

THE CMTA Report

NOVEMBER/DECEMBER
2015

Information on Charcot-Marie-Tooth Disorders for Patients, Families, and the Scientific Community ★ www.cmtausa.org



Charcot-Marie-Tooth Association

OUR MISSION:

To support the development of new drugs to treat CMT, to improve the quality of life for people with CMT and, ultimately, to find a cure.

OUR VISION:

A world without CMT.

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Lessons from TeamJulia: Seven/Family/Bench

BY HERB BERON, CHAIRMAN, CMTA BOARD OF DIRECTORS

Over the years, I've written several newsletter articles documenting the TeamJulia swims named after my 15-year-old daughter, who suffers from Type 2E. The swim has raised close to \$700,000 for the CMTA since its inception in 2007. This year, watching our friends and loved ones—volunteers all—gathered to support our family and our mission of a world without CMT, three words stood out for me: SEVEN, FAMILY and BENCH.

SEVEN. I'm not referring to the uniform number of Mickey Mantle, Phil Esposito or John Elway. I'm referring to the number of full-time CMTA employees. Why is this important? Because everyone else involved with this incredible, dynamic organization is a volunteer—all of my fellow Board members, the entire Advisory Board, every branch leader, every branch member and every person who is a member of the CMTA ... everyone. Because of the size of our staff, we rely on volunteers to help spread the word, help raise awareness and help fundraise. It is critical that we operate this way. Every member of the Board has committed to doing a major fundraiser each

year. We ask every branch leader to organize a fundraiser for his/her branch. As Awareness Month 2015 came to a close, on our Facebook pages we encouraged our members to post pictures of themselves captioned with the phrase "1 in 2500." (Shout-out to Bridget Sarver,

this disease. Although I don't have CMT, I feel like I understand how good it feels when Julia takes her PHAT braces off at the end of the day. Reading our Facebook pages and seeing the interaction that our social community members have with one another only reinforces this

family atmosphere. And frankly, it's precisely because we have all created this family that we now need to take this to the next level from both an awareness and a fundraising standpoint.

When we are organized and committed as one, there is no reason that we can't have every governor in the country issue a state proclamation next September, and eventually have a presidential proclamation for a nationally recognized Awareness Month! It's time that we take

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★ CELEBRATING ★ AWARENESS MONTH 2015

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branch leader from TN for coming up with this fantastic idea!). The resulting photos were gathered in a huge album that illustrates how we are truly one big family, connected to one another and committed to finding a solution to this disease together (<http://on.fb.me/1gSRi2D>).

FAMILY. Yes, we are one family. We stand up for one another and support one another. We understand about the falls, the bumps and bruises on the knees, the calluses on the feet and all of the other things that come with

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STAR 101

BY ELIZABETH OUELLETTE, VICE CHAIR, CMTA BOARD OF DIRECTORS

At the end of 2007, the CMTA's Board of Directors met in Palo Alto, California, to discuss methods of advancing CMT research. At the time, medical research grants were awarded to the scientists whose proposals had the

most potential to break open new territory in the field of CMT, hopefully paving the road to a cure. We were not satisfied with this model, however; it was costly, time-consuming and ineffective. We only had the capital to fund one or two pro-

jects a year, most of which took two to three years to complete. In retrospect, discovering a major breakthrough using this traditional method would have been like finding a needle in a haystack. We had nothing but the best intentions, but discovering a major breakthrough in the world of CMT research would have been a long shot.

Discussions in Palo Alto focused on how to change the face of CMT research by adopting a more proactive and strategic approach, loosely modeled after a few key organizations that had started to apply a business strategy approach to medical research. Key elements of this new approach included:

- Clearly articulating the strategy to achieve our vision and goals.
- Identifying the best researchers in the world to implement plans in support of this strategy.
- Defining metrics to measure progress and linking future funding to achieving success.
- Encouraging and facilitating active collaboration and sharing among our researchers.
- Developing intellectual property to encourage partnerships with pharmaceutical companies and potentially help fund future research.

We called this new model our "Strategy to Accelerate Research," or STAR. STAR promised to speed up the pace of CMT research by capitalizing on advances in scientific knowl-

OUR STAR STRATEGY COMPRISES SIX DIFFERENT ELEMENTS:

1. Creation of Cell lines/Assays (tests). Our scientists replicate the effects of CMT-causing mutations in cells grown in laboratory dishes.

2. High-Throughput Screening (HTS). We then robotically test large collections of 10,000 to 2 million compounds on these cells to see if any of these potential drugs inhibit the CMT-causing mutations without causing unwanted side effects.

3. Laboratory Models. In parallel with the creation of cell-based assays and the HTS process, the CMTA supports the creation and utilization of laboratory models with each disease type so that promising compounds can be tested immediately.

4. Pharmaceutical Partnerships. The CMTA works in collaboration with top pharmaceutical, biotech and governmental organizations like Sanofi-Genzyme, Addex, Pfizer and the National Institutes of Health. In fact, between the NIH and Sanofi-Genzyme, we've screened well over 2.4 million compounds to date. In the coming months, this 2.4 million will be narrowed down to the most promising one or two leading drug candidates, with the goal of beginning clinical trials in the next couple of years.

5. The Human Element: Skin Cells to Stem Cells. Realizing that testing on animal models does not always translate into cures for humans, the CMTA partnered with the New York Stem Cell Foundation (NYSCF), an organization that transforms blood and tissue samples of people with CMT into human stem cells, which are further differentiated into nerve cells and Schwann cells. Once differentiated, promising medications are tested on human cells.

6. Clinical Trials. Human clinical trials for candidate therapies will take place at the CMTA-sponsored Centers of Excellence (www.cmtausa.org/coe). Envisioning clinical trials in the very near future, it is critical that everyone in the CMT community join the CMT Patient Contact Registry (www.rarediseasesnetwork.org/INC/register/index.htm). By joining the Registry, you will be informed of current and new research studies and upcoming clinical trials.

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edge and technology to find a treatment to stop the progression of CMT.

Our new drug discovery initiative requires the collaboration of the world's best CMT scientists, working together, sharing and communicating ideas, discoveries and research findings in real time. These teams of top scientists work hand in hand with the CMTA's STAR Advisory Board to advance CMT research using a translational approach (applying discoveries generated in the laboratory to human beings).

STAR's multipronged efforts are paying off on a number of different fronts. We are currently working on CMT1A, CMT1B, CMT2A, CMT2E, CMTX and CMT4, which constitute 90 percent of all types of CMT. For more information on the work being completed on each type, please visit our website: www.cmtausa.org.

Why give to STAR? There is more hope and promise for a world without CMT than ever before. The CMTA does not receive governmental grants or external money and is 100 percent funded by our Board of Directors, community members, friends and families. As we near the end of 2015, please consider donating to the CMTA's drug discovery program. By supporting the CMTA, you are investing in the future of millions throughout the world. To donate today, please visit www.cmtausa.org/donate. ★



LESSONS FROM TEAMJULIA

(continued from page 1)

this incredibly involved membership that we've created and turn it into a fundraising machine. My wife and I consistently encourage our daughter to be her own advocate, and I encourage all of you to continue to increase your involvement within the CMTA! We ALL need to be our own advocates. We ALL need to go out and raise the monies needed for research and program services. Donations to the CMTA represent an investment in our shared future and it is imperative that we have as close to 100 percent participation as possible to make this vision a reality! And so I ask each of you from the bottom of my heart: Get off the bench!

BENCH. We owe it to ourselves and our children to be involved. We simply cannot get to the end goal of a treatment without a complete and total "buy-in" from everyone! Over the past four years we have expanded our Advisory Board from four members to 17, and these professionals are providing invaluable services to our constituents (including webinars,

newsletter articles, answering questions that come into our website and making appearances at branch meetings). We have increased the number of Centers of Excellence from four to 20, enabling patients across the country to seek out the best medical advice in these critically important multidisciplinary centers. We have increased the number of branches across the country from 25 to 80, enabling our branch leaders to seek out others in their local communities with CMT and spread the message about what the CMTA is delivering—help for today and hope for tomorrow. Lastly (and most importantly) we have substantially increased our level of commitment to funding research, spending close to \$1.5 million this year on new and existing projects. Over the next several years, we hope to expand all of these even more—to reach more people with CMT and to increase the services that we are working so hard to provide.

So, as you're reading this now and when you think about how you can help the CMTA change our collective future, please remember these three words and how they'll determine the path in front of us: SEVEN, FAMILY and BENCH. ★



TeamJulia 2015

The New Genetic Testing Landscape

BY CARLY SISKIND, MS, CGC

CMTA CEO Pat Livney recently said, “Having a genetic diagnosis plays an important role in the quality of life and clinical care for [patients with CMT].” The number of genes thought to cause CMT when mutated grows every month. More and more genetic testing laboratories are offering testing. How do you decide whether to do testing, where to go and how to interpret the results?

Genetic testing is a personal decision. When deciding whether to have it, people usually weigh the pros and cons. On the pro side of the equation, having positive genetic testing means that there is finally an answer to all the sprained ankles and tingling feet, dropped mugs

and torn jeans. If other family members are affected or concerned about having CMT, they can have testing for the same variant, which often means a less expensive test for other family members. More informed family planning decisions are possible with positive genetic testing. And while one con to doing testing is that there are currently no genetic-specific treatments for any type of CMT, information provided by genetic testing helps the CMTA improve the quality and speed of its research.

In the past, cost was a sometimes insurmountable barrier to genetic testing. As recently as a few years ago, only one lab in the United States offered testing for CMT and the technology hadn’t changed in over a decade. Today, 12 labs in the United States do testing for CMT, most of which are using next-generation sequencing, a quicker and cheaper technique. Genetic testing is still expensive, particularly if your insurance company does not cover it, but some labs offer testing for a fraction of its former cost.

Choosing which lab to use for genetic testing is a complicated decision. The labs in the United States currently testing for hereditary neuropathies are (in alphabetical order): ARUP Laboratories, Athena Diagnostics, CGC Genetics USA, Connective Tissue Gene Tests, Emory Genetics Laboratory, Fulgent Diagnostics, GeneDx, HIBM Research Group, Invitae, MNG Laboratories, Transgenomic, and

Quest Diagnostics. These labs differ in the number of genes they offer per panel, cost of testing, experience with CMT genes, customer service and variant interpretation/reporting. These factors are always evolving, which makes picking a lab a fluid decision that changes based on time and the patient situation.

The interpretation of results is perhaps the most important and difficult part of genetic testing. With every gene added to a panel comes an increased likelihood of finding a variant in the genetic code—something that differs from what is called the reference sequence, which is essentially the expected genetic sequence. A change in the code could be the cause of a person’s CMT, but it could also just be a change that makes two people different. PRX, for example, is notorious for having variants that do not likely have any impact on a person’s CMT, versus GJB1, where every amino acid-changing variant is disease-causing. Figuring out these differences is challenging for the lab and can be frustrating for the person with CMT undergoing testing (and for the genetic counselor).

With time, these issues will be resolved. Ultimately, we hope that everyone who wants to know the genetic cause of his or her CMT can have testing and that the technology and interpretation will provide the answers they seek. ★

Carly is a Senior Genetic Counselor at Stanford Health Care and a member of the CMTA’s Advisory Board.

WINTER’S COMING!

Make a recurring donation to the CMTA and get a warm fuzzy knowing that you made a difference with your monthly gift:

- ★ A monthly gift of \$15 helps the CMTA’s 80 branches hold regular meetings in North America.
- ★ A monthly gift of \$30 helps the CMT Centers of Excellence to provide high-quality care in 17 clinics worldwide.
- ★ A monthly gift of \$50 helps the STAR Scientific Team work toward the first treatment for CMT.

When you make a monthly gift of \$30 or more at www.cmtausa.org/monthly, you’ll receive a snuggly CMTA blanket.*

Invest today in the CMTA—the end of CMT begins with you!



*Please allow 6-8 weeks for delivery.

Shoe Shopping for CMTers: The Basics

BY DAVID MISENER, BSC (HK), CPO, MBA

As an orthotist and an individual with CMT1B, I view footwear as the base of the body, much like the foundation of a house: You need to have a solid footing beneath you to build a stable and supported body.

In finding the perfect shoe, one type does not suit all. Some CMTers need footwear suitable for bracing. Others don't need bracing, but are looking for stability and comfort.

The features of a good shoe for the traditional CMT (normal to higher arch) foot are:

- A wide base of support to help the wearer's foot resist ankle sprains and instability
- A strong heel counter to grab the wearer's heel to further resist sprains and instability
- A cushion for shock absorption due to the CMTer's strong and more rigid foot structure
- Ease of donning/doffing (Laces are preferable, but a Velcro closure is fine if it has multiple Velcro straps to pull across the foot and grab it better.)
- Durability (A leather upper adds to durability and breathability. A leather shoe also typically contains better materials, which often means better construction.)

Try to avoid really flexible shoes that you can twist along their length. They offer little to no support.



In finding the perfect shoe, one type does not suit all.

Tips for buying shoes for foot orthotics (FOs) and ankle-foot orthoses (AFOs):

- Take your FO/AFO with you and walk around the store.
- If you are shopping for someone else, check return policies, keep your receipt and test the shoes in clean areas so they can be returned if necessary.
- Buy multiple shoes and return the ones that don't work.
- Wider shoes work better, providing room for a foot orthosis or ankle-foot orthosis. They will also provide additional room to limit pressure points within the foot and toe pressure.
- Removable standard/stock insoles create more room for your orthosis whether it is a simple foot orthosis (FO) or ankle-foot orthosis (AFO).
- The most compatible shoe is a closed lace-up type shoe, such as a sneaker, athletic shoe or walking shoe.

- Don't forget to pull the insole out for a better fit. Try to find shoes that don't have the insole glued into the shoe. These easily removable insoles are often thinner and create more room in the shoe.
- Look for shoes with a wide toe-box.
- Look for lace-up shoes that will allow you to open the shoe as widely as possible. ★

SOME OF MY FAVORITE SHOES THAT FIT OVER ORTHOTICS:

For children:

Hatchbacks, Stride Rite, Sure Fit, Keeping Pace, New Balance

For adults:

Sneakers:

New Balance, Brooks, Avia, Aetrex

Dress/walking:

Keen, Clarks, Rockport, Drew, P.W. Minor

Hiking:

Keen, Merrell

This list isn't exhaustive, but it is representative of successful shoe styles that my clients and I have reported wearing over the years.

HAPPY SHOPPING!



CMTA Member Spotlight: James Cuizon

BY CLARK SEMMES

James Cuizon is a busy guy. Diagnosed with CMT Type X when he was 20 years old, James currently works as the executive director of a large nonprofit organization, works part-time for another non-profit, and somehow still finds time to train and compete as a world-class physically challenged triathlete.

Born to a single mother and raised with the help of his grandmother and two uncles in Waianae, Hawaii, James knew that he was clumsy as a child, but he didn't know why. At 20, he got a job at a paint store that required him to be on his feet eight hours a day. James found

the standing incredibly tiring and repeatedly asked his boss for sitting breaks. His boss advised him to see a doctor; one doctor led to another, and eventually James was diagnosed with CMT and outfitted with leg braces. The diagnosis left James stunned. He initially rebelled and threw his AFOs in the trash. While he later relented and got new AFOs (this time paying out of his own pocket), James was determined to not let his CMT get in the way of his dreams.

James' first "real" job was working as an investigator for the Bank of Hawaii. The job was interesting and financially rewarding, but bad for his health. In just two years, James watched his weight balloon from 140 to 200 pounds. Determined to get his weight under control, James went online and found the CMTAthletes website (now at www.facebook.com/groups/cmtathletes). He was amazed to learn that people with CMT were competing in full-distance Ironman triathlons. He decided that if they could do it, so could he.

James started training, quickly dropping the pounds and increasing his fitness. In time, he started entering competitions. He started with a sprint triathlon, then completed the Tinman Triathlon, and by 2012 had decided to aim for the big time, the 2013 Ironman World Championships in Kona, Hawaii.

To train for the Ironman World Championship, James competed in three races in 2012:

The Dick Evans Road Race (a 112-mile bike ride), the Waikiki Rough Water Swim (2.4 miles) and the Honolulu Marathon (26.2 miles). Then it was time for an Ironman. James won a lottery slot for the Kona Ironman World Championships, but needed to complete an Ironman race to validate his slot. James' first full-distance Ironman triathlon was in Coeur d'Alene, Idaho. Only two racers showed up to compete in the Physically Challenged Division, James and a man named Edward Sproull. When Edward finished the swim with a substantial lead, James thought he was in trouble, but he managed to overtake his rival during the cycling portion and never relinquished his lead. James won first place in his division and headed to the Ironman World Championship in Kona, Hawaii!

Limited to just 2,000 athletes, the Ironman World Championship is one of the premier athletic events in the world. During the race, James reports that his thoughts were on all of the people who supported him on his journey, especially his mom, a cancer survivor, his family and all of the people affected by CMT around the world. James finished in third place in his division and made everyone in the world with CMT incredibly proud!

Recently, James was appointed as the new executive director of Network Enterprises Inc., which provides vocational rehabilitation, job training, job

Ironman James Cuizon



placement and support services to Hawaiian residents with physical, social, economic and/or intellectual/cognitive challenges. James is thrilled to be working for the good of his community and is proud to report that he is close to securing a new seven-figure contract for NEI that will help more people in Hawaii's disabled community land well-paying jobs.

James says that his CMT presents him with challenges every day, including opening toothpaste caps, buttoning his shirt, typing, texting, working on his bike, working with knives and working with anything hot. James puts on his TurboMed* braces as soon as he gets out of bed in the morning. Despite his myriad challenges, James has big plans for the future. In addition to directing the work of the NEI, James plans to compete in next year's Boston Marathon (his second) and a Honu Ironman 70.3 in Hawaii next June.

James advises everyone with CMT to engage in some form of exercise. In his words, "A fit body is the key to everything else. If you don't feel healthy, you won't perform at your best in any part of your life. Don't worry if others are better than you. Do the best you can. The only person you are really competing with is yourself." ★

**James says that before he got his TurboMed braces, he was breaking a pair of carbon fiber AFOs about every six months. He recently became a TurboMed sponsored athlete and says the braces, which he calls the best he has ever used, appear to be virtually indestructible. The company offers a two-year warranty and a 100 percent refund if returned within two months (www.turbomedorthotics.com/).*

NEW MEMBERS JOIN CMTA BOARD OF DIRECTORS, ADVISORY BOARD



Laura Fava joined the CMTA Board of Directors in August

"I had the pleasure of meeting Herb Beron, Susan Ruediger, and Pat Livney at the CMTA family conference in Stanford in September 2014. I was impressed with their level of dedication, organization, and spirit and the progress the CMTA had made in such a short period of time. I met so many wonderful people, in particular a mother all the way from Australia, who had a little boy with type 4E. I walked away from the conference feeling like I had to contribute in some way, not only for my own family, but for everyone struggling with this

disease. I was delighted and honored when some months later I was invited to join the board. I am a lawyer in Toronto, and my hope is to contribute to the CMTA through fundraising and helping to initiate CMT Canada."

—Laura Fava

NEW ADVISORY BOARD MEMBER

SABRINA PAGANONI, MD, PHD, is an Assistant Professor at Harvard Medical School. She obtained her MD degree at the University of Milan in Italy and a PhD in neuroscience at Northwestern University in Chicago. She completed her medical training at Harvard Medical School with a residency at Spaulding Rehabilitation Hospital and fellowship at Brigham and Women's Hospital/Massachusetts General



Hospital. Dr. Paganoni's clinical and research activities relate to her subspecialty interests of neuromuscular medicine and clinical neurophysiology (EMG), with a particular focus on Amyotrophic Lateral Sclerosis (ALS) and the rehabilitation of neuromuscular diseases. By combining her training in neuromuscular and rehabilitation medicine, she assists people with neuromuscular diseases in maximizing function and quality of life.

Boston PFC Draws Largest Crowd Ever

The CMTA hosted its largest Patient/Family Conference to date August 29 at the sleek Seaport World Trade Center in beautiful Boston, Massachusetts. With an all-star cast of speakers, the event drew 215 CMTers from all over New England and the Mid-Atlantic states for a day full of briefings on scientific advancements and tales of personal CMT experience and growth.

The conference started sharply at 9 a.m. with an introduction by CMTA Board of Directors Vice Chair Elizabeth Ouellette, who warmly welcomed everyone in attendance. Local CMT experts filled the morning agenda: Dr. Bill David, Director of the EMG Laboratory and Neuromuscular Diagnostic Center at Massachusetts General Hospital, kicked off the program with a detailed description of the amazing services now being offered at Massachusetts General Hospital, the newest CMT Center of Excellence. Dr. David was followed by Dr. David A. Chad, Associate Professor of Neurology at Harvard Medical School, who spoke on the clinical spectrum of CMT, and Dr. Vera Fridman, the Co-Director of the CMT Center of Excellence at Massachusetts General Hospital. Dr. Fridman spoke about some of the current obstacles to CMT clinical trials, and how they can be overcome.

After the morning break, the conference shifted away from the medical and towards the personal, as the CMTA's

own Director of Social Media, Bethany Meloche, took to the podium to deliver a speech she entitled "Tumbling Forward." The speech was a captivating account of Bethany's personal journey with CMT and the five rules she has learned through hard-fought experience (#1—Teenage boys can wait, #2—Don't trust handicapped doors, #3—Be willing to forge a new path, #4—Face your fears, #5—We are all tumbling forward). The speech garnered a standing ovation.

In a talk that blended the medical and personal, CMTA CEO Patrick Livney spoke

"STAR has shifted the paradigm."

—CMTA CEO Patrick Livney

briefly about his own journey with CMT (even lifting his pant leg to reveal a slender ankle impacted by his own struggle with the disease) before detailing some of the amazing accomplishments and the promising future of the CMTA's Strategy to Accelerate Research (STAR). By getting people "in our sandbox" and requiring them to talk to each other and share their findings, STAR has "shifted the paradigm," Livney said.

Lunchtime offered an opportunity for informal conversations facilitated by the placement of one CMT expert at each table in the conference hall. The break also created an opportunity to cruise the vendor and sponsor tables in the hall-

way right outside the conference room. Conference sponsors included Genzyme, a Sanofi Company, PsychoGenics, Allard USA, GeneDx, Invitae, and newcomers The New England Foot Drop Center and TurboMed Orthotics.

Post-lunch, Paul August, Senior Director of Genzyme Pharmaceuticals, spoke about the ongoing collaboration between the CMTA and Genzyme directed toward finding a drug treatment for CMT1A. Genzyme's Innovation Center in Tucson, Arizona, has screened over 2 million small molecule compounds and now has a list of promising compounds that are being reviewed as possible CMT treatments. "Without you, this project wouldn't be happening," August told the conference.

The next two speakers focused on how to deal with CMT through physical therapy and bracing. Dr. Sabrina Paganoni, an Associate Professor at Harvard Medical School and now a member of the CMTA Advisory Board, told attendees that the goal of physical therapy is to improve strength, mobility, independence, and quality of life through exercises to improve balance, muscle, endurance and flexibility. Noting that the CMTA's research "is on the verge of big changes for CMT," Paganoni urged attendees to prepare for those changes with five minutes of balance and strength training three times a week. She suggested that CMTers consult

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Rylee Sweeney Featured in Film by Famous Danish Artist

While Jeana Sweeney is well-known in CMTA circles as the CMTA's Director of Community Services, her 10-year-old daughter Rylee moves in even bigger circles—the high-octane world of international art. Rylee recently starred in a film by renowned audiovisual artist Jesper Just, and was then treated to an all-expenses-paid visit to Paris to see it.

The film focused attention on CMTA in publications like *Architectural Digest* (AD), which reported that the Danish-born, New York-based Just has long been interested in how buildings and public spaces are set up to accommodate (or not, as the case may be) people with disabilities. "Servitudes" is composed of nine, nine-minute clips shot in and around New York's Freedom Tower, at the site of the former World Trade Center. At the renowned Palais de Tokyo in Paris, the film was shown on transparent fabrics in a basement space navigated by nearly 400 feet of wheelchair-accessible ramps.

It took Just months to get permission to film at Freedom Tower, but according to AD, the artist wanted to use the architecturally and emotionally fraught building as an infrastructural character and mediator between his two human characters—Rylee and the model-actress Dree Hemingway.



Rylee on the big screen

For Rylee, the adventure began last spring when a talent agent called Jeana from out of the blue, looking for a young girl with CMTA who could play the piano. Jeana sent the agent an iPhone recording of Rylee on a Friday, spoke to the director via Skype on Tuesday and by the following Friday was on her way to New York City with Rylee and older daughter Hayley to begin filming.

Rylee first met with a piano teacher who taught her the piece she would play in the film—a one-handed piece that she was to play with two hands. Then Rylee went to wardrobe and makeup and was given a keyboard on which to practice her piece. Filming began the next day at an abandoned restaurant with a white baby grand piano.

Rylee, it turned out, was a natural born star who took direction like a seasoned professional and played her piece to perfection. For more than seven hours she sat at the piano as the filmmakers documented her performing her piece.

The next phase of filming took place at the Freedom Tower. There Rylee studied her reflection in the glass windows

and was instructed to take a rock in and out of her pocket and tap on the building. Five hours later, the filming finally concluded and Jeana and her family headed home.

With no idea that they would be invited to the

Paris premiere, Jeana and her daughters returned to normal life. Then, in early June, Jeana received an e-mail inviting her family on an all-expenses-paid trip to Paris to see the exhibition. Unfortunately, they missed the premier because Rylee did not have a passport, but Jeana, Rylee, Hayley and Jeana's mother arrived a few days afterward.

Not knowing if or when they might return to the City of Light, Jeana, Hayley and Rylee played tourists with a vengeance, seeing every site Paris offered. The culmination of their trip, however, was their visit to the "Servitudes" exhibition at the famed Palais de Tokyo building and viewing the film starring Rylee Sweeney. Jeana reports that the experience was surreal, her daughter's performance was flawless, and Rylee was thrilled with her portrayal.

Jesper Just and his team hope to bring the exhibition to New York and Los Angeles sometime in the near future. And look for more from Rylee Sweeney in the not-so-distant future. The girl is a STAR! ★

Rylee Sweeney and Jesper Just



AWARENESS MONTH 2015

We predicted the biggest and best Awareness Month ever and that prediction came true:

CMTA branch leaders and CMTA community members took these events to an incredible level—more than 500 people nationwide participated in 34 All-Star events, raising \$212,000 for STAR research. Our thanks to each and every one of you: You truly are ALL-STARs!

In addition to the All-Star events, a record 28 states proclaimed September 2015 CMT Awareness Month. Our deepest gratitude to all who contacted their governors for a proclamation. And, for anyone who'd like to do it next year, a request template can be found at www.cmtausa.org/governorrequest.

A total of 30 people signed on for a unique fundraiser called "Go Blue 4 CMT." They promised to dye their hair and/or eyebrows BLUE for CMT and the CMTA if their fundraising goals were met. Their goals were met and the CMTA benefited to the tune of \$20,763.

"Going Blue" wasn't the only creative way community members came up with to raise awareness about CMT: They decorated cakes, wrapped trees in blue ribbon and put the letters "CMT" up in lights. Here are just some of the stories and photos from an amazing month.



THEY WENT BLUE!

TOP ROW L to R: Karen Moss Brown, Ann Dwan, Hayley Sweeney; MIDDLE ROW L to R: Jeanette Thompson, Rachel Rivlin, Donna DeWick, Yohan Bouchard; BOTTOM: Chantelle Lawrence and Barbie

CENTRAL ALABAMA

Twenty-four members of the Central Alabama Branch came out for their Walk4CMT at Veteran's Park in Alabaster, Alabama, on September 19, 2015. The members (and one dog) walked a half-mile circle, some twice, and raised more than \$1,000 for CMT research. They also raised awareness with their hand-made posters. Best of all, they spent quality time with family and friends, both old and new. They plan on making it even bigger and better next year!

NORTH ALABAMA

The branch held its first Annual Walk4CMT on September 19. Forty-two people came out on a beautiful day to show their love and support for everyone with CMT!

SOUTHERN CONNECTICUT

The Southern Connecticut Branch's Cycle/Walk/Run4CMT drew 45 people from across the state—and two from Massachusetts—to the Farmington Canal Trail in Hamden, Connecticut on September 13. For some, it was the first time participating in a CMT event. Angellys Diaz, who has CMT, and her boyfriend, Axel Rivera, traveled over an hour from Springfield, Massachusetts, to walk. Angellys had never met anyone locally with CMT and was excited to be a part of the event. Jessica Purcell, her daughter, Maria, and their team of "Maria's Minions" were first-timers to a CMT event as well. The event raised \$8,585 for STAR research.

CHICAGO AREA

More than 100 friends and family members turned out for the 6th Annual "Reach for the STARS - Walk & Roll for the CMTA" on September 19, 2015. The walk took place at Lake Katherine's Botanic Gardens & Nature Center, a beautiful location with a one-mile scenic path around the lake. Branch members worked together setting up all the breakfast goodies, decorating, and selling T-shirts and raffle tickets for more than 20 baskets and gifts. The group raised more than \$1,500 selling raffle tickets and T-shirts and surpassed its fundraising goal by reaching \$11,000 with more company matches on the way!

INDIANAPOLIS, IN

Forty-seven people participated in the Indiana Branch's first annual Walk and Roll for CMT on September 26, 2015, including lots of young children. It was a day marked by fun and smiles, with a raffle at the end!

IOWA CITY, IA

Thirty-six people, including six with CMT, came out for the Iowa City Branch's First Annual Walk4CMT on September 26. The majority of the group walked one lap around the path. After walking, the kids (some big kids too) put on CMTA tattoos and played with shark squirt guns filled with ice-cold water from the cooler. Everyone received a participation certificate and a CMTA pin. The adults had a good time meeting and talking and raised \$1,455 for CMT research.

BOSTON, MA

Branch members enjoyed a beautiful day at Hopkinton State Park for their first annual Walk4CMT on September 26. They raised \$9,398 from 19 supporters, three teams and 121 donors. Thanks to everyone who joined in to celebrate Awareness Month and to all who make the Boston Branch a warm and welcoming group for people with CMT.

CENTRAL MINNESOTA

The branch held its 1st Annual Dam Walk4CMT at the Crosslake Dam Campgrounds on Saturday, September 26. The 23 walkers started their 2K walk in the fog, but the weather turned sunny by the end. A few people stopped by just to contribute, bringing the total raised to \$1,550.

CLEVELAND, OH

The Cleveland Branch raised more than \$8,000 at its first Walk4CMT on September 19, far exceeding its \$3,000 goal! The rainy weather didn't stop 75 people from coming out. Members walked for nearly an hour, then celebrated with a raffle and their annual CMT Awareness Month picnic. The group is excited about making the walk an annual event. The next meeting will be held in November.

GRANTS PASS, OR

The branch held its "First Annual Walk for CMT, Knowledge is Power" in Grants Pass, Oregon, on September 5, 2015. More than 30 people came out for the event, which included a three-mile walk, a raffle with amazing gifts donated by local businesses, and an after-party at Gilbert Creek Park where Twinkles the Clown distributed animal balloons and kids had their faces painted. The group raised more than \$1,300 for research, and members are proud to have been a part of this groundbreaking event.

CENTRAL TENNESSEE/ SOUTHERN KY

The Central Tennessee/Southern KY CMTA branch held its first fundraiser at the Gallatin Street Festival October 3, raffling gift baskets and selling baked goods and art tiles made by Gallatin High School art students. The day was cold and wet, but the group capitalized on the weather by selling hot chocolate for \$1 a cup. It was a great opportunity to raise awareness. The group raised \$500, quite a feat given that they had to pack up everything early due to the rain. Next year they're going to bring tarps!

NASHVILLE, TN

The Nashville Branch's Nature Walk took place on a crisp fall morning at Long Hunter State Park in Hermitage, Tennessee, on September 20, 2015. The 55 walkers started the walk with a prayer service and breakfast goodies. The crisp morning turned quite warm by the end of the two-mile walk around Couchville Lake and there was lots of wildlife to be seen. The group raised \$5,965 and plans to hold its 2nd Annual walk at the same location on Saturday, September 23, 2016.

DALLAS, TX

Two Great Danes joined 38 walkers in the Dallas Stars Walk4CMT on September 12. Thanks to everyone's efforts, the group raised \$5,295 for CMT research in its very first walk! Post-walk, the group began planning next year's walk, which will be held at the same park with a BBQ afterward.

28 STATES (AND NUMEROUS LOCAL GOVERNMENTS) MADE PROCLAMATIONS



OFFICIALLY AWARE: Alabama, Arizona, Colorado, Connecticut, Florida, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Nevada, New Jersey, North Carolina, Ohio, Oregon, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Virginia, Washington and West Virginia



ALL OVER AMERICA WE WALKED, ROLLED AND RAN 4 CMT...

VIDOR, TX

In one of the most unusual All-Star Events, the Vidor Branch hosted a 5K Zombie Run/Walk, with a 3K route for those who wanted to take it easy. The local high school's art department did zombie make up for those who wanted it. Thirty volunteers staffed the event and 65 people ran, walked, and staggered like zombies. An area news anchor judged the zombie costume contest. The event raised approximately \$6,000, including a donation from the mayor. Feedback was encouraging and people want to do it again next year.



FLORENCE, AL:
Walk4CMT

HARRISONBURG, VA

Thirty people attended the Harrisonburg Branch's covered dish picnic on September 12. Several items were donated for a Chinese auction, raising \$130. A local building supply company donated a bench, which raised another \$300. The Verona Moose Lodge also made a nice donation. After the meal, everyone introduced themselves and explained how they were connected to CMT. A great time was had by all and plans for next year are underway.



VERMONT:
Second Annual Cycle 4 CMT



SAN FRANCISCO, CA:
Walk to Run 4 CMT

SOUTHEAST, WI

More than 75 people participated in the branch's Twilight Walk for CMT at the Mitchell Parks. They raised more than \$6,500 for CMT, made new friends, spread awareness and agreed to do it all over again next year! Thanks to Sandy Faloran of Mitchell Park Domes for making it possible for the group to gather, walk and enjoy the beautiful CMTA rings that crowned the Domes in blue and yellow.



RESEARCH TRIANGLE, NC



MIAMI, FL



PEAKS ISLAND, ME



CENTRAL MINNESOTA: Dam Walk4CMT



NASHVILLE, TN: CMTA Awareness Month Nature Walk4CMT



TAMPA BAY AREA, FL: Walk4CMT



ATLANTA, GA: Walk and Roll 4 CMT



WEST CHESTER, PA: Shooting Stars Walk4CMT



SOUTHERN CONNECTICUT: Cycle/Walk/Run 4 CMT



NORTH BAY, CA: 5K for \$5K!



DALLAS, TX: Dallas STARS Walk4CMT



CHICAGO, IL (South):
Reach for the STARS - Walk & Roll for the CMTA

AWARENESS MONTH 2015

AWARENESS MONTH 2015



At the CMTA, we're grateful every day of every month for our members, for our branch leaders and for our branches. That was especially true during Awareness Month. Not all of the events were held by branches, however, and we'd be remiss in not recognizing a few inspired individuals who stepped up to host Awareness Month events, including a fishing tournament, a beauty salon "Go Blue for CMT," a bike race and a month-long awareness campaign at an elementary school.

IN KLAMATH FALLS, OREGON, 6-year-old Cydney Rae Cornils, who has the rare CMT2E/1F, inspired everyone around her to "Wrap a Tree for CMT." Her class and school (Shasta Elementary) showed their support by wrapping a tree in front of the school with a blue ribbon and attaching a poster explaining what CMT is. Everyone signed the poster and all of the teachers in the school and her closest friends wore a blue ribbon for the whole month of September. Cydney's entire neighborhood also wrapped the trees on its streets with blue ribbons. Marci Cornils says her daughter "humbles us all on a daily basis" with her positive attitude and outlook on life.

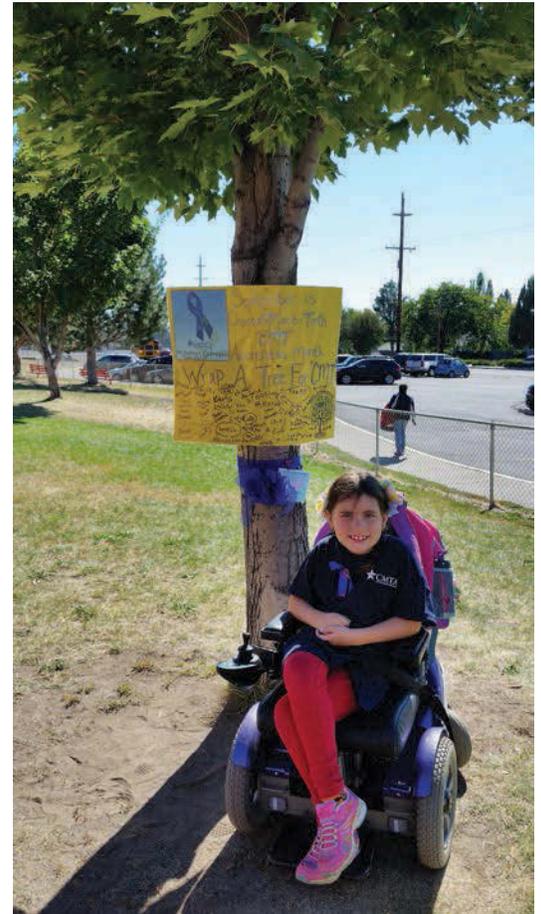
IN MATLACHA, FLORIDA, Ellen Eagle teamed up with Little Caesars franchise owners Jim and Maralisa Addis for the 2nd Annual CMTA Shark Fishing Tournament on September 19. Ellen, her son Joel Lodolce and her sister Patty Bolton started the tournament because they all have CMT and recognize just how crucial funding the research is. Ellen was scouring the community for sponsors—and had almost reached the end of her rope—when she reached out to the local Little Caesars. The request hit close to home for Jim and Maralisa: Unbeknownst to Ellen, CMT touches three generations of the Addis family. The tournament, raffle and silent auction raised \$3,404 and at the close of the afternoon, the Addis family presented the CMTA with a \$10,000 check from Little Caesars, family and friends. The organizers all believe that the fundraiser had divine intervention—and they hope and pray that the 2016 event will be even more successful in the search for a cure for CMT.



ALSO IN FLORIDA, Tom Siddons organized the members of the Virginia Key Bike Club to ride 10 laps for CMT research on September 12. They've raised \$5,225 so far! Two hundred people came out, 160 of them cyclists who rode all day, then joined the others for a big picnic. According to Tom, a local woman whose grandson has CMT handed out water and got a golf cart tour of the trails. The boy's mom and grandma both reached out to him afterward to share how inspired the boy was and to ask if they can bring him back to the club so he can learn to ride a bike!

IN SAUGUS, MASSACHUSETTS, Ann Dwan and The Hair Lounge (where her daughter Alicia Dwan is a stylist) raised \$200 with their "Go BLUE to End CMT" on September 24. For a \$10 donation, salon patrons could add "BLUE to their do" with a blue hair extension. Ann, who was diagnosed with CMT1A in 2007, was on hand during the entire event to hand out educational materials and CMT awareness bracelets and answer questions. Many salon clients made donations after learning about CMT.

Finally, we have to pat two of our own staffers on the back. CMTA Director of Social Media Bethany Meloche and her friends and family raised \$13,941 with the 3rd Annual Bethany's Walk to Run 4 CMT in Birmingham, Michigan, on September 5. And CMTA Finance Director Kim Magee held her very first fundraiser for CMT Awareness Month, walking with family and friends in Philadelphia on September 27 to raise \$1,495 for CMT research.



Wrapping a Tree for CMT



Bethany's Walk to Run in Birmingham, Michigan

THANK YOU.



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AL—North Florence

North Alabama CMTA Branch
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CA—Los Angeles Area

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(This branch will be in
Spanish.)

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**Most CMTA Branches
can be accessed via
the CMTA Online
Community at
www.cmtausa.org.**



THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS:

IN MEMORY OF:

CARL ADAMS
Mr. and Mrs. Steve Koenig

KENTON BERNHARD
Ms. Janice Hinduja
Mr. and Mrs. Jimmie Johnson

RHODA BLOOMENTHAL
Mrs. Belle Sohnen

THERESE COOPER
Mrs. Christina Kealey
Mr. and Mrs. Joe Rawson

GRACE CURRAN
Mr. and Mrs. Patrick Curran

MARY ELLEN FEENEY
Mrs. Gail Feeney-Coyle

DOLORES GASPER
Ms. Lola Langner
Ms. Karen Magid
Ms. Heather Meade
Ms. Diane Minton
Ms. Naomi Niemiec
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Mr. and Mrs. Bob Vasquez
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Ms. Holly Ricks

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and Family
Mr. and Mrs. Ronald Cornett
Mr. and Mrs. Kenneth
Hansome
Mr. and Mrs. Shawn Harris
and Family
Mr. and Mrs. Todd Harrison
and Family
Mr. and Mrs. Lou Randall
Mr. and Mrs. Kenneth
St. Clair, Jr.

KEVIN SUTHERLAND
Ms. Nancy Bevaacqua
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Mr. Robert Tolster
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BETTY WEIGLE
Mrs. Beverly Buhl

LOIS WILLIARD
Mr. Steve Williard

MARY E. YORK
Mr. and Mrs. Robert York

IN HONOR OF:

ELLIOT ADLER
Mrs. Patricia Ostrander

RILEY ASHE
Mr. John McCarthy

KENTON BERNHARD
Ms. Kara Smith

**ETHAN HUNTER
BIDWELL—Happy 13th
Birthday!**
Mr. and Mrs. Steve Junis
Ms. Cecelia McCall
Ms. Ruth H. Todd

ELLIE BUDDEN
Ms. Audrey Budden

GRACE CALDERONE
Ms. Katherine Gibson

**MARY COLE—
Happy Birthday!**
Ms. Karen Cole

CHLOE CUNNINGHAM
Ms. Nancy Cunningham
Ms. Tiffany Jones
Ms. Jeannette Mitchell

**MR. AND MRS.
BARRY EMBODY—
Happy Anniversary!**
Mr. Christopher Kline

GAIL FEENEY-COYLE
Ms. Marian Bakken

ALEXIS H. FOLEY
Mrs. Kay Foley

LORI GORDON
Ms. Karen Suzor

RICKI HAMILTON
Mr. and Mrs. A. Kenneth Fine

KRISTA HERRIN
Mr. and Mrs. Kenny Rutledge

CARTER HUBER
Ms. Lisa Landry

STEPHEN JOYCE
Ms. Judy Joyce

WILLIAM KENNERLY, JR
Ms. Suzanne Kennerly

**PAM AND ROBERT
KLEINMAN**
Mr. Stephen Hess

**ALAN AND RUTH
KOROWITZ—
Happy Anniversary!**
Mr. and Mrs. Norman
Korowitz
Mr. Eric Wollman

THANK YOU!
The Men at Plymouth Estates

**ZACHARY KOROWITZ—
Happy 16th Birthday!**
Mr. and Mrs. Norman
Korowitz

DIANE KOSIK
Mr. and Mrs. Bruce Rose

MADDIE LEARD
Ms. Kristin Leard

JEFF LePAGE
Mrs. Peggy LePage

CLINT LePAGE
Mrs. Peggy LePage

JORDAN LePAGE
Mrs. Peggy LePage

BARBARA LLOYD
Mr. and Mrs. Rick Fansler

TYLER LOPEZ
Mr. and Mrs. Donald Krause

JACOB MATTHEISS
Mr. and Mrs. Robert Hunt

STACI MAUGHON
Meadowcrest Homemakers
Club

MARYANN MOHRMANN
Ms. Charlotte Stoughton

ERIKA POMYKALA
Mrs. Edith Pomykala

**TERRIE AND GENE
ROSENGARDEN**
Mr. and Mrs. Bill Levin

**CHARLES ROTENBERG—
Happy Birthday!**
Ms. Esther Cohen

**STEVEN SCHERER, MD,
PhD**
Mr. Barry Cooper

SAMANTHA SHERIFF
Mrs. Nancy H. Headrick

MARY SPAHN MIRACLE
Ms. Lynne Norton

DEB STETOR
Mrs. Laurie Barnett

**STACEY AND ADALIE
TUMAN**
Mr. Daniel Tuman

**HARRIET WEISS
AND FAMILY**
Mr. and Mrs. Stan Katz

MARK WILLIS
Ms. Barbara McMorrow

JOY WYATT COLBY
Mrs. Nancy Wyatt

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

VISA MasterCard American Express

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____

Flying Tips for CMTers

BY BETHANY TONGATE

With the holiday travel season fast approaching, many of us will be flying to visit friends and loved ones. Flying is tough in the best of conditions. Add CMT and it can really be rough. Here are some tips for making your travel safer and smoother:

Contact the airline. Tell them that you are handicapped and request a wheelchair to transport you through the airport. Major airports are always crowded and require a lot of walking that can be exhausting. A wheelchair comes in handy, allowing you to avoid escalators, trams and people movers. It also eliminates worry about people rushing to their flights tripping you. Plus, the workers know shortcuts to get to your destination.

Request extra leg room if wearing your AFOs. If you choose to wear your AFOs while flying, request extra leg room, if possible. This way you can stretch out your legs so they don't go to sleep.

Allow plenty of time for airport security. Request an alternate security screening and use your Disability Notification Card. Going through security can be a pain, particularly if you're required to remove your shoes. If this isn't possible, show the TSA Agent your Disability Notification Card and ask for an alternate screening. If you don't have a CMTA Notification card, contact your Branch Leader or the CMTA office to get one. Alternately, you can print a generic card from the TSA website

(www.tsa.gov) if you don't have time to get one from the CMTA. You should have the right to an alternate screening, whether it be a body scan or having your braces swabbed. Just know that doing this can take up a significant amount of time since you may have to be swabbed multiple times. If you have any questions or concerns about going through security contact the TSA (1-855-787-2227).

Get a TSA Pre ✓ Pass. If you plan on flying a lot in the next five years, you might want to look into a TSA Pre ✓ pass. To find out more, visit www.tsa.gov/tsa-precheck. The pass costs \$85 and is valid for five years.

Remember to pre-board the plane. The gate agents will make an announcement for people who need assistance or extra time to board first. That is you! Take advantage of this opportunity. You can take your time walking down the ramp, watch your step getting on the plane and get to your seat safely without fear of backing up the people behind you. To be safe, tell the gate attendant you need to board first, so they do not skip the call.

Don't be embarrassed to walk around on a plane to stretch your legs. Walking on a flight can be scary. Just take your time and use the backs of seats for balance if necessary. Even people who have great balance need to hold onto the seats when walking on a plane.

CHECK OUT

www.songbirdmigration.com
for more tips about
traveling with CMT.

Let others exit the plane before you. Upon arrival, wait until the majority of people have exited the plane. If you requested a chair, the person will be waiting in the sky ramp or at the end of the terminal at the gate. Give them your name and they will assist in loading your carry-on under the chair, and/or hand you your luggage in the event you have to hold it.

Remember that these are just tips and sometimes things go wrong. Don't be afraid to speak to a gate attendant or notify the airline as soon as you can. ★

Bethany Tongate is the Central Alabama CMTA Branch Leader and writes a blog about traveling and how to travel with CMT.

GIVE THANKS— AND GET MATCHED!

Thanks to the generosity of one CMTA family, all donations designated for CMT1A will be matched dollar-for-dollar during the month of November in a "Thanksgiving Match." Here is their message to the community about what inspired their challenge:

November is the month of Thanksgiving and those of us who daily live with CMT do, indeed, have much for which to be grateful. Even when we are tired, in pain, discouraged and feeling alone, there are scores of scientists around the world diligently working on our behalf, focused on finding a treatment for CMT. Please give generously this Thanksgiving month for our future and that of our children and grandchildren.

BOSTON CONFERENCE

(continued from page 8)

with a physical therapist or check the CMTA's exercise videos when designing an exercise or physical therapy plan.

Ken Cornell of Cornell Orthotics and Prosthetics addressed the designs and attributes of the many braces currently available for those with CMT. According to Cornell, the goals of bracing include aligning the skeleton, limiting or enhancing specific joints, preventing deformity, and restoring balance. "There's no one brace for CMT," Cornell said, noting that

some CMT patients have low "gadget tolerance" and "poor acceptance" of bracing. He cited the improving quality of dynamic carbon braces as one of the most exciting developments in bracing. Addressing the concern that ankle-foot orthoses (AFOs) might make the legs of CMT patients weaker, Cornell cited an eight-week trial of 19 patients that found that calf circumference decreased with traditional designs but actually increased with dynamic carbon designs. Walking speed also increased and fatigue decreased, he added. "Balance and stance can consume every minute of

every day for CMT patients," Cornell said, and AFOs can be "life changing."

Once again shifting from the medical to the personal, CMTA Director of Community Services Jeana Sweeney recounted her own journey with CMT as well as that of her youngest daughter, Rylee. Initially indifferent and unknowledgeable about CMT, Jeana's life took an abrupt turn with her daughter's diagnosis, and she is now one of the most committed CMT activists on the planet.

With so much information being shared, questions were inevitable, and at the end of the afternoon all of the speakers were invited back on stage as a panel to answer written questions from the audience. The panel fielded questions on topics ranging from insurance coverage for braces, the timing of clinical trials, the expense of genetic testing, the usefulness of vitamin therapy, the value of tendon surgery, and the amount of time devoted to CMT in medical school (not enough).

The conference concluded with closing remarks from CMTA Board Chairman Herb Beron. Herb, whose daughter has CMT, issued a call to action to conference attendees. "We're in this fight together," he told the assembled group, "and as far as we've come we have so much more to do." Noting that charities need money to grow, Herb urged everyone present to "get off the bench" and participate in raising the funds needed to find a treatment for CMT. ★

A FAMILY RALLIES FOR A CURE: SECOND ANNUAL CYCLE 4 CMT RAISES \$230,000!

The Ouellette family engaged Vermonters and their enthusiasm for outdoor activity in the Second Annual Cycle 4 CMT on September 20, 2015, raising \$230,000 for CMT research and increasing awareness among the 150 people who attended. Inspired by Yohan Bouchard (Chris Ouellette's nephew, diagnosed with CMT at age 11), the event was a family affair. It was organized by Chris Ouellette (a CMTA Board Member) with the ongoing support and participation of his wife Mía, his sister Elizabeth Ouellette (Vice Chair, CMTA Board of Directors) and Chris and Mía's children, Warren and Lila, as well as other family members.

Cyclists chose from a number of spectacular routes through the picturesque towns of Charlotte and Shelburne, Vermont. Routes varied from 6.5 miles to 45 miles, but all provided cyclists incredible views of the Green Mountains, the Adirondacks and beautiful Lake Champlain.

The after-party was held at the charming Old Lantern Inn and Barn in Charlotte, Vermont, where both cyclists and non-cyclists enjoyed live music, fantastic food, local beer and a silent auction consisting of products from over 60 local Vermont companies, including Burton Snowboards, Ibex Clothing, J Skis, Patagonia Burlington, and Ski Rack. Each cyclist received an amazing swag bag produced by Select Design that included a CMTA drawstring bag, T-shirt, water bottle, event bracelet and various cycling products. Yohan, Elizabeth and CMTA Director of Community Services Jeana Sweeney provided the highlight of the party with emotional and educational speeches chronicling their own struggles with (and triumphs over) CMT.

The event raised \$115,000, which was matched dollar-for-dollar thanks to a 1A challenge grant, resulting in a fundraising total of \$230,000. The Ouellette family has already started planning for the Third Annual Cycle 4 CMT event: Mark your calendars now for August 28, 2016!



Cousins Lila Ouellette, Yohan Bouchard,
Warren Ouellette



CMTA BRANCH NEWS

• Central Alabama

Ten members (four with CMT) attended the branch's latest meeting on August 22. Members discussed silicone braces, and CMTA Development Director Susan Ruediger spoke about current CMT research. The group also discussed the steps involved in getting into a clinical drug trial.

• Central Arkansas

Eleven people came out for the inaugural meeting of the Central Arkansas Branch on October 3. Members introduced themselves and shared their experiences living with CMT, taking great comfort in meeting others who walk the same path. The branch will continue to meet at Harmony Grove High School in Benton, Arkansas. The next meeting will be a Holiday Potluck in December.

• Sarasota, FL

Rachel Rivlin, the Sarasota Branch's Fearless Leader, arrived for the group's September 12 meeting with blue hair and blue eyebrows for Go Blue for CMT. Members applauded the announcement that Florida Governor Rick Scott proclaimed September as CMT Awareness Month in Florida. Rachel also announced a \$5,000 challenge grant for the group, which prompted one generous member to write a check meeting a large part of the challenge. The group will hold its CMT Walk and Roll at the Sarasota Square Mall on November 7, 2015. Betsy Lieberman from Project Home demonstrated Tomboy Tools, ergonomic tools that are easier



to use for people with hand challenges. Members also shared tips about traveling from companies that specialize in trips for travelers with disabilities, pain relief, and jewelry helpers to make putting jewelry on easier (magnetic clasps, necklace length extenders, elastic bracelets and stretchy rings, Little Fingers Earring Helper, and the Bracelet Buddy fastening tool).

• Fort Wayne, IN

Six people came out to hear physical therapist Brian Roth's presentation at the Fort Wayne, IN Branch meeting on October 11. The presentation was informative, and stimulated attendees to share their experiences. The group also discussed plans for a fundraiser.

• Baltimore, MD

Yoga instructor Cindy Prudhomme led Baltimore Branch members in a session of chair yoga at their September 27 meeting. On the fundraising front, members discussed the importance of becoming "actual" members by paying

membership dues and Anna and Nina Zacharias presented the group with a homemade quilt to be auctioned off at next year's Oxford Biathlon. The next meeting will be on December 6 from 2 to 4 p.m. at the Cockeysville branch of the Baltimore County Library, located at 9833 Greenside Dr, Cockeysville, MD 21030. The guest speakers will be Johns Hopkins neurologist Dr. Tom Lloyd and Allard representative Jayme Brendle.

• Central NJ

Dave Codisco, a Certified Accessible Travel Advocate with Dreams-N-Destinations Travel LLC, was the guest speaker at the Central New Jersey Branch's September 19 meeting. According to Dave, special needs/accessible travel is the fastest growing segment of the travel industry. He is part of a wide network that provides special needs travel for people who need assistance with things like mobility and oxygen. Through Dave's Special Needs Group, he

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CMTA BRANCH NEWS

(continued from page 19)

has access to hotels, cruise ships, theme parks, convention centers and more. The 14 members in attendance spoke freely about their travel experiences—including their fears, hints, and dream travel. An unedited video of the meeting is available at www.youtube.com/watch?v=eeW8tzhpsU. Members were also encouraged to “Wrap Your Tree for CMT,” an easy, non-embar-

rassing, no-stunts-involved way of raising both awareness and funds.

• Pittsburgh, PA

The Pittsburgh Branch’s inaugural meeting went off without a hiccup on October 3. Twelve CMT patients attended along with their guests for a total of 25 people. Everyone loved the Canonsburg location and members were very grateful to have a branch in the Pittsburgh area. The next meeting is set for November 7, 2015.

• Chesapeake, VA

Thirteen people attended the branch’s September 13 meeting, which included a guest speaker from the Muscular Dystrophy Association. Genetic testing was a hot discussion topic for the group, which plans to host a guest speaker on the subject at a future meeting. The next meeting will be held on November 8, 2015, from 2 to 4 p.m., and the branch will meet every other month thereafter. ★



WHAT’S ON YOUR MIND? ASK DAVID.

Dear David,

The other day I was alone in my kitchen and my knee gave out and down I went. No one was home so I crawled over to a chair to prop myself up. When my wife came home, I told her what happened and spontaneously began to sob like a baby. I surprised and scared myself because I am not a crier and honestly can’t remember the last time I cried. My crying went on for about 10 minutes. My wife just let me get it out and hugged me. I have had many challenging situations living with CMT but this was a first for me. Why now at almost 60 years old?

David replies:

The real question is what took you so long to finally let it out. I would have said years ago that men in general have a hard time allowing themselves to be vulnerable and cry, but these days I see just as many women who see crying as an act of shame or weakness. I cannot stress enough that showing our feelings takes

courage and strength. How else can we truly connect to ourselves or anyone else for that matter? Men often turn vulnerability into rage, getting angry or shutting down, anything to avoid appearing weak.

Often we feel the pressure of having to be strong for others and responsible to the people around us so we become out of touch with our own needs. Breaking down allows our hearts to open up to life. Our sadness is a part of life, and suppressing it keeps us from experiencing the full range of feelings, which also include love and joy. We are not robots. We are real people with real feelings. Celebrate all of them. Did you ever notice that after an emotional experience you often feel more tranquil? Sorrow can be transformed into tranquility.

It’s so interesting that when we witness someone else cry we



Write to David at
info@cmtausa.org.

usually feel empathy, but have little tolerance for our own tears. When an episode of crying occurs suddenly and intensely it may indicate the stress of holding back tears for too long. I feel some sadness every day from

the moment I try to get out of bed and put my braces on. I try to acknowledge the feeling, experience it fully, and then move on to the day. I know by now that denying it doesn’t work. Acknowledging sadness makes room for other feelings throughout the day that can include joy, peace and gratitude. Allow all your feelings to flow through you every day. This is the secret to feeling truly human and alive. ★

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.

THEIR TOMORROW BEGINS WITH YOUR COMMITMENT TODAY

There is no greater gift than the gift of hope. You have the ability to give the children of our community the gift of hope-and the promise of a better tomorrow.

Your generous donation will allow children like Jeffrey, Addison, Olivia and Emily to enjoy a better tomorrow because of your commitment today.

Simply fill out this form, or donate online at www.cmtausa.org/donate, and help our children realize their dream of a future without CMT.



YES! The children and families affected by CMT can count on my tax-deductible contribution to accelerate research for treatment for CMT. Please accept my gift in the amount of:

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- \$50
- \$100
- \$250
- \$500
- \$1,000
- \$ _____

DONOR INFORMATION

(The information you provide is confidential and will not be used for any other purpose.)

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CMTA eNews Updates: Yes No

Payment Information

My check is enclosed.

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Detach and mail to:

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PO Box 105
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The Waves

The waves come crashing on the sand
What shall we do? Run for dry land?
Or take our chances and lift our feet
And ride the tide, our fortunes to meet.

We wake up each and every day
To work, and plan, and dream, and play
And strive not to trip or stumble or fall
Our pride intact, our confidence tall.

But the truth comes shining through you see
We have challenges to face, we have CMT.
Our feet are funky, our balance unsure
Our weakened hands are reaching for a cure.

And while we wait for the cure to arrive
We must challenge our fears, we must constantly strive
To teach those around us with the way we face
This challenge with strength and truth and grace.

Try not to be normal, seek not who to blame
Don't add to the weight of your feet with your shame.
Walk your own way, stumble with style
Do more than survive this, thrive this and smile
Go beyond the boundary where your comfort ends
You'll be strengthened by the wisdom it lends
And when the waves come crashing, do your best to be brave
Lift your feet and ride the wave. . . .

—Jonah Berger



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CMTers Give Nike's FlyEase 'A' for Looks And Entry, Mixed Reviews for Fit

BY CLARK SEMMES

LeBron James and I are like brothers. The similarities are uncanny. We're both male, we both live in America, we both speak English, I could go on and on. Now LeBron and I have another thing in common. We both wear the same sneakers. I recently ordered a pair of LeBron Zoom Soldier VIII FlyEase Men's Basketball Shoes. These are the exact shoes that LeBron James wears, but with one crucial difference. The FlyEase feature allows me to slip my feet into the back of the shoes like a comfortable old house slipper rather than having to struggle with the laces.



Nike FlyEase

Look out NBA! LeBron James and I are now doppelgängers!

Nike's new FlyEase technology, essentially a zipper in the back of the shoe that can be zipped shut with one hand, was created in response to a letter from then 16-year-old Matthew Walzer, a young man with cerebral palsy. In the letter, Matthew requested that Nike create a line of more accessible footwear for people with disabilities. As fate would have it, Tobie Hatfield, Nike's director of athletic innovation, had been working for years to make sneakers more accessible. Nike CEO Mark Parker had tasked him with developing the sneaker to help

Two Easy Ways to Help the CMTA . . . And Get Your Holiday Shopping Done!

It's that time of year again—the shopping season is upon us and many of us will choose to avoid the malls and do that shopping online. Two shopping sites will give the CMTA a portion of everything you spend—and it's super easy to sign up. Neither costs you anything—all you do is shop! Think of it as your gift to the CMTA!

More than 1,700 merchants participate in **iGive.com**, including the Apple Store, Best Buy, Drugstore.com, Eddie Bauer, Enterprise Rent-a-Car, GAP, Hilton Hotels, JC Penney, Kohl's, Land's End, L.L. Bean, Macy's, Nordstrom, Office Depot, Radio Shack, Target and so many more. Signing up is simple. Go to www.igive.com/welcome/lp15/wr34.cfm?c=18732. Choose the Charcot-Marie Tooth Association (CMTA) as your cause. Install the iGive.com button and start shopping!

Amazon Smile works the same way. To sign up, simply go to <https://smile.amazon.com/ch/22-2480896> from the web browser on your computer or mobile device. Tens of millions of products on AmazonSmile are eligible for donations. You will see eligible products marked "Eligible for AmazonSmile donation" on the product detail pages.

Thanks in advance for your iGive and Amazon Smile gifts!

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| <p>Subscription Membership Benefits:</p> <ul style="list-style-type: none"> • Online access to valuable information about living with CMT • Access to the CMTA's Online Community, including access to CMTA Branches and Discussion, Circle of Friends and CMTAthletes groups • An information kit and a 10% discount at the CMTA store • Bimonthly delivery of <i>The CMTA Report</i>, (electronic and/or hard copy) • The <i>CMT Facts VI</i> series (electronic copy) | <p>STAR Membership Benefits:</p> <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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*Quantity discounts for these items available online				ORDER TOTAL

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the company's first employee, Jeff Johnson, after he had a stroke.

Anxious to increase the similarities between LeBron and myself, I went on Nike's website and ordered the only shoes currently available with FlyEase technology, the LeBron Zoom Soldier VIII. Less than 48 hours later they arrived at my door.

I am happy to report that the Zoom Soldier VIIIs do work as advertised. A Velcro strap attached to a zipper on the back of the shoe ensures that the shoes can easily be put on by those lacking the manual dexterity to tie laces. They are also very stylish. The ones I ordered are black and grey and way more stylin' than my regular Asics or New Balances.

On the downside, however, these particular kicks may not be ideal for folks with CMT. My big toes are as crooked as a barrel-full of fishing hooks, and only an extra-wide shoe will accommodate them. The Zoom Soldier VIIIs are not currently available in wide sizes and may be too snug to accommodate AFOs, braces, or orthotic inserts.

I'm not the only CMTer who found the FlyEase lacking. One Facebook reviewer said that he wasn't sure his Turbomed brace would fit because of the rear entry feature of the shoe and that they're really tight with his Ottobock AFOs. He might just keep them as a collector's item.

On the other hand, the parent of a CMTer who describes herself as a "shoe detective" on a perpetual quest for the perfect shoe for her son is hopeful that the shoes will work for him. She says that while she initially ordered them too small, and is returning them for a larger size, they seemed to give him lots of support and prevent the ankle rolling that requires him to wear ankle roller bumpers with other shoes. ★

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)
Gold salts
Ixabepilone (Ixempra)
Leflunomide (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)
Fluoroquinolones (Cipro)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in US)
α-Interferon

Negligible or doubtful risk:

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

THE CMTA Report

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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.