

Address: _____

Amount Enclosed: _____ Check Enclosed

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Signature _____

Gift Given By:

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Address: _____

In Sickness and in Health

BY LAURA J. MCGOUGH

Everything was going well until our plane caught fire shortly after takeoff from JFK International Airport. My husband Olaf and I were seated in the second to last row. The smell of burning rubber filled our nostrils and ran down our throats.

I heard the pilot's calm Midwestern voice over the speaker. "You'll see a lot of emergency vehicles as we land. Don't worry. Leave all your belongings and exit immediately."

The tarmac was covered in fire engines, ambulances and people in hazmat suits. I tried to breathe slowly and stay calm as we waited our turn to get off the plane, but my mind filled with questions. Would the engine explode? Would my husband be able to move his legs quickly enough? What IS wheelchair assistance for emergency plane evacuations anyway? Outside, in the blustery, cold wind, I prayed, "Please let Olaf get down those stairs before the plane explodes."

He did. The plane didn't even explode.

We were living overseas at the time and had traveled halfway around the world for a very important appointment the next day at the Mayo Clinic in Minnesota. The journey felt like a pilgrimage. We'd been trying for a decade to find out why he could barely walk and why he felt so much pain. Muscle spasms shook his whole body at night and robbed him of sleep. His legs buckled without warning. His toes curled 90 degrees, his feet arched, and his calf muscles disappeared, leaving thin chicken legs above

bony ankles. He bobbed across the room to avoid falls and bounced himself against walls, as if he were caught in a giant pinball machine. Fearful of being stepped on, the dog scurried out of his path when Olaf walked near.

We tried many doctors before we arrived at the famous Mayo Clinic that cold November day. My hopes were high. They'd fix him, I figured, like a car in need of an expert mechanic, and he'd be able-bodied again.



Laura McGough with husband Olaf

Even the plane fire didn't stop us. Twelve hours later, we arrived in Rochester, Minnesota, a wind-swept little city on the prairie. The clinic's multiple gray towers dominated the skyline, but inside the complex felt like a comforting cocoon. Underground tunnels protected us from the outside cold, while the muted earth-tone decor and the comfortable reclining furniture lulled us. A tuxedo-clad man played classical music on a grand piano. Friendly receptionists with lilting Minnesota accents handed us printouts

of Olaf's appointments. Everything ran on time. I started to believe we were on vacation.

Everything was going well at the Mayo Clinic until the neurologist explained why Olaf couldn't see the surgeon. "His problem isn't surgical," he said. "He has CMT." We looked at him with blank expressions.

"It's a progressive, incurable, neurological disease," he explained.

Progressive. Incurable. Neurological disease.

I stopped breathing.

I waited till the neurologist left the room. Olaf and I held each other. "He said it's not life shortening," I blubbered. "I'll still have you."

The doctor and his assistant returned and offered medical terms as comfort, like buttered toast and tea—degeneration of the myelin sheath, ataxic gait, comorbid scoliosis. Fancy words that mean you can fall flat on your face at any time and doctors can't do anything about it. In the world of neurological diseases, they explained, CMT is not really all that bad—it's not the deadly ALS, the disease that locks you in, or even multiple sclerosis.

We knew we were supposed to feel relieved.

We didn't.

We tried to feel relieved, we really did. We left the doctor's office, packed our things, and checked out of the hotel.

The plane looked bigger and more forbidding on the way home.

Olaf fastened the buckle of his seat belt, leaned close to me and

spoke softly. “I want you to promise me something.”

I smiled. It was an exchange we often had—promise that you’ll love me forever, that sort of thing.

“Ok,” I said. “I will.”

“Promise to leave me behind. If there’s a fire—or a terrorist attack, run. You have to take care of our daughters.”

It felt like he had knocked the wind out of me: a straight punch to the solar plexus, searing pain in my belly and my lungs struggling to find any air. I turned away from him and stared out the small window overlooking the empty tarmac. It was the worst thing he had ever said to me.

Back home, his words haunted me. What would I do in an emergency? Could I save him? Maybe I could be the hero? I could get stronger, I thought, and be the one to rescue us both.

The realization that Olaf would not get better changed something between us in ways

that was hard for both of us to understand, acknowledge and discuss. I took on some of his roles within the family. It was now me lifting and carrying heavy things. For a tall, muscular former athlete, who had crisscrossed the United States on his bicycle several times, the change in our roles felt humiliating to him at times.

Sometimes he talked about his sense of loss. Sometimes he retreated into himself. I didn’t know what to do. Sometimes we were kind to each other. Other times we fought.

His diagnosis brought another change: I became aware of my own vulnerability. I could not take my body and good health for granted. As my friends bemoaned the inevitable losses of middle age, I instead took delight in what my body could still do. I was planning to fight in a masters boxing tournament for my 50th birthday.

Olaf cheered me on as I trained for this fight. It wasn’t easy

for him. As his muscles atrophied, mine grew stronger.

A punch that landed on my right eyeball ended my boxing dreams. My retina detached. I needed multiple emergency surgeries to retain my eyesight. The post-surgical recovery required me to lie on one side for five days. Olaf prepared my meals and took care of me. That was nearly three years ago.

Recently, we flew to Phoenix to celebrate his mother’s 80th birthday. She has CMT too.

As the plane took off, I held Olaf’s hand, and squeezed it. He looked into my eyes. “I love you, Laura,” he said.

I don’t know what we’ll do if our plane catches fire. All I know is that whatever happens to us, we’ll face it. Together. ★

Laura is a maternal and child health technical advisor at the U.S. Agency for International Development. She and Olaf live in Arlington, Virginia, with their daughter Rose and their dog.

THE CMTA IS LOOKING FOR A FEW GOOD CAMP COUNSELORS

The CMTA is looking for volunteers to staff the second annual Camp Footprint, to be held at Camp Kon-O-Kwee, 40 miles north of Pittsburgh, from August 14 to 18. The deadline for applications is March 15.

Camp Footprint will double in size this year, with 75 campers already enrolled and room for up to 90.

Camp Co-Director Jonah Berger will conduct phone interviews until April 1, when all applicants will get final decisions on their applications.

Camp counselors must be able and willing to: lift 50 pounds, actively engage with their campers for an entire day without breaks, walk independently for long distances and assist campers with mobility and personal care needs when appropriate.

What’s it like to be a Camp Footprint counselor? In 2016, Harrisburg PA Branch Leader Erin Gaul was “first in line to volunteer to be a counselor,” but then almost immediately felt hesitant. The doubts and fears crept in and she wondered whether she would be able to keep up with a whole group of kids excited about camp. Erin decided that she would just “figure it out,” an approach that became the motto of the week for the entire camp.

Today, Erin says “It’s crazy to think how close I came to missing out on one of the greatest weeks of my life!” For the first time in her life, she says, she was able to fully participate in every available activity. She saw herself in every camper that week, remembering exactly how she felt at every age level, and knowing that she would have thrived if given an opportunity like this as a child.

To register as a camper or apply to be a camp counselor, visit www.cmtausa.org/camp-footprint.



The CMTA Is Looking for Leaders! *Will You Step Up?*

Do you have CMT or know someone who does? Are you looking for a way to make a difference? If so, the CMTA is looking for people just like you to start a branch or volunteer in your area!

CMTA branches are for those who have Charcot-Marie-Tooth disease and their loved ones. A CMTA branch is a local group of active and caring individuals who share resources, ideas, CMT-related information, and personal experiences, building friendships and a support system in the process. Meetings, which often include guest speakers, focus on CMT education, awareness, research updates, fundraising initiatives, advocacy and current events.

You do not have to be an expert in the field of CMT to start a branch, nor do you have to be trained in facilitating groups. The most essential requirements are motivation, a time commitment, genuine people skills and a sincere dedication to the group and its members. Remember, you will not be alone in taking on this new endeavor; the CMTA is here to help you!

What can being a branch leader do for you? Sarasota Branch Leader Rachel Rivlin says that while she can't do much to change her CMT or prevent it from progressing, being a branch leader allows her to stay informed about what is happening at the CMTA and with the STAR research program. It also allows her to help other members of her branch do the same, making it a place where they all come together to share,



Branch leaders at 2016 Leaders Conference

learn and laugh, all of which helps in dealing with CMT.

Kansas City Area Branch Leader Aron Taylor says that as a branch leader he has the privilege of meeting and serving other families affected by CMT in his community. "You don't have to be an expert to bring people together in your own community and to make an impact through raising awareness and fundraising for this disease that afflicts us all," Aron says, explaining that "by pooling our resources and learning from each other and our guest speakers, we all help each other."

Jo Koenig and her daughter Jill, who both have CMTX, are the co-leaders of the Cincinnati, OH Branch. Several years ago, they were looking for a group near them, but didn't find one so they decided to start their own group. "We are so excited about meeting other people who also are affected

with CMT, sharing thoughts, helpful hints, support and so much more," Jo says today.

If you don't have the time to be a branch leader, you can still get involved with the CMTA by becoming a STAR volunteer. In 2008, the CMTA launched STAR as a strategic research program to maximize breakthroughs in genetics and dramatically speed up the pace of CMT research. As a volunteer, you can create fundraisers in your area, you can participate in our national CMTA Awareness Month, or you can help local branches in your region. By volunteering, you are not only raising funds for STAR, you are also raising CMT awareness in your community.

To join us in our mission to support those with CMT, please contact CMTA Community Services Director Jeana Sweeney at Jeana@cmtausa.org. ★



CMTA BRANCH NEWS

CENTRAL ARKANSAS

More than 100 people registered for the branch's first fundraiser, a Walk4CMT on November 5, 2016. Members raised more than \$8,000 for research, including over \$600 on walk day from donations, raffle tickets and a bake sale. Making the experience even more amazing, participants encountered two men whose significant others had CMT and had never met anyone with the disease. Thanks to the branch's awareness efforts, those ladies will no longer have to feel alone and isolated with their diagnosis.

SOUTHERN CONNECTICUT

Twenty-two people, including six new ones and three members from the Hartford, CT branch, came out to hear Dr. Sabrina Panagoni on October 24, 2016. Dr. Panagoni, a CMTA Advisory Board member and assistant professor at Harvard Medical

School, spoke about the benefits of exercise for CMT patients. She emphasized finding what works best for each individual and the importance of improving balance and flexibility (stretching). One helpful tip was to choose a favorite song and stretch to it every day. Branch Leader Lynne Krupa shared that the group's Cycle/Walk/Run 4 CMT event in September raised \$10,115. She also discussed the CMTA's Stand to End CMT campaign and gave an update on the progress being made through STAR.

SARASOTA, FL

Thirty-one people attended the January 21 meeting of the Sarasota, FL CMTA Branch to hear Dr. Mario Saporta, director of the Miami CMTA Center of Excellence (COE). Dr. Saporta spoke about the genetic causes of CMT, what the Center of Excellence does, the various clinics at the center, how to make appointments and more. He also answered many questions from the group about CMT, orthotics and types of CMT. It was a very lively meeting and several people planned to make appointments at the Miami COE afterward. The branch's new co-leader, Manuel Goldberg, led the group in some exercises and helped facilitate the meeting. In 2016, the Sarasota, FL CMTA Branch raised \$16,929!

SOUTH FLORIDA

Nearly 20 members attended the branch's monthly/holiday meeting at the Boca Raton Community Center on December 11, 2016.

The group spent the bulk of the meeting talking about 2017 plans, including member communication, coordination of off-site social gatherings, new guest speakers and, most importantly, how to build and encourage local fundraising and increase membership.

GREATER MINNEAPOLIS

Nine members, including two new ones, took part in a round-robin discussion of the impact of CMT on each member's life. The remaining portion of the meeting focused on outreach to increase member involvement and raising funds for research. Members agreed to contact all the neurology clinics in the metro area to make sure they tell all their CMT patients about the branch. Co-Leader Marilyn Menser also presented the "Change for Change" fundraising idea and distributed jars for everyone to take home.

SOUTHEAST WISCONSIN

Eleven people gathered at Badger Orthotics in Delafield, Wisconsin, on January 28 for a presentation about the latest techniques used to make state-of-the-art orthotics. CEO John Huenink gave a tour of his shop, where orthotics are precisely constructed using computer technology and various lightweight and flexible materials. Members left with enormous respect for his expertise and hope for what he might be able to do for each of them in the future.

Whatever your 100% looks like...



GIVE IT!



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Most CMTA Branches can be accessed
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Kelly Hall
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Interested in starting a branch in your area?

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

BRANCH LEADER SPOTLIGHT: Roy Behlke, Naples FL

Roy Behlke is a rare bird. He leads not one but two CMTA branches (the only leader to do so), one in his hometown of Hartford, Connecticut, and the other as a snowbird at his winter home in Naples, Florida.

Roy always had trouble with the arches of his feet and foot drop. As a young man, he joined the Boy Scouts, but the mandatory 10-mile hikes were exhausting and frequently required crossing creeks on logs and homemade bridges. Roy ended up falling in the creeks on more than one occasion.

The Boy Scouts were quickly forgotten as Roy developed an interest in airplanes and joined the Civil Air Patrol—the official auxiliary of the United States Air Force—as a cadet. While Roy was less than successful as a Boy Scout, he was a natural as a cadet and soon began rising up the ranks, eventually becoming the Civil Air Patrol leader for the state of Delaware. Roy's love of airplanes also influenced his career decision. After obtaining a BS in aeronautical engineering from the University of Maryland and a master's from Rensselaer Polytechnic Institute, he worked for Pratt & Whitney Aircraft for 45 years, designing compressors for jet engines.

Roy eventually saw an orthopedic doctor, who diagnosed him with arthritis and said he would need to have his all his major joints replaced, one by one. Alarmed at the diagnosis, Roy saw a rheumatologist, who pointed him to a neurologist and finally a correct diagnosis of CMT at the age of 55. The neurologist informed Roy that his nerve con-

duction is just 50 percent of what is considered normal.

Happy to have a correct diagnosis, Roy signed up for the CMTA newsletter, and eventually started his branch in Naples and then Hartford. Jeana Sweeney was the first speaker at his Naples group and even stayed an extra day to help the group get off the ground. Jeana says, "It takes much dedication, patience and organizational skills to be a CMTA branch leader. But it takes a Roy Behlke to be a branch leader of two different branches!" Roy says he gets a great deal of satisfaction from being a branch leader, particularly in meeting folks who have never met another person with CMT. Roy has two children and four grandchildren, none of whom show any current signs of CMT.

Roy is recovering from a heart attack he suffered last December, doing cardiac rehab and gradually getting back to golf and leading

his branches. He says his only problem is that he occasionally forgets which speakers have spoken to which of his groups.

Roy recently penned a CMT-centric version of Lincoln's Gettysburg address, which he delivered at the Branch Leaders' Conference in Tampa, Florida, complete with stovepipe hat. Roy's fascination with the Gettysburg address began when he was just a toddler and his mother recited the famous speech to him while she was washing the dinner dishes one evening. Roy asked to hear it again and the recitation soon became an evening ritual. Within weeks Roy had memorized the speech and would recite it at any opportunity, at home or at the grocery store. Roy's familiarity with this address made it easy for him to reinterpret it as a battle cry in the war against CMT—and made him the Lincoln of the CMTA. ★



Roy Behlke
delivering his
Tampa Bay
Address

Roy Behlke's Tampa Bay Address (with thanks to Abraham Lincoln)

*Six score and 11 years ago our fathers Charcot, Marie and Tooth brought forth
On the European continent a new disorder, conceived in specific symptoms
And dedicated to the proposition that the offspring of all men with CMT
are created with a 50% chance of inheriting the disorder.*

*Now we are engaged in a great medical war testing whether CMTA and its
Partners so conceived and so dedicated can help CMT patients to long endure.*

*We are met here in Tampa on a great battlefield of that war
We have come as leaders to rededicate our efforts to help those with CMT.*

The world will little note nor long remember what we say here

*But it can never forget the brave men and women who have gone before us
To do research, raise funds and help patients with CMT.*

*It is rather for us the CMTA leaders to dedicate ourselves to the unfinished work
which they have fought for and so nobly advanced*

So that this nation and world shall have a new freedom from CMT

And all forms of Charcot-Marie-Tooth disorder shall perish from the earth.

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

Dear David,

I am a 42-year-old woman with CMT. I consider myself fortunate because although I have begun to wear AFOs for stability, I have a career that is satisfying and a long-time boyfriend. I was not interested in having children for reasons unrelated to my CMT. I am writing because I find myself obsessing about the future and worrying that my CMT will one day prevent me from enjoying life. I hate the word progressive or degenerative. My boyfriend and friends keep reminding me to be positive, but frankly, that really annoys me and makes me feel that I'm doing something wrong by feeling down.

David replies:

I completely understand your frustration. I find it particularly unhelpful to cover up very real wounds with a Band-Aid of positive thinking. We only end up suppressing our true feelings while wearing a fake smile. I don't want anyone to tell me to look on the

bright side. I just want someone to say that they get it and they're sorry to hear about my struggle. It's a challenge to let others see us when we're in a rough place. Sometimes pushing ourselves to think positively pushes people away and hides our authentic selves. It's only by letting others see our vulnerability that we can get close. Let's not rob someone of the opportunity to feel true empathy.

Now I would like to address your concerns about CMT being a progressive or degenerative disease. Creating a narrative in your mind that has you helpless and homeless, living a dark and lonely life is not uncommon, but it couldn't be further from the truth. As I mentioned earlier, pushing ourselves to be "happy" and denying the challenges we face every day is unrealistic and inauthentic. Yes, CMT is progressive, but as I'm sure you know, there is no way to



Write to David at info@cmtausa.org.

predict how CMT will manifest. We are all different. I have learned that understanding the "progress" in progressive is about accepting the impermanence of life. To grasp the thought that nothing should change can leave you in a constant state of anxiety.

Everything in life changes, whether we like it or not. Uncertainty is not the enemy. The stories that we make up in our minds are what we need to learn to control. The key to stopping these fearful scenarios is to catch yourself as soon as you begin to form the fearful thought in your mind and simply note that you're doing it again and gently change the thought to something more neutral. The more you bring yourself back to the present from fantasizing about the future, the easier it becomes to live your life at peace in the present moment.

What we need even more than strong legs is a good reason to get up in the morning. That can be a job, someone who needs you, a pet, a garden, a call to a local councilman to voice your opinion about something close to your heart or simply the joy of being alive. The acceptance of "what is," as opposed to how we want things to be, can bring peace to our lives and lead us to see how much we already have that we take for granted. ★

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.

BRING A WALK 4 CMT TO YOUR NEIGHBORHOOD!

Holding a Walk 4 CMT is a great way to bring your community together and create a lasting impact for everyone with CMT. Get together with friends, family and colleagues to raise critical funds for CMT research. You will have 100 percent support from the CMTA and tons of fun in the process! Ready to find out more? Email Director of Community Services Jeana Sweeney at jeana@cmtausa.org.





CMTA MEMBERSHIP, PUBLICATIONS & ACCESSORIES ORDER FORM

YOGA

(continued from page 13)

okay to wobble around, or walk over to the wall for a pose, or kneel when everyone else was balancing on their toes. It is my practice, and no one else's. It was such a relief to accept that.

That was the foundation for what is now a three-year-old weekly practice. After some career exploration, I have a solid job that I enjoy. I had to move to a larger Saturday yoga class, still taught by my wise friend, but I had gained confidence to do what I needed in class and not worry so much about what other people thought of me. I also gained, and continued to gain, strength to be able to navigate my life with more physical confidence. I purposefully stand in the middle of the room and try to do balance and upright poses. It may not look pretty, but at least I try and can see if I am improving.

Yoga seems uniquely suited to those with CMT since there is so much work with the feet, and stances where we work the peroneal muscles on the front of the lower leg, the hip and pelvic muscles and the core, all so critical for balance. Even though my focus is my lower body, I also am experiencing loss of strength in my hands and lower arms. I am convinced that downward and upward facing dog have helped keep my wrists stronger and more flexible.

I know I'm working against the degenerative aspects of CMT, but I continue to see improvement in my own body. It gives me so much personal hope that I wanted to share with others with CMT. I know everyone's symptoms are different, but a message of compassion can apply to all who experience CMT. We can all practice kindness toward ourselves to stay as strong as possible, physically and mentally. ★

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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)
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Cisplatin and Oxaliplatin
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Dichloroacetate
Disulfiram (Antabuse)
Eribulin (Halaven)
Fluoroquinolones
Gold salts
Ixabepilone (Ixempra)
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
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Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
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Lansoprazole (Prevacid)
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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.