

FALL 2016

# THE CMTA Report

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STAND  
TO END  
CMT

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**OUR VISION:** A World Without CMT.

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# CMTA Launches Stand to End CMT

BY SUSAN RUEDIGER, CMTA DIRECTOR OF DEVELOPMENT

In October, the CMTA launched “Stand to End CMT,” a campaign designed to raise funds for treatment and, ultimately, a cure for CMT.

The effort was largely inspired by Julianna Snow, a 5-year-old girl who gained international media attention in January when her parents made public her choice to go to heaven rather than continue the painful treatments that helped her breathe. While CMT is rarely fatal, Julianna had an uncommon form that affected her breathing. Julianna and her family spent the days before her death in June 2016

raising funds and awareness for the CMTA, the nation’s leading organization supporting CMT research and treatment.

CMTA CEO Patrick Livney, who also lives with the disease, explained the impetus behind the campaign: “When Julianna died, so did my patience. We do not have the luxury of time because I don’t want any other family to know this type of pain. This disease needs to be destroyed, and we need money to do it,” he said. “When you stand with the CMTA by making a donation and spread-

(continued on page 4)



*The late Julianna Snow, pictured here with her mother Michelle Moon, inspired the new Stand to End CMT campaign.*

Stand ambassador Cooper pictured with his local fire department



## STAND TO END CMT

(continued from page 3)

ing the word, you are putting us closer to clinical trials for treatments for CMT,” Livney said, adding, “There must be a sense of urgency to fight this disease.”

Supporters of Stand to End CMT are asked to “Stand and Give Me 5” by making a donation of \$5, \$50, \$500 or more, which goes to the CMTA to fund research in search of a first treatment for CMT. After making a donation, participants are encouraged to share the campaign with friends and family via social media using the hashtags #StandAndGiveMe5 and #EndCMT.

Julianna is one of several “ambassadors” for the Stand campaign. Ava, 4, pictured “giving five” with her family on the cover, is another. Ava was diagnosed when she was just 2. Ava’s mom

Karon says her reaction to the diagnosis was: “Wait, what did you say? Charcot Marie who?” Knowing that the diagnosis had forever changed their world, Karon vowed to make spreading awareness about CMT her lifelong mission. “Our family stands with Ava because one day she might lose the ability to stand at all,” Karon says. Cooper, 12, is also a Stand ambassador. Cooper loves to hunt with a crossbow, but his hands are so weakened from CMT that he has trouble holding it, or even giving his friends a high five. Cooper is asking everyone he knows, including his hometown fire department, to Stand with him to End CMT.

“CMT is a genetic disease and there is an explosion of knowledge in this field,” said Michelle Moon, Julianna’s mother. “I believe this campaign will put



*Ava stands to end CMT*

us that much closer to treatments. We are taking a stand for Julianna, and for all the children fighting CMT, because we don’t want any other family to know this type of loss.” ★

*Learn more about Stand to End CMT by visiting [www.Stand2EndCMT.org](http://www.Stand2EndCMT.org).*



**stand.**  
to end CMT

**Join the  
Movement**

## Stand to End CMT was created to raise funds for treatment, and ultimately a cure, for CMT.

Julianna Snow, age 5, was a huge inspiration for our Stand to End CMT effort. She passed away this summer from CMT. She loved tea parties, but most of all she loved the idea of a world without CMT. While she was not able to physically stand, she took a stand to end CMT. Please stand with us and with all of our ambassadors to honor Julianna. Your gift will help fund clinical trials for treatments, and ultimately, a cure. Donate to end CMT.

**YES!** THE CHILDREN AND FAMILIES AFFECTED BY CMT CAN COUNT ON MY TAX-DEDUCTIBLE CONTRIBUTION TO ACCELERATE RESEARCH FOR A TREATMENT FOR CMT. PLEASE ACCEPT MY GIFT IN THE AMOUNT OF:

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# We Are All 'Awkward Unicorns'

BY MICHELLE MOON

Earlier this year, the CMTA asked for people to organize walks all around the country for CMT awareness. "It would be so great to get Julianna out for something like this," I thought. I knew she'd love it, but it was the same old story: stupid CMT. It was hard for her even to leave her room.

After she died, I contacted the CMTA. "We want to walk," I told them. We didn't have the energy to organize it, but if someone stepped up, we would be there. We'd bring Awkward Unicorn (a Julianna surrogate) and walk—for her, and because of her.

And it happened. On October 8, in a park with soaring trees, we gathered for Portland's first-ever CMTA walk.

Believe it or not, this was the first time we came together—in person—with the CMT community. We'd known for years that Julianna had CMT, but didn't think to reach out. Yes, we were very busy keeping Julianna alive, but it was more than that.



Awkward Unicorn Walk

Our CMT is like a freak of nature. In two generations, it went from almost nothing (my husband, Steve) to deadly (Julianna). What does that? (We will have an answer soon—I know it). So even though we had a diagnosis, I didn't feel that we fit in with the CMT community.

On October 8, I met and learned of others with CMT who also don't feel like they fit in.

There are over 90 different types of CMT, and a wide range of severity even within the same type. Many are the first in their family to be diagnosed. So ... none of us "fit in." We are all awkward unicorns.

CMT is a frustrating disease. It's hard to explain, hard to predict, hard to diagnose—and I say this as a neurologist and a mother who has suffered the ultimate loss because of this awful disease. I have wanted to throw my hands up in the air many, many times. Except that it killed our daughter—so I can't. I won't.

My plea (to the world, but especially to the CMT community) is this: We are each other's best hope. If we come together, we can beat this thing. If we don't act, who will?

Whatever you can do—walk, talk, write, give, get people to give, educate, be educated, dye your hair blue—do it. Even if it feels awkward. ★

## ULTIMATE FRISBEE 'MORRISFEST' RAISES \$2,200 FOR CMTA

Ten Ultimate Frisbee teams faced off at Morrisfest 2016, gathering in Long Beach, California, for a fun weekend to raise money for the CMTA. The second annual Morrisfest raised more than \$2,200 through sales of merchandise, team donations, entry fees and a sports bar. Tara and Brent George started Morrisfest (named after their fat cat) last year to raise money for the CMTA in honor of their niece, Rylee Sweeney.

In a bit of serendipity given Julianna Snow's mascot, the Unicorns won the tournament, with members wearing unicorn onesies and custom unicorn fanny packs. Other themed teams included The Ultimate Scientists, who all dressed up in lab coats, and Party in the Back, who all sported mullet headbands. The Georges have great plans for this tournament in the coming years and are always looking for ways to raise awareness for those affected by CMT.



# BREATHING AND CMT

*While uncommon, some particularly severe forms of CMT can affect breathing.*

BY MICHAEL E. SHY, MD, CMT CLINIC, UNIVERSITY OF IOWA HOSPITAL

**W**e receive a number of questions in our CMT clinic about how Charcot-Marie-Tooth disease affects breathing. CMT affects peripheral nerves called “somatic nerves” that carry motor and sensory information to and from the brain. These include the phrenic nerve that goes to the diaphragm and the intercostal nerves that go to the rib cage. Both the phrenic and intercostal nerves are necessary for these muscles to contract during respiration. When they don’t function, breathing is impaired.

Like many other somatic nerves that go to the arms and legs, the phrenic and intercostal nerves are myelinated, so both the myelin and the axon surrounded by the myelin can be affected by CMT. The question then becomes how severely CMT damages these nerves. The answer depends in part on the specific type of CMT a patient has and how severely CMT affects him or her. The bottom line is that most patients with CMT do not develop clinical evidence of breathing problems even if some abnormalities can be detected on detailed evaluations.

## Most Patients

CMT1A, the most common form of CMT, is slowly progressive and has slow nerve conduction velocities. Even though clinical symptoms typically affect the lower legs and hands, all myelinated somatic nerves will have slow nerve conduction velocities. The reason that hands and feet are affected clinically has to do with interactions between abnormal myelin and their axons. These abnormal interactions cause weak-

ness at distal body parts (feet and hands), which are at the furthest ends of the longest nerves. The phrenic or intercostal nerve conduction velocities are also slow in patients with CMT1A; however, partly because these nerves are not as long, patients with CMT1A rarely develop significant respiratory or breathing problems. The same is true for other common types of CMT such as CMTX.

## Unusual Patients

Unfortunately, some particularly severe forms of CMT can affect breathing. In these cases, a profound weakness is usually present in infancy or early childhood. As with other neuromuscular diseases such as muscular dystrophy or spinal muscular atrophy, children have in rare cases died because of respiratory failure. Some adults with very severe forms of CMT have also succumbed because of respiratory problems. In these rare cases, patients suffer from what is called “restrictive” lung disease and become unable to breathe without ventilator support. To emphasize, these cases are very rare, but they illustrate that CMT is not always a “mild” or slowly progressive disorder.

## Diaphragmatic Impairment and Pulmonary Evaluation

From time to time, particularly in cases of CMT4 or CMT2, patients have developed phrenic nerve abnormalities that result in phrenic nerve impairment so that one-half of the diaphragm becomes paralyzed or doesn’t move. The phrenic nerves are constructed so that one connects to the right side of the diaphragm

and the other connects to the left. I have never seen a case that progressed to the point that neither phrenic nerve functioned, although even then a patient would still have intercostal nerves to help with breathing. In situations with phrenic nerve paralysis, patients often ask us about diaphragmatic pacing through electrical stimulation of the nerve. To the best of my knowledge, this has not been shown to work. When we see patients with impaired respiratory function, we have them evaluated by a pulmonologist (lung specialist) who has experience in neuromuscular diseases including CMT. They typically perform pulmonary function tests (PFTs) and blood tests that can help measure the volume of air patients can move in and out of their lungs, the force they can use to inhale and exhale, and the amount of oxygen that makes it into their blood. Results from these tests provide guidance as to what, if any, therapy is required.

## Sleep Apnea

It is increasingly recognized that patients with all types of CMT may develop sleep apnea. Sleep apnea—repetitive pauses in breathing at night—may be caused by obstructions in the upper airway, which may be caused by CMT, although the exact mechanism is unknown. Sleep apnea can result in daytime drowsiness and fatigue. It is typically associated with heavy snoring at night. Sleep apnea can be treated by techniques such as continuous positive airway pressure (CPAP) masks, although these devices can be uncomfortable to wear.

## Vocal Cord Paralysis

Some patients, particularly those with CMT2A or CMT4A, have been identified with paralysis of at least one side of their vocal cords. This can make it difficult for them to generate force or loudness when speaking. It can be associated with shortness of breath. We usually have these patients evaluated by ENT (ear, nose and throat) specialists, who are best equipped to evaluate vocal cord function. Artificially building up the vocal cords is a concern in these situations because of the potential for the vocal cord to close the airway. In extreme cases surgical interventions such as tracheostomies may be necessary.

## Summary

What I presented above is a summary based on our experience from over 20 years of running CMT clinics. While I believe this information to be correct, many issues concerning breathing in different forms of CMT have yet to be studied in controlled trials. Details of respiratory function in patients with CMT are not yet available, though we are starting to address this in our Inherited Neuropathies Consortium (INC) with support from the CMTA. Over the years, we have performed some studies of pulmonary function tests in patients with CMT1A and these have generally been normal, although we have not looked at changes over time. Clearly, more work needs to be done with this important issue. In the meantime, we also need to encourage patients not to smoke or do any other activities that are harmful to their lungs. ★



Dr. Shy is the director of the CMTA Center of Excellence at the University of Iowa Carver College of Medicine.

## CMT FOUNDATION DONATES \$50,000 FOR BREATHING STUDY IN HONOR OF MARAH GRIFFITH

Julianna Snow wasn't the first beloved daughter to suffer respiratory failure from Charcot-Marie-Tooth disease. JD Griffith's 16-year-old daughter, Marah, died of it on Christmas Day 2001. In August 2016, the CMT Foundation, which JD founded after Marah's death, made a \$50,000 donation to the CMTA to sponsor a breathing study in her honor.



Marah Griffith

The study will be conducted by Michael Shy, MD, head of the CMTA's Center of Excellence at the University of Iowa Carver College of Medicine. JD said he hopes the study will "result in the recognition and documentation of respiratory problems as a result of Charcot-Marie-Tooth disease, the diagnosis of these problems and their ultimate treatment."

In the months and years following his daughter's death, JD joined the CMTA, started the Johnstown, PA Branch, created the Charcot-Marie-Tooth Foundation (with considerable help from CMTA Director of Community Services Jeana Sweeney), helped organize a Charcot-Marie-Tooth clinic at the local hospital and raised money for the CMTA. He acknowledges that raising money for the CMTA is "critical," but says the serendipitous discovery of Jeana Sweeney at the Johnstown Branch's first meeting was a true gift.

Marah expressed her feelings about living with CMT in poetry. While JD found it heartbreaking to watch her struggle "to maintain the illusion that she was normal" while expressing her torment through her poetry, today he finds those poems a comfort. He shared one written after she was blown over into a mud puddle in front of her classmates.

### ***Come Take a Walk in My Shoes*** BY MARAH GRIFFITH

*Down the crowded street I walk trying to stand tall  
People look down and stare at me  
I know exactly what they are staring at.  
It hurts me.  
It's like an arrow piercing my heart  
If I could change it I would  
With the blink of the eye I would change it  
But I can't.*

*I can't sit and wonder why I have this pain and others don't  
But instead I have to wake up each morning  
And try as hard as I can to be as strong as steel  
And know that in the end I will be the stronger and wiser person.  
So, next time don't laugh and gawk.  
Maybe think about what it is like to be me  
Why don't you take a walk in my shoes for a little while.*





# CMTA MOUNTS FIRST-EVER

Forty campers and 25 staffers converged on Camp Kon-O-Kwee in August 2016 for the first-ever Camp Footprint, a free, five-day sleepaway camp for youth with CMT. For many campers, the experience was life-changing. This was just the beginning. Plans for the next Camp Footprint are already underway. It will again be held at Camp Kon-O-Kwee, 40 miles north of Pittsburgh, from August 14-18, 2017. Campers can register at [www.cmtausa.org/camp-footprint](http://www.cmtausa.org/camp-footprint). In the meantime, enjoy these camp stories from the CMTA's CEO and community services director, the camp director, a camp counselor and a camper...

## Oh, What a Feeling!

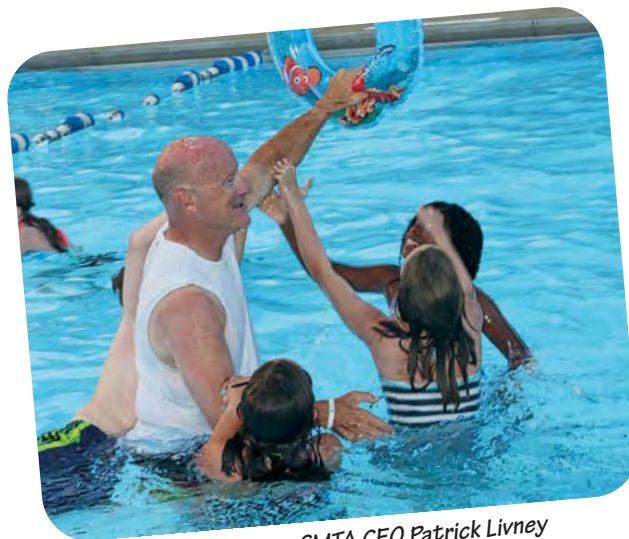
By Patrick Livney, CEO (and camper)

After serving as a camp counselor for the Muscular Dystrophy Association kids' camp for several years, I dreamed of a camp devoted solely to kids affected by CMT. This year that dream came true. We were all in an environment where everyone understood everyone else. There was no pretension and plenty of helping hands and shoulders to lean on. While this camp was for kids with CMT, I too participated in the historic week, and felt young again!

Camp Footprint, staged in the beautiful western hills north of Pittsburgh, was an incredible experience for campers and counselors alike. There were no limitations, and when faced with speed bumps, we all "just figured it out!"

Zip-lining, fishing, archery, midnight walks, campfires, arts and crafts, trolley rides, glitter wars and treasure hunts were all part of the mix. With 100 percent participation in all events, the smiles, the accomplishments, the tears and the new friendships will forever be etched in my brain.

As the CMTA strives to meet our mission of a first treatment, Camp Footprint is now in place to provide tangible improvement in the quality of life for many CMT kids. I'm so proud and honored to have been a part of this incredible week. On to year two! ☀



CMTA CEO Patrick Livney





# CAMP FOR KIDS WITH CMT

## Campers, Counselors Share Profound Connection

By Jonah Berger, 2016 Camp Footprint director

A lot of energy went into planning Camp Footprint, and the results far exceeded expectations. United by excitement and enthusiasm, the dedicated staff of volunteer counselors came together for training the day before the kids arrived, decorating the cabins, getting to know each other and mapping out the week. The campers arrived at the Pittsburgh airport on Monday, August 23, from every corner of the United States, as well as Mexico and Australia! The first day was all about getting to know each other and soaking in what it's like to be surrounded by others who deal with similar challenges and hold similar wisdom.

Over the next five days, campers accomplished a lot: kayaking, canoeing, swimming, wall climbing and traversing high rope obstacles. They also sang and laughed without limit! On Wednesday evening, when the sun went down, the group gathered at the edge of a thickly wooded trail. What happened over the next hour was pure magic: The entire group of imbalanced and funky-footed

campers and staff set out on a night-time hike in the total dark, with not a flashlight to be found. Campers and staffers alike faced fears, built trust and made it to the other side. It was a highlight of the week!

The final night of camp found campers on a treasure hunt, complete with a buried treasure chest full of camp goodies. A local restaurant catered an amazing luau afterward, with dancing, awards and reflections on the week spent with this amazing community.

In looking back over this fantastic week, a number of things stand out—the activities, the devoted staff, the beauty of the Pennsylvania woods, and the bravery of the campers in taking on feats that most would deem out of their range of ability. What stands out far above the rest, though, was the connectivity of the campers and staff and how quickly the shared challenge of CMT brought them all together. By the second day of camp, friendships were forming, leg brace comparisons were abounding, and stories of life



*Jonah Berger, 2016 Camp Footprint director, with Timothy*

with CMT—the good and the challenging—filled the air.

A collection of individuals aged 10 to 18 connected into one group, united by their CMT. They looked out for each other, helped each other over tough terrain, encouraged each other to participate in all of the activities, and most of all, felt normal. For once, they were not the one person in their family, among their friends or at school dealing with difference. When they looked around, they saw that everyone was struggling and overcoming struggles in the same way. It was a profound connection that affected every person there. ☀

# The Sloth is My Spirit Animal

By Carly Ann Blaukat Sizemore, 17, camper

I never thought I'd find someone who would understand what it's like to have CMT. Then my mother saw a little banner on Facebook about Camp Footprint, the first annual camp for kids with CMT. I was shocked, but without hesitation I said, "Let's do it." In no time, I was booking a flight to Pennsylvania.

I've known I've had CMT almost all of my life. It affects my legs and now it's starting to slowly affect my hands. I've never let that stop me from being an adventurous person, but I hid my CMT from the world because I thought no one would understand. When I tried to explain, people would ask if CMT stood for Country Music Television or look at me puzzled like maybe I stuttered.

I'm a naturally slow person. If I had a spirit animal, it would be a sloth. When I go fast I can hurt myself or look like a fool. But like my mom says, the world "doesn't revolve around Carly" so I've adapted and overcome. With

every ankle sprain and fall, I've learned to get back up and laugh along. I held back the tears from all the apathetic people and looked down to see where I was going so I wouldn't fall again.

Camp Footprint was different. All through the week I felt something I've never felt before—empathy. All around me were people who understood my pain, my weakness and my troubles. We all had a joke when we started talking about CMT. Someone would freak out and

say, "Wait, you have CMT?? I have CMT! This is crazy!" Then another person would chime in and say, "I do too!" and we would all freak out because almost everyone there had it.

Every day was something new and never once did I ever feel alone, degraded, or like someone wouldn't understand if I needed to take a break or if I fell down on some air. Nothing was rushed, we could be sloths and that was okay because everyone was a sloth. Many people came into camp



Erin Gaul, second from right, with Camp Footprint staff

Dear Camp Footprint,

I want to thank you for the gift you gave me last summer at the first-ever camp for kids with CMT! I don't know how I got lucky enough to be a part of something so special, but you will forever hold a place in my heart!

I was first in line to volunteer to be a counselor, and then almost immediately felt hesitant! The doubts and fears crept in and questions popped in my head about how I would be able to keep up with a whole group of kids excited about camp. I decided that I would "figure it out," which ironically became the motto of the week for all of us! It's crazy to think how close I came to missing out on one of the greatest weeks of my life!

Camp Footprint, you brought together a diverse group of adults and kids who all share a common bond that has now developed into life-long friendships. I was wiped out that week for sure! I would like to say it was due to my CMT, but I think my age played a bigger part! In fact, CMT didn't keep me from a darn thing! For the first time in my life, I was able to fully participate in every activity that was available!

Camp Footprint, you gave us all the opportunity to be FREE! I saw myself in every camper that week. I remembered exactly how I felt at every age level, and how I would have thrived if given an opportunity like this when I was a kid. I am so grateful for all the people I met that week, who have now become my family! Thank you for amazing memories, friendships, opportunities, FUN & FREEDOM!

Until we meet again Camp Footprint,

Erin Gaul

Camp Footprint counselor (and Harrisburg, PA branch leader)





Camper Carly Ann Blaukat Sizemore (facing camera)

wanting to go back home on the first day, and then cried the last day saying they would pay rent and clean the camp trolley if they could stay. Jonah Berger, the camp director, told us on the way from the airport to the camp that we might be spread out on the bus on the first day, but he promised that going back to the airport we would be a family. Just like he said, the last day we were all huddled together, three to a seat.

Every night at camp we had “foot time,” when we all got together in the common area to care for our feet and have foot baths and massages. Every day we had little talks about CMT. Every single person had empathy, love, compassion and something to offer. It was truly a little miracle.

Without this camp, I wouldn’t be as confident with my CMT as I am now. I wear my shirts and bracelets loud and proud. I talk about it constantly. I want to make people more aware, find a cure and get this thing done. Without this camp, I also wouldn’t have known what true friends are. I’ve made friends who will be in my life forever and ever. I have friends in Australia! I still fall, but what keeps my slow self going is that I always have something to look forward to. And that would be seeing my CMTA Camp Footprint family again. 🌟



Jeana Sweeney, CMTA community services director, with Vanessa

## Words Cannot Describe

By Jeana Sweeney, CMTA community services director

*E*xhilarated. Happy. Loved. Tired. These were just some of the words that the kids at Camp Footprint used to describe it. The kids got to experience so many things that those of us with CMT long for, but I think that the most important was freedom—freedom to fit in, to be themselves and to try what they thought was the impossible. Trying—and succeeding at—canoeing, fishing, swimming and so much more—gave the campers self-confidence and a sense of independence. Within this bubble of freedom, campers and camp staff built bonds that will never be broken. Thanks to social media, those relationships will be maintained.

CMTA staff started talking about doing a camp several years ago. CMTA CEO Pat Livney was passionate about the idea because of his experience as a counselor at a Muscular Dystrophy Association camp for kids. He wanted chil-

dren living with CMT to have the same experience. The CMTA lobbied the state of Pennsylvania for funds to start the camp (not an easy task) but lo and behold, we got a YES! The state granted the CMTA \$100,000 to hold Camp Footprint, helping the CMTA make history!

For many campers, the feeling of fitting in was a new one. One child’s experience is typical. This camper had never really felt like she fit in with her peers and often sat alone reading a book during lunch time at her school. She thought things would be the same at camp. She had no expectation of fitting in there either, so she packed a book with her things. As the week went on she began to open up and talk to those around her. Asked to name her favorite part of camp, she said, “Everyone here knows my name.” She returned home happy, her book still unread. 🌟

# SUMMER FUN(D)RAISERS

## THIRD ANNUAL CYCLE 4 CMT IN VERMONT

More than 150 people attended the 3rd Annual Cycle 4 CMT in Charlotte, Vermont, on Sunday, August 28. With more than 500 donors, the event brought in a whopping \$120,000, which will be dedicated to the CMTA's STAR drug development program. Friends and family from near and far attended the event, including Drs. Mike Shy and Steve Scherer. Organizer and CMTA board member Chris Ouellette extends a sincere thank you to all attendees, donors, volunteers and sponsors. He's already planning for next year's outing, which is scheduled for August 27, 2017.



jewelry, and even Trump-brand Champagne. Vittorio shared his story of living with CMT and people left the party feeling great and proud to have helped out. At the end of the night, Vittorio and his friends formed their biggest cheerleader pyramid yet—four people high—and held it for about four seconds before collapsing on top of each other.

## EIGHTH ANNUAL JOHNSTOWN SOFTBALL TOURNAMENT RAISES \$16K, ILLUSTRATES IMPORTANCE OF VOLUNTEERS

Sixteen teams raised \$16,000 in the Johnstown, PA CMTA Branch's

8th Annual softball tournament August 13-14! Family and friends from Johnstown and surrounding

areas came together for a friendly game of ball, cheering opposing teams in support of one cause. Even kids dedicated their time grinding out snow cones, running games and painting faces.

The reason this tournament is

so successful (and the way it can become even more successful) is the volunteers. Yes, Jeana Sweeney does an amazing job, but she cannot do it without help. The tournament needs players, bake sale workers, sign makers, and donors to make it a true success. Most of us recognize that if volunteers didn't exist, efforts to better our lives or the world around us could not be achieved. The diseases, natural disasters, and personal losses can be overwhelming, but with support and dedication, we can lessen the burden of these enemies.

How do you decide where to give your volunteer time? For me, participating in fundraisers that directly benefit a family member is definitely the most rewarding effort. My sister (Jeana) and niece have been diagnosed with CMT. My loved ones show strength and determination on a daily basis. They have dedicated their lives to finding a cure. Their passion influences everyone around them. Because of this, I choose to donate my time and dollars to the CMTA. The belief in finding a cure is contagious and the love and support we show our family

members just fuels their strength to fight! Volunteering for causes that affect your loved ones has to start with us. Teach your chil-

dren to show this type of compassion. They learn how to appreciate what they have and it teaches them the value of family, friendship, and, most importantly, self-worth.

—Tonya Lane



## VITTORIO'S FUNDING THE FIGHT CMTA FUNDRAISER

One hundred people came out on July 9 for the 4th Annual (Vittorio's Funding the Fight) CMTA Fundraiser in Gloucester, Massachusetts, raising a record \$26,000 for STAR! Vittorio's high-school friends arrived early to help cook the sausages and burgers under "the watchful, sometimes overbearing, eye" of his father. Auction items included fishing rods, Patriots tickets, homemade






## NORTHERN NEW JERSEY'S 4TH ANNUAL STAR WARS FOR CMT AWARENESS

On Monday, August 15, the Northern NJ CMTA Branch held its Fourth Annual CMT Awareness Night (the third with a Star Wars theme) at the Somerset Patriots in Bridgewater, New Jersey. This popular baseball fundraiser



brings out tons of baseball and Star Wars fans, as well as CMTA supporters! The CMTA logo was displayed on the scoreboard throughout the evening as numerous announcements reinforced the message and spread awareness for Charcot-Marie-Tooth Disease. Special game-worn R2D2 Jerseys were auctioned off after the seventh inning with proceeds benefiting the CMTA. The event brought in close to \$5,000 for the CMTA, and a grand total of almost \$16,000 when combined with a local match! ★




Many thanks to the



# Hanger

CHARITABLE FOUNDATION

...for funding two grants for Camp Footprint. Because of its generosity, 15 campers were able to travel to camp without any personal expense. The Hanger Charitable Foundation also funded Transcend CMT Day, dedicated to enabling campers to overcome their physical challenges for a day.

## *Big Thanks to All Federal Employees!*

Thank you very much for your past support of the CMTA through the Combined Federal Campaign. By the end of September 2016, contributions for the year amounted to more than \$9,000. These contributions allow the CMTA to meet its mission of improving the quality of life for those with CMT by providing community members with resources and information, increasing awareness about CMT and funding research for the development of treatments for all types of CMT. Our progress includes:

- Creating 77 Branches throughout North America, providing local resources for those with CMT
- Building our social media presence and interacting with more than 25,000 people through Facebook, Twitter, LinkedIn and Pinterest
- Spreading the word about CMT to physicians and clinicians through trade magazines and partnerships
- Gathering a robust STAR Advisory Board, identifying experts in the industry, and forging partnerships to develop protocols and pathways for 90 percent of all types of CMT—1A, 1B, 2A, 2E and X

Your generosity has helped us achieve these major milestones. In the coming weeks, the CFC will open for the 2017 giving year and the CMTA is once again approved as a national charity for 2017. The CMTA has earned a four-star rating from Charity Navigator and has consistently been awarded the Independent Charities Seal of Excellence. Our CFC number is 10597. We ask that you please give generously once again. Thank you!

# How to Talk About CMT When People ask What It Is

BY THOMAS MELOCHE

If you are reading this magazine, you fall into a special group of people. You have to explain CMT. You may be talking to friends, family, co-workers or complete strangers who have probably never heard of it before. You may be asking them to give to the CMTA. You may be answering a question about your struggle. You may be telling them about CMT research. In all cases they eventually ask, "What is CMT?"

What do you say back?

Here are a few suggestions  
about how to reply:

1. **Keep it simple**—Speak below an eighth-grade level.
2. **Make it personal**—Talk about how CMT makes you feel.
3. **Ask them to join us**—Never miss an opportunity to grow our community.

I must confess, the CMTA is not always a good example of keeping it simple. We have lots of doctors and research scientists, which is a good thing. But they talk like doctors and research scientists, which is not as good. CMTA scientists need to be very accurate as they look for treatments and cures. But that very accuracy causes problems in day-to-day conversations. Normal humans do not understand it.

At what grade level are you writing and talking? If you want to be clear, lower it. Here is how a scientist who is trying to be accurate might describe CMT:

Charcot-Marie-Tooth Disease, or CMT, is a group of inherited disorders that affect the peripheral nerves, which are the nerves outside the brain and spinal cord. There are more than 90 kinds of CMT, each caused by a different mutation, and more causes are being discovered every year. CMT is just one kind of neuropathy (also called peripheral neuropathy), meaning simply that the peripheral nerves are damaged.

This text is written at the college level. It evaluates around

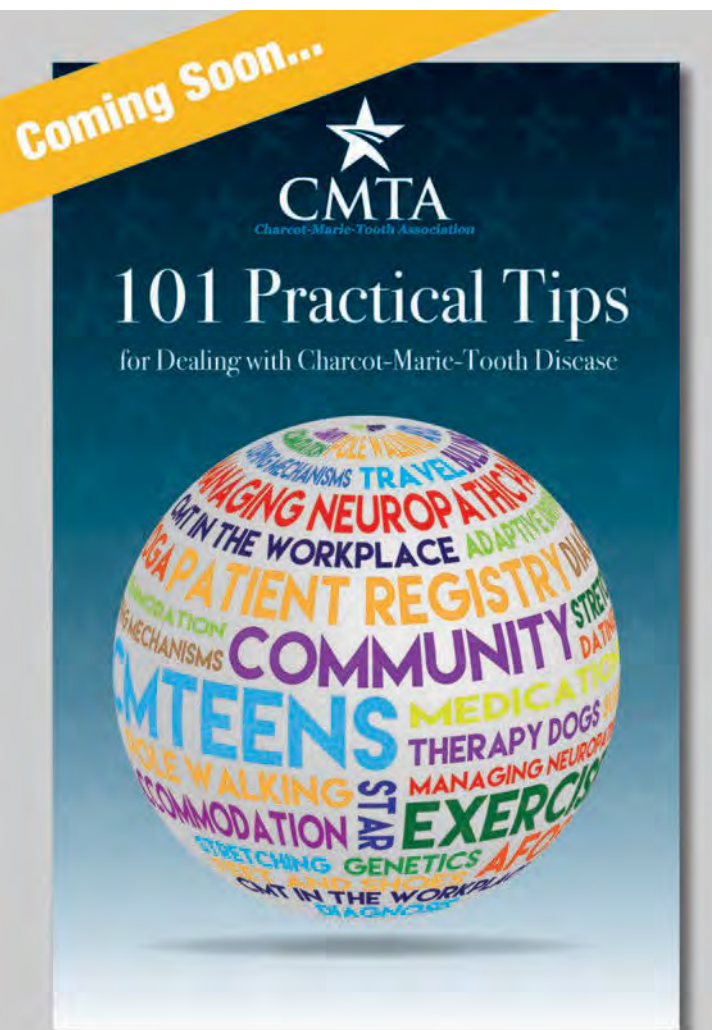
grade level 13. This means it is very hard for most people to understand.

To be honest, when people ask me “What is CMT?” a part of me likes saying stuff like, “It is an inherited peripheral neuropathy.” It makes me feel smart and I like feeling smart. There is just one problem. They will not likely understand a word I say. I need to lower the grade level. Before I give you an example of what I might say, I want to cover another point.

The most powerful answer to the question “What is CMT?” is both simple and personal. Tell the person asking what CMT means to you. How do you feel about having it? How does it feel to have a son, daughter, brother or sister with CMT? Many times it is more powerful to provide a personal definition of CMT, rather than a clinical definition. Help the questioner feel the answer.

Below is an answer that is both simple and personal.

CMT is a disease that makes our nerves sick. They leak. Leaky nerves make our muscles weak. Our feet and hands change shape. It makes it hard to walk. I trip and fall a lot. Some people have it so bad they can no longer walk at all. It is hard to grab and hold things. We drop things. And sometimes it hurts, for no reason. We just feel sharp shooting pain. It is a genetic disease. A lot of people inherit it from their parents. About 1 in 2,500 people have it. Most don't even know it.





While this answer is written at the fourth-grade level, there is a lot of information in it. How does it feel to you? Emotions are what make us human. In giving an answer to the “What is CMT?” question, I try to educate people and connect them emotionally to the answer. Sometimes the sign of a truly good answer is when both you and the other person are about to cry after you give it.

You don't need to copy this answer. Just copy the idea of making it simple and personal.

### Ask Them to Join Us

Never miss the opportunity to build our tribe. If someone is interested enough to ask “What is CMT?” and patient enough to listen to your answer, then you should ask them to do something.

It doesn't need to be difficult. You may ask someone to sponsor your fundraising walk. Or, you may ask, “If I send you a link to our Facebook page, will you LIKE it?” We are trying to spread the word about CMT. We want them not only to learn what CMT means; we want them to join us.

Both of these are easy to ask. And they are easy for people to say “Yes” to. Make your descriptions simple. Describe how CMT affects you personally. Invite people to participate and join us. Together, we can treat, and someday even cure CMT. ★



*Thomas Meloche is a professional writer, speaker, teacher, coach and member of the CMTA Advisory Board.*

*Note: This article was written at the seventh-grade level. A free on-line readability calculator was used to keep it simple. You can find the tool at: [www.online-utility.org/english/](http://www.online-utility.org/english/)*

## CENTER OF EXCELLENCE AT UNIVERSITY OF ROCHESTER MEDICAL CENTER

**D**r. David Herrmann heads the Center of Excellence at the University of Rochester Medical Center (URMC). The Charcot-Marie-Tooth Inherited Neuropathy Clinic at URMC takes a comprehensive approach to patient care, ranging from diagnosis with genetic confirmation, to genetic and family counseling to the prevention and management of secondary symptoms. Care providers and researchers work diligently to improve the quality of life of children, adolescents and adults affected by inherited neuropathies.

The clinic offers a team of experts in different specialties to meet the unique needs of patients with CMT. The interdisciplinary team of physicians, nurse practitioners, physical therapists, orthotists, a social worker and clinical technologists work collaboratively with patients and family members. Patient and family input is truly valued as an integral and vital component to care.

URMC designed the clinic to maximize busy families' time with care providers by offering consultation from multiple care providers during a single visit. Additionally, clinical services are coordinated in conjunction with schools and other providers to ensure continuity and consistency. Patients also receive access to clinical research studies and therapeutic trials. URMC's research over the past several decades has led to advances in treatment for patients with neuromuscular disorders. From research in molecular genetics to clinical research, including natural history studies and therapeutic trials, researchers work tirelessly to continue to learn and advance care provided to patients affected by CMT and related inherited neuropathies.

The clinic is located in Rochester, New York.

*For more information about the clinic, please call Erin Collins at 585-275-2559. For research inquiries please contact Janet Sowden at 585-275-1267.*



*The URMC COE Team with a patient (from left to right): Deb Guntrum, FNP; Janet Sowden, Research Coordinator; Katy Eichinger, DPT and Dr. David Herrmann, Division Chief, Neuromuscular Disease*





# CMT AWARENESS MONTH: WE'VE COME A LONG WAY— TOGETHER!

**T**he word “awareness” seems too small to convey the magnitude of the Awareness Month efforts made by our CMTA branches!

In September, branch members jumped in with both feet, braces and all, young and old. Community members sponsored walks, bike rides, swimming events, bake sales, golf events, art events, dinners, a book fair, and bowling and softball tournaments, just to name a few. Together we raised over \$300,000! This grassroots effort is therapeutic for everyone who participates, leading the way to a better understanding of CMT, and proving that a proactive approach to fundraising actually makes a difference in our quest for a cure!



Branch Leader Margaret Lee with North Carolina proclamation.  
Pictured Above: Chicago South 2016 Reach for the STARS-Walk & Roll 4 CMT

It is emotional and heartwarming for me to see the transformation in the CMTA support groups of five years ago, when CMTers and their families and friends gathered to exchange stories about CMT. Today, those support groups are a vast network of branches that take action to raise awareness about CMT and fundraise for a first treatment.

I am convinced, more than ever, that no one person, entity or government agency will fund the pathway to a cure for CMT. CMTers and their families and circles of influence will help the CMTA reach that goal. I am proud of this effort and have enjoyed meeting so many new friends. I know that Awareness Month will only continue to grow in future years. A job well done by all!

—Patrick Livney



# Thanks to YOU...

Awareness Month 2016 was a huge success on many levels, thanks to YOU. Our CMTA Branch Leaders, branch members and community members stepped up and stepped out to spread CMT awareness, sharing information on Facebook, passing out brochures, participating in CMT awareness events and putting on fundraisers.

A few fun facts to share:

- ▶ A total of 22 Walks, Cycles and Swims 4 CMT were held in the month of September. More than 1,500 people nationwide came out to support and participate in these incredible events, raising \$152,600 in September alone.
- ▶ Because CMT affects approximately 1 in 2,500 people worldwide, we created a fun #1in2500 Twibbon for people to upload to Facebook. The response was phenomenal. Over 2,300 people uploaded the Twibbon to create awareness on their social media pages!
- ▶ We also created and sold 176 #1in2500 T-shirts to help raise awareness 365 days a year. Not only do these shirts raise awareness, but they raised over \$2,000 for the CMTA STAR Research Program.
- ▶ We picked the 2016 Extraordinary People: The I'm A Shooting Star Winner is Cody Aguiar from South Carolina, and the I'm A STAR Winner is Tim Aldrich from Michigan (see article p. 20).
- ▶ 22 states proclaimed September CMT Awareness Month.

CMTers are a creative group when it comes to raising funds and awareness. The letters CMT went up in lights on an office building in Portland, Maine, and a bridge in Johnstown, Pennsylvania, was bathed in orange and blue light. Blue hair was in again this year: Utah Branch Co-Leader Melissa Arakaki sported blue highlights that raised some \$600 for STAR, and Jeff Lefkowitz raised almost \$1,500 in his I Dye 4 CMT campaign, though he says his wife drew the line at him dying his goatee. Harrisonburg, VA Branch Leader Jeanette Thompson did her first fundraiser this year—first selling CMTA Stars at a local Wendy's, followed by Moose Lodge #1 and Moose Lodge #3. In addition, one lodge's pool table money for the month of September went to the CMTA. If you can believe it, Jeannette says she used to be shy. She also used to be a fundraising novice, but that's all changed now.



RAISING FUNDS AND AWARENESS (pictured, clockwise from above): Harrisonburg Branch Leader Jeanette Thompson, Jeff Lefkowitz of New Jersey, and Utah Branch Co-Leader Melissa Arakaki.

## AWARENESS MONTH ACTIVITIES ACROSS NORTH AMERICA:

### PHOENIX, AZ

Branch leaders celebrated CMT Awareness Month by participating in the Got Nerve campaign, raising \$970 from 21 supporters. Co-leader Christina Fisher displayed CMT brochures, bracelets, pens and posters at her workplace and each Friday she wore either the #1in2500 shirt or the official Shark-O-Marie-Tooth shirt to spark conversations. The local group is also raising awareness through media links and building relationships with local businesses in the community.

### LOS ANGELES, CA

The Los Angeles Walk & Roll for CMT Awareness on September 24 brought out 100 participants and raised a stunning \$17,950! Following a one-mile walk around the Alondra Park lake, participants enjoyed delicious BBQ and bid on over \$2,000 worth of raffle and silent auction prizes, all donated by local sponsors. Special guest James Kimo Cuizon, CMT athlete, traveled all the way from Hawaii to walk and give an inspirational speech.



### SAN FRANCISCO, CA

The 2nd Annual Walk to Run 4 CMT was held at Mitchell Park in Palo Alto, California on September 17, with more than 150 in attendance and over \$50,000 raised (for the second straight year). The walk was followed by an inspirational talk by Paralympic cyclist Anthony Zahn, a fellow CMTer, and the winner of a bronze medal in the individual time trial road event at the 2008 Beijing Paralympics. Yohan Bouchard, who experienced childhood onset of CMT, shared stories about growing up, adapting to and being open about his condition.

### HARTFORD, CT EAST

More than 40 people came out to celebrate CMT Awareness Month at Lenny and Joe's Fish Tale, a popular seafood restaurant on the Connecticut shore. A table at the entrance offered CMT brochures and bracelets to anyone interested and Branch Leader Roy Behlke displayed a #1in2500 poster for the event. The restaurant management donated a percentage of their proceeds to the CMTA, and a total of \$800 was raised for STAR.

### SOUTHERN CONNECTICUT

Some 70 people gathered at Brooksville Park in Hamden for the 2016 Cycle/Walk/Run 4 CMT on September 11. Branch members, along with friends and family, walked the scenic, tree-lined Farmington Canal trail to spread awareness and celebrate CMT Awareness Month. CMTA sweatbands, bracelets, brochures and other giveaways were quickly snatched up and there was plenty of blue and orange to be seen. The event has raised \$10,115 to date!



### TAMPA, FL

The 2016 2nd Annual Tampa Bay Area CMT Walk-n-Roll and Picnic was a success thanks to help from friends and family. About 40 friends, old and new, gathered under the oak trees at MacFarlane Park to support the CMTA and each other. The group played games, popped water balloons, shared tasty sandwiches and started making plans for next year's walk. The event raised \$6,470 for STAR.

(continued on page 18)





PORTLAND, ME  
BRANCH LEADER MARY LOUIE



CHARLOTTE, NC

## AWARENESS MONTH ACTIVITIES (CONTINUED)

### ATLANTA, GA

The Atlanta Branch hosted its 2nd Annual Walk-n-Roll on Saturday, October 1. This year's walk was dedicated to Julianna Snow, the 5-year old girl who inspired this year's Stand to End CMT Campaign. By day's end, the group was halfway to its fundraising goal of \$15,000, with \$2,200 raised during the event alone.

### CHICAGO (SOUTH), IL

The branch held its 7th Annual "Reach for the STARS-Walk & Roll 4 CMT" on Saturday, September 24. More than 100 family and friends came out for the walk at Wolf Wilderness Refuge, a beautiful nature walk preserve. Raffle ticket sales raised more than \$1,400, helping the branch reach its \$10,000 fundraising goal.

### INDIANAPOLIS, IN

Fifty people came out for the branch's 2nd Annual Walk and Roll 4 CMT September 17 at Shadyside Park in Anderson, Indiana. The trail was beautiful and everyone enjoyed the walk. The Shelton family worked very hard to get donations for the raffle, and they even got a bike for a donation! The walk raised \$5,800!



### PORTLAND, ME

The Fourth Annual Peaks Island Walk for CMT was held on Sunday, September 11 on fabulous Peaks Island! The walk began at the Inn at Peaks Island where more than 70 walkers took in the gorgeous views of the coast as they made their way around the island. Participants were welcomed back at the Inn with a fabulous lunch. The branch's Awareness Month Committee also got a special Proclamation from the City of Portland declaring September CMT Awareness Month and held several fundraiser nights at local spots such as Elsemere Barbeque, Otto Pizza and MJ's Wine Bar with portions of those nights' proceeds going directly to the CMTA. All in all, the branch raised a total of \$6,000 for the CMTA!



### BOSTON, MA

The 2nd Boston Walk 4 CMT was a smashing success, raising more than \$6,300 and helping everyone who lives with or supports someone with CMT. A big thank you to Craig and Evan Zeltsar, who together raised \$4,400 of the total.

### CENTRAL MINNESOTA

The branch's walk drew 64 walkers this year, more than twice as many as last year. Three new families affected by CMT participated and one family drove more 350 miles roundtrip to walk! Over 5,000 people were in town for Crosslake Days, giving branch members the chance to raise awareness and answer questions from people who were not knowledgeable about CMT.

### CHARLOTTE, NC

The Charlotte branch hosted an awareness event and fundraiser at Qdoba Mexican Eats on September 11. Eighty-five people from 20 families attended and Qdoba donated 15 percent of its profits for the evening to the CMTA. Branch members handed out brochures and awareness bracelets and Qdoba decorated the restaurant with blue and white balloons and streamers in honor of the CMTA.

### STATEN ISLAND, NY

Caroline Puma and her family donated half of the proceeds from their regular \$35/seat painting party to the CMTA. Puma, whose family is affected by CMT, held the Painting with a Purpose fundraiser in her Staten Island studio to help spread the word about CMT and raise funds for research.

### CINCINNATI, OH

The branch held its first annual Walk 4 CMT and surpassed its fundraising goal! Perhaps even more importantly, the group met several new members and helped raise awareness about CMT in the Cincinnati area.



### TULSA, OK

Congrats to the Greater Tulsa Area Branch for its first-ever Walk 4 CMT on September 17. Ten people raised \$150 in their first time out. The branch had a blast and is fired up for next year, promising even bigger and better things to come.

### GRANTS PASS, OR

Forty-five people walked three miles at the Second Annual Walk 4 CMT on September 10, raising \$1,526 in the process! Following the walk, participants mingled, read CMT literature, enjoyed food and won some exciting raffle prizes. Twinkles the Clown performed and it was a beautiful, sunny, fun day for all.

### BUCKS COUNTY, PA

The branch hosted a buffet dinner in September for Awareness Month. As everyone arrived, kids received a goody bag and adults received a key chain with a chance to win a door prize. The evening also featured a basket raffle and 50/50. Dinner was fabulous with a great turnout! Everyone in attendance watched the Power of One video before the prizes were announced. The event raised over \$700 for STAR and branch members are excited to do this again next year.

# C E L E B R A T I N G AWARENESS MONTH





STATEN ISLAND, NY



GREENVILLE, SC



JOHNSTOWN, PA



AUSTIN, TX

**ERIE, PA**

The branch held its Second Annual Cycle 4 CMT on Sept 24 at Erie's Glenwood YMCA. Cyclists Keith Allen and Joyce Steinkamp each pedaled recumbant stationary bikes for a distance of 26 miles in three hours! Cheerleaders Mary Ann Brothers, Doria Allen and Janet Satyshur decorated the area with CMTA balloons and featured a snack table with educational materials to spur conversation with YMCA members, spreading awareness of CMT in the Erie community. Pennsylvania Governor Tom Wolf's CMTA Awareness Month Proclamation was proudly displayed.

**PENN STATE**

On September 18, 27 people turned out for the Penn State Student CMTA Branch's 1st Annual Walk 4 CMT. The group surpassed its \$1,000 dollar goal by \$300 in its two-mile lap around the scenic Penn State Campus. Participants answered spectators' questions about CMT as they walked, raising awareness and leaving them proud of their efforts. The students look forward to making their walk an annual event.

**GREENVILLE, SC**

This first-time fundraiser surpassed all expectations at its walk on September 10. More than 42 people came out to walk laps for the CMTA. The walk passed its \$5,000 goal, raising \$5,526 and handing out prizes to people who raised the most money.



FERGUS, ONTARIO

**NASHVILLE, TN**

Co-leaders Bridget Sarver and Gwen Redick were joined by 37 walkers September 17 for the 2nd Annual Nature Walk 4 CMT at Long Hunter State Park in Hermitage. They raised \$7,575. The morning started off sunny, but by the time the group reached the bridge over Couchville Lake, it was cloudy and overcast. Except for a few sprinkles, the rains held off until everyone was packing up to go home. The group will hold its 3rd Annual walk in the same place on September 16, 2017.

**DALLAS, TX**

The rain held off until the 2nd Annual Dallas Stars Walk 4 CMT on September 24 was over. The walk drew 44 people and one Great Dane to South Lakes Park in Denton, Texas. Participants had a ton of fun painting their hands and feet, enjoying breakfast tacos and bagels, listening to a DJ and raising over \$5,400!

**HOUSTON, TX**

The Houston Branch had a fantastic "Sweat on the Swamp" September 25, with 65 people participating. Following the two-mile walk, participants enjoyed breakfast, drinks, and time to visit and peruse the CMTA awareness boards. A genetic counselor from Memorial Hermann was available to answer questions, and CMTer Vivi Melody and her family provided musical entertainment.

**FREDERICKSBURG, VA**

The Lowell E. Wassum Memorial 5k Walk/Run 4 CMT was held in Fredericksburg on Saturday, October 1. In spite of the torrential rains early in the morning, every registered participant showed up in support! This walk was the first in the area and was a small step in raising awareness and funds for CMT and the CMTA. One very special participant with CMT Type 2A victoriously completed the entire 5k, proudly wearing her AFOs for all to see.

**WASATCH FRONT, UT**

Branch Co-leaders Melissa Arakaki and Emily Hunsaker hosted a GoBlue4CMT campaign! They raised over \$600 and Melissa sported blue highlights in her hair for Awareness Month.

**SOUTHEASTERN WISCONSIN**

More than 125 people turned out for the Wisconsin Walk 4 CMT October 1, raising \$18,003 while strolling around the Pettit National Ice Center. The walk was followed by delicious munchies, great music, a fantastic auction, and an awesome greeting from CMTA CEO Pat Livney. What a wonderful group of generous, caring Americans who will never make headlines but are definitely what makes America great right now!

**SOUTHERN ONTARIO CANADA**

The 6th Annual Walk for CMT—Fergus Fundraiser was held on Sunday, September 25 and was a HUGE success. Over 85 participants came together on the warm, sunny morning to raise awareness and much needed funds to find a cure for the disease. The event was inspiring, motivating and fun for all who attended and raised more than \$9,000.

# 2016



# 2016 STAR AWARDS

The **CMTA STAR Awards** celebrate the energy and enthusiasm of people who live with CMT. Recipients are nominated by friends and family, and the awards are presented during CMT Awareness Month. The 2016 winners are profiled below.



## THE "SHOOTING STAR" WINNER: CODY AGUIAR

*Nominated by Lisa Aguiar*

We knew from any early age that Cody probably had CMT. It wasn't until he was 7 years old that we got an official diagnosis. It has been three years since he was diagnosed and he continues to inspire and motivate me and those around him. Everything that he does shows others that despite a disability, if you work hard enough and want something bad enough you can achieve it.

Cody suffers from severely flat feet. He wears orthotics in his shoes and wears braces and tape for his martial arts. That was hard at first as he was worried about what the others might say, but it has only helped make him stronger and better. He cannot jump and does not have the hand strength to do typical everyday tasks. Walking long distances is too much for him as is doing a lot of climbing or things that require use of his legs and hands. Cody is home-schooled because the pain in his feet made being in public school too physically taxing.

Cody chooses to rise above his CMT and challenge his disability through martial arts, including Jiu-Jitsu, and wrestling. As far as

Jiu-Jitsu goes, he is one of the best students in his dojo. He is currently a purple belt in American mixed martial arts and his instructors have unofficially ranked him a white belt in Jiu-Jitsu.

He does his very best not to let his CMT stop him or keep him from doing something. When he is not doing martial arts, he enjoys riding dirt bikes and four-wheelers as well as going fishing with his Dad, who also has CMT. Cody is my hero. In my eyes he will always be my shooting star.



## THE "I'M A STAR" WINNER: LOUIS "TIM" ALDRICH

*Nominated by Adele M. Aldrich*

I want to tell you about my amazing CMT Star, my husband Louis "Tim" Aldrich.

Tim was first diagnosed with CMT1A in his early 30s. This was in the early 1980s. He was married and had two little boys, and worked for a major auto manufacturer, though he had weakness and coordination issues. His mother had the same symptoms, and was wheelchair-bound. But it was thought that she had post-polio problems. Through genetic test-

ing, Tim and his mom and son were all found to have CMT. His mom passed away 20 years ago. His son is now in his 30s and is doing well.

Tim worked too long and died for many years. He continued to go to work every day, even though some days were a struggle. He was told he would be in a wheelchair by the time he was 40, but he continued to walk until his mid-50s. When he could no longer walk, he went to work in a wheelchair. The company he worked for took him off of the factory floor and into the office, where he did computer work until his retirement in 2011.

Unfortunately, Tim's two former marriages did not survive the trials of having CMT. I met Tim through an online dating site. I have rheumatoid arthritis and have used a wheeled walker since I was in my 30s. So, we understand each other and work together as a team. We met in 2010 and in 2014 built a home together that is handicap equipped for our needs. We got married in June 2015. We have four sons and four grandsons.

Tim never complains. He has lost the use of his hands and legs from the knee down. In addition to CMT, he is a survivor of colon, liver and skin cancer. But, he doesn't let anything keep him down. He is a master woodworker, a huge Michigan football fan, and he loves baseball. We travel extensively and enjoy every day that we have together. He has a can-do attitude! He is truly my CMT Star. ★



# STUDY FINDS A KEY TO NERVE REGENERATION

BY DAVID TENENBAUM

Researchers at the University of Wisconsin-Madison have found a switch that redirects helper cells in the peripheral nervous system into “repair” mode, a form that restores damaged axons. Axons are long fibers on neurons that transmit nerve impulses. The peripheral nervous system, the signaling network outside the brain and spinal cord, has some ability to regenerate destroyed axons, but the repair is slow and often insufficient.

The new study suggests tactics that might trigger or accelerate this natural regrowth and assist recovery after physical injury, says John Svaren, a professor of comparative biosciences at the UW-Madison School of Veterinary Medicine, and the chairman of the CMTA’s Scientific Expert Board. The finding may also apply to genetic abnormalities such as Charcot-Marie-Tooth disease or nerve damage from diabetes. CMTA support has helped the Svaren lab explore how nerve injury shares some common aspects with the chronic issues affecting nerves in individuals with CMT, which is a focus of ongoing research.

Svaren, senior author of a report published August 30 in *The Journal of Neuroscience*, studied how Schwann cells, which hug axons in the peripheral nervous system, transform themselves to play a much more active and “intelligent” role after injury.

Schwann cells create the insulating myelin sheath that speeds transmission of nerve impulses. In repair mode, Schwann cells form a fix-up crew that adds house cleaning and stimulation of nerve

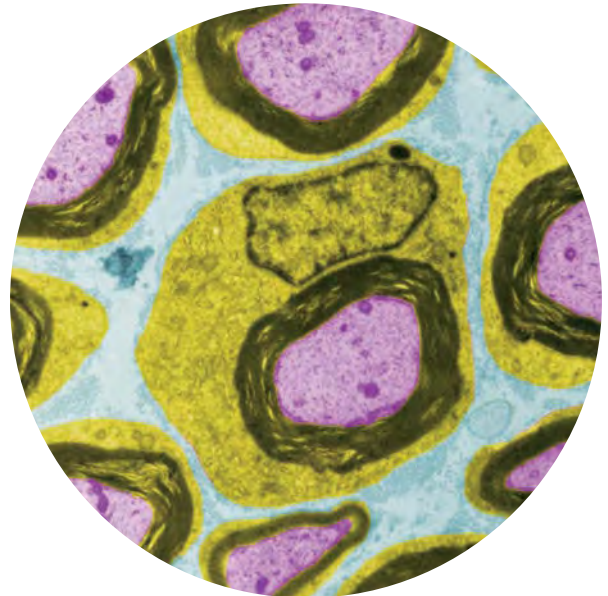
regrowth to their usual insulating job. Svaren and his graduate student assistant, Joseph Ma, compared the activation of genes in Schwann cells in mice with intact or cut axons. “We saw a set of latent genes becoming active, but only after injury,” says Svaren, “and these started a program that places the Schwann cells in a repair mode where they perform several jobs that the axon needs to regrow.”

In the repair mode, but not in the normal one, Schwann cells start cleaning house, helping to dissolve myelin, which is essential for proper functioning but ironically deters regeneration after injury. “If you invite Schwann cells to a party,” says Svaren, “they will clean up the bottles and wash your dishes before they leave the house.” This cleanup must happen within days of the injury, says Svaren, who directs the cellular and molecular neuroscience core at the Waisman Center on the UW-Madison campus. The Schwann cells also secrete signals that summon blood cells to aid the cleanup, and they map out a pathway for the axon to regrow. Finally, they return to the insulator role to grow a replacement myelin sheath on the regenerated axon.

Unexpectedly, the Schwann’s transition into repair mode did not entail a reversion to a more primitive form, but rather was based on a change in the regulation of its genes. “Almost every other nervous-system injury response, especially in the brain, is thought to require stem cells to repopulate the cells, but there are no stem cells here,” Svaren says. “The Schwann cells are reprogramming themselves to set up the

injury-repair program. We are starting to see them as active players with dual roles in protecting and regenerating the axon, and we are exploring which factors determine the initiation and efficacy of the injury program.”

After the human genome was deciphered, epigenetics—the study of gene regulation—has moved to the forefront with the realization that genes don’t matter much until



**Colorized photo of Schwann cell**

by Holly Hung/  
Harrison Pantera

they are switched on, and that genetic switches are the fundamental reason why a skin cell doesn’t look like a nerve cell, and a nerve cell functions differently from a white blood cell.

In epigenetics, as elsewhere in biology, processes are often regulated through a balance between “stop” and “go” signals. In the Schwann cell transition, Svaren and Ma identified a system called PRC2 that usually silences the repair program. “This pathway amounts to an on-off switch that is normally off,” Svaren says, “and

(continued on page 30)

## NEW MEMBERS JOIN BOARDS

*The CMTA has gathered the top people in their fields to serve on its Board of Directors, Advisory Board and STAR Advisory Board. Their expertise is unparalleled and they give it selflessly to the benefit of everyone who has CMT. In 2016, the CMTA added board members at all levels of leadership, starting at the top.*

**GILLES BOUCHARD** took over as the chairman of the CMTA Board of Directors in March, saying that while he is “excited and delighted” with the progress made by the CMTA’s STAR research program, there’s still much work to be done before a first drug treatment for CMT reaches the 2.8 million people who have the disease.

Gilles’ history with CMT dates back to 2001, when his son Yohan was diagnosed. Gilles has been involved as a volunteer advisor to the Board since 2007, when he organized the strategic retreat in Palo Alto where the STAR program was initially defined and launched.

Gilles praised Herb Beron, his predecessor as chairman, saying, “Herb was instrumental in taking the organization to a whole new level, and we’re grateful to him for all his hard work over the years.” Beron, who remains on the board, was chair from 2011 to 2016.

Before becoming chair, Gilles was chairman and CEO for LiveScribe, a leader in the smartpen market. Previously, Gilles was the CEO of Opnext, a maker of fiber optic components, originally founded as part of Hitachi.

Earlier, Gilles spent 17 years at Hewlett-Packard, working his way up to executive vice president of Global Operations and



Gilles Bouchard  
with his son Yohan

*Gilles’ history with CMT dates back to 2001, when his son Yohan was diagnosed with the disease.*

CIO, reporting directly to CEOs Carly Fiorina and Mark Hurd. Gilles was instrumental in the company’s dramatic turn-around in the mid-2000s, earning recognition as one of CIO Magazine’s Top 100 executives. Earlier in his career, Gilles built HP’s North American consumer PC division into a multi-billion dollar business, growing the HP Pavilion brand into the industry leader.

Prior to HP, Gilles served as a researcher at the IBM Watson

Laboratories, earning the prestigious “IBM Outstanding Technical Achievement Award.”

A native of Paris, France, Gilles is an avid cyclist, equestrian, mountaineer and skier with a certification as a backcountry ski guide. He holds an MS in mechanical engineering from UC Berkeley, a BS in engineering from Ecole Centrale de Lyon, France, and executive education degrees from INSEAD and Harvard Business School.



*Two new members have joined the Therapy Expert Board, the component of the STAR Advisory Board responsible for ensuring that each research project has translational value for the CMTA's STAR mission of developing therapeutics for CMT patients.*

**DR. CHRISTOPHER KLEIN** is a professor of neurology at the Mayo Clinic in Rochester, Minnesota.

His interest in neurodegenerative disease started in graduate school at Ohio State University, where he worked on the genetics of muscular dystrophy. After completing his neurology residency and a research fellowship in neurogenetics, he has focused on identifying the genetic causes and underlying pathogenesis of inherited neuropathy. Dr. Klein is board certified in neurology, electrophysiology, nerve pathology and neuromuscular disease. He has been applying next-generation sequencing technology to identify novel mutations of neuropathy, and his publications reflect an ongoing interest in translational discovery of pathogenesis for neurodegenerative diseases. He sees patients with a variety of forms of neuropathy in the Mayo Neuromuscular Clinic. He has helped develop comprehensive next generation sequencing testing to expedite molecular diagnosis, which is the first step for individualized medicine. Dr. Klein is convinced that the collaborative efforts of researchers and patients will significantly accelerate the discovery of rational treatments for CMT patients.



**DR. DAVID HERRMANN** is professor of neurology and pathology and chief of the Division of Neuromuscular Disorders at the University of Rochester. Clinically, his interests are in the diagnosis and care of patients with various types of peripheral neuropathy, with a particular interest in inherited neuropathies (Charcot-Marie-Tooth neuropathy and related disorders). Dr. Herrmann additionally established one of the first cutaneous innervation laboratories for diagnosis of small fiber neuropathy in the United States at the University of Rochester. Dr. Herrmann's current research centers on inherited neuropathies and he is principal investigator in Rochester for the NIH sponsored Inherited Neuropathy Consortium Rare Disease Clinical Research

Center. Dr. Herrmann focuses on new gene identification for inherited neuropathies, development of novel neuropathy outcome measures and biomarkers and experimental therapeutics.



*The CMTA is also pleased to welcome two new members to its Advisory Board.*

**TOM MELOCHE** is a professional writer, speaker, teacher and coach. He is currently focused on spreading awareness of the power of ceremony to transform organizations. His passions include innovation, advertising and human social interactions. Tom founded and sold Menlo Innovations, wrote *Ultimate Guide to Facebook Advertising* with Perry Marshall and *Ceremony as Strategy* with Kyle Griffin, consults for The Understanding Group and runs Meloche Consulting Inc.



Diagnosed with CMT1B in 2013, CMT activist **CLARK SEMMES** has wasted no time plunging into CMTA fundraising and community development. Shortly after founding the Baltimore CMTA Branch, Clark partnered with long-time CMTA Board Member Steve O'Donnell to transform the Swim4CMT into the Oxford Biathlon. The Oxford Biathlon, now in its third year, brings much of the mid-Atlantic CMT community to the tiny town of Oxford, Maryland for a day of fun, fellowship and crabs in late May. Clark also writes articles for *The CMTA Report* and recently compiled many of those articles and some additional material into a book titled *The Tribe of the Thin Ankles*.





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

**Dear David,**

*I am a school teacher who has midlife-onset CMT. I like to wear dresses and skirts when I teach. I have never had to wear braces before and have some anxiety about showing up at school one day with braces on my legs. Most people do not know that I have CMT. How do I start that conversation?*

*David replies:*

Having some anxiety about showing up at school wearing braces is completely normal. Before you decide how you want to deal with the reactions of others, it's important to look at your own feelings about having CMT. We all go through an adjustment process after being diagnosed. Giving yourself the time you need to go through the entire range of feelings is crucial. The way others react to you will have a lot to do with how you feel about yourself. The emotions you experience around having CMT can swing from embarrassment to sadness to anger and then to acceptance. There is no order in how you experience these feelings, but your

adjustment will get easier with time if you allow yourself to truly feel each feeling and then move on. You may even find that gratitude is in the mix because the technology exists to keep us moving with confidence. Wanting to look attractive is certainly

understandable, but feeling secure and stable on your feet is equally important. Worrying about falling will interfere with the freedom to be yourself in the classroom.

This is an incredible opportunity to teach your students about diversity. All students feel different at some point in their life. Insecurity is universal and showing students that you can be different and strong at the same time is invaluable. If you feel comfortable, you might even bring it up first with your students in a humorous or lighthearted way. Tell them that your high-tech apparatus has a feature that can tell you how much they have studied! Teaching them that feeling good about yourself even if you do not have a perfect



Write to David at  
[info@cmtausa.org](mailto:info@cmtausa.org).

body is particularly relevant in these times.

Confidence is not about perfection, but rather the ability to take the risk to be yourself and celebrate your uniqueness. Accepting and having compassion for your own imperfections will lead your students to be more

sensitive and kind towards others. (I have always thought kindness and compassion should be taught in schools, along with reading, math and history.)

Giving your students a role model for a powerful voice is a gift, even if braces are needed. I do not think it's necessary to have a conversation with your boss. If he brings it up in conversation, just remember how fortunate he is to have you on his staff! ★

*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.*



## CMTA REMEMBRANCES

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

### Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

### Occasion (if desired):

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

### Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

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Amount Enclosed: \_\_\_\_\_ ☐ Check Enclosed

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# Replacing Brush with Brushes App, Irish Artist Adapts

When UK artist Derek Culley found that his CMT no longer allowed him to paint with oils while standing at an easel, he faced a crisis of confidence. He wondered whether his loss of grip strength and the fatigue in his “jelly legs” would end the only profession he had ever known. His answer came while watching a documentary on the artist David Hockney, who uses the Brushes app and a stylus to “paint” on an iPad. The documentary spurred Culley to try his hand at digital art. The medium took some adjustment after so long working in paint on canvas or paper, but after a period of trial and error, he found that he had a new way to make art.

Born in Dublin, Ireland, Derek “caught the bug” from his art teacher at the age of 15 and had his first studio at the age of 16. The studio was a garage in the alley in back of his house, and he worked at a local bar cleaning and serving drinks to pay for it. Derek started at Dublin’s National College of Art and Design but only lasted three weeks because he didn’t like his fellow artists. A series of “food on table” jobs followed while he taught himself art. He later completed a master’s degree in marketing at Brunel University, concentrating on the visual arts in Britain.

The self-taught artist has participated in numerous group and solo shows since 1986 and received a Pollock-Krasner Foundation Grant in 2006. According to one critic, Derek is known for his instinctive approach, which “combines a bold primary color palette and expressive handling of

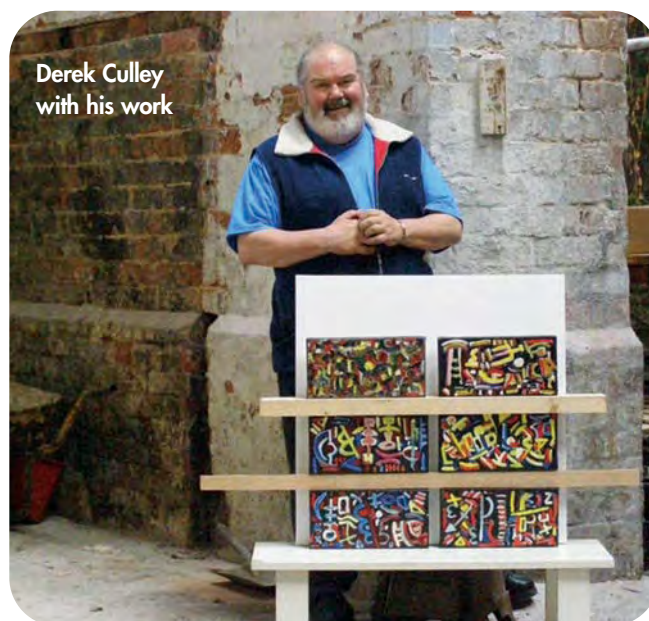
form to create paintings of undeniable power.” Derek demonstrates a strong influence from the New York School, this critic said, and his admiration for painters like Jackson Pollock is readily apparent in the composition of his abstracts and the energy of his mark-making.

Derek didn’t discover that he had CMT until he was 40. His young son Russell was a “floppy child,” a state of low muscle tone involving reduced muscle strength. Russell fell a lot and authorities suspected Derek and his wife of mistreating him. But after two weeks of testing at Our Lady’s Children’s Hospital, Crumlin, Russell was diagnosed with CMT1A. Derek’s diagnosis followed.

Today, Derek needs orthotics to walk. He has chronic fatigue and greatly impaired balance. His arms are withering away, his hands are losing strength and grip, and he can’t hold a knife or fasten a button. On the plus side, he says, he no longer has to do dishes.

Making art on an iPad takes a lot of patience, Derek says. But it has restored his confidence and forced him to think outside the box. He now does ink-jet prints on canvas, paper and acrylic panels. With the technology of the iPad and the Brushes app, he can replicate images and make a series using the original iPad painting as a template.

Derek’s CMT also informs the subject matter of his work. His take on *The Last Supper* was



the first work he did that directly evolved from his personal challenges with his feet. It depicts the feet of Christ and the disciples, rendered in plaster of Paris. Christ’s foot is completely painted—spiritually complete—while the toes of the 12 disciples’ feet remain bare. It’s the first work Derek did directly evolving from his personal challenge with his own feet. The “anonymous” feet are a mix of folks with CMT, diabetes and other foot complications. ★

*Derek’s digital art is available at [www.seditionart.com/derek-culley/artworks](http://www.seditionart.com/derek-culley/artworks). Sedition Art is offering readers of THE CMTA REPORT 10 percent off a single Culley edition through April 2017. Simply input the code CMT\_DC1 during checkout. Anyone wishing to purchase the collection of six works together should use the code at this link: [www.seditionart.com/derek-culley/collection/brushes-odyssey](http://www.seditionart.com/derek-culley/collection/brushes-odyssey). Thirty percent of the revenue will go to the CMTA. Derek’s non-digital art is available for purchase at [www.derekculley.com](http://www.derekculley.com).*

## CMTA RV Speeds Toward a Cure

The CMTA Land Speed Racing Motorhome became the fastest “Class A” RV on the planet August 15, reaching a top speed of just over 122 miles per hour at the 67th Annual Speed Week held on Utah’s Bonneville Salt Flats.

Sponsored by the Southern California Timing Association (SCTA), Bonneville Land Speed Racing is a unique sport that consists of very determined people



Pilot Steve Snow with the CMTA Land Speed Racing Motorhome

who drive hot rods, roadsters, belly tankers, motorcycles, streamliners, and even diesel trucks to

“shoot the salt” in a simple quest to have their name added to the list of record holders.

Thanks to RV owner and racer Britt Palmer and pilot Steve Snow, thousands of SCTA spectators, fans and racers now know about CMT. Britt invited Steve, a veteran US military

fighter pilot, to join Team MoHo this year after reading about his 5-year-old daughter, Julianna,

## THE CMTA PARTNERS WITH THE MDA TO ACCELERATE SEARCH FOR TREATMENT

The CMTA and the Muscular Dystrophy Association (MDA) recently announced a partnership aimed at advancing CMT research, therapy development and clinical care. The partnership also aims to increase awareness and understanding of CMT by improving education for affected children and adults, medical professionals and the public. CMT is one of the neuromuscular diseases MDA fights as an umbrella organization with a big picture perspective on finding treatments and cures for children and adults whose weakening physical strength and loss of mobility make the most basic daily activities extraordinarily challenging.

“MDA is strategic in pursuing collaborative partnerships and

motivated in our efforts to align and work together with other organizations toward common goals,” said MDA President and CEO Steven M. Derks. “When we partner to share knowledge and resources with respected and capable organizations like the CMTA, we can make a greater impact—one that will make a difference in the lives of individuals and families with CMT. We are committed to freeing people from the harmful effects of neuromuscular disease, and we know that our goal is most easily accomplished if we unite with others and work together.”

CMTA CEO Patrick A. Livney said, “The CMTA’s STAR (Strategy to Accelerate Research) platform has been working tirelessly to fund translational

projects on the pathway to finding a treatment for various types of CMT. This partnership will work to enhance that effort, maximize resources and hopefully put us on a faster track toward the ultimate goal of a cure.”

Partnership goals include developing new therapies and treatments for CMT, improving communication among all stakeholders in the field and increasing collaboration among research and clinical investigators. With the launch of this partnership, MDA and CMTA plan to co-fund research and training grants, collaborate on infrastructure initiatives, coordinate advocacy efforts at the national, state and local levels and work together on communication outreach to CMT families.



who died from a rare form of CMT in June 2016. The event also raised \$12,000 for STAR research, thanks to the special efforts of sponsor Jim Kanomato with Applied GMC and the entire GMC Motorhome community.

Britt, a self-avowed motor-head, began his quest for the world's fastest RV and a cure for CMT a few years ago while in the middle of a "pity party" over his CMT. Deciding that he wasn't going to let the disease slow him down any more, he began perusing Craigslist and came across a 1977 Kingsley GMC Motorhome for sale. His initial intent was to use the motorhome for camping, but while researching its history, he came across an article about a GMC Motorhome holding the 2006 World Land Speed Record of 102.7 mph at the Bonneville Salt Flats.

From there, it didn't take long for Britt and his motor-head friends to come up with a plan to build the World's Fastest Motorhome (that could still be used for camping after the race). Instead of letting CMT slow him down, Britt and his team decided to build awareness for CMT by going fast.

At the 2013 Speed Week, the MoHo stole the show. People stopped by to confirm that the team was actually racing the RV and that it wasn't just there as a support vehicle. With 12,000 people attending the event and many international news organizations covering it, it was a great opportunity to let people know about CMT. That year, Team MoHo got the RV up to 120.8 mph.

The race was rained out in 2014 and 2015, so the crew headed back in 2016 to finish the job. ★

## The CMTA Gratefully Acknowledges Gifts:

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Interested in starting a branch in your area?

Contact CMTA Director of Community Services Jeana Sweeney at [Jeana@cmtausa.org](mailto:Jeana@cmtausa.org)



## BRANCH LEADER SPOTLIGHT: Virginia Canonguez-Mamone

**"D**ance like no one is watching." That's how Virginia Canonguez-Mamone grew up in Los Angeles—dancing to the beat of her own heart. Being Latina, music and dancing were part of every family gathering. When she was little, she dreamed of being a professional backup dancer. When she was old enough to go clubbing, she was the girl who hit the dance floor by herself. But when she was diagnosed with CMT at the age of 35, the mother of three was afraid that her dancing days were over. She would never have guessed that her role as a brand ambassador for Allard would take her to Sweden for ballroom dance lessons.

Virginia noticed that her hands were starting to lose muscle tone after the birth of her first child, but her doctor told her she was just thin. At 85 pounds, she couldn't disagree. Things got a little worse after the birth of her second child, when she began losing muscle tone in her legs, but she was a busy single mother working and going to school and she again blamed it on not having time to eat. Eight years later, after the birth of her third child, something happened that forced her to confront the changes in her body. Virginia was carrying 6-month-old Bella in her arms when she tripped and almost fell on top of her baby. Luckily she was able to toss her daughter onto a bed as she fell, but the fall took her to the emergency room. A long series of tests followed, including three nerve conduction studies and a spinal tap. Eighteen months later, a UCLA neurologist finally diagnosed her with CMT.

Virginia's first thought was: "How am I going to raise three children with this disease?" Thinking about it depressed her. Her doctor telling her that there was no cure for CMT and that she shouldn't "waste her money on false hopes" didn't help. Virginia's depression turned to guilt after two of her three children were also diagnosed. But in time, Virginia realized that she couldn't just sit around, cry and wait for her legs to give out. Instead, she had to get back up so that she could not only be the best mother that she could be, but inspire her children to never give up on what they want out of life.

Virginia comes from a long line of folks with CMT1A. Her great-grandmother had it and lived into her 90s believing it was arthritis. Her grandmother and her aunt both had it and thought it was polio. Her great uncle had it and still worked construction into his 60s. Her father had it but never knew what it was.

As time passed Virginia's legs got skinnier. When her sister-in-law commented on her thin legs, Virginia stopped wearing shorts. She wore long pants even during the hot Las Vegas summers, when temperatures can climb to 120 degrees. Virginia eventually joined the Las Vegas CMTA Branch. She bought ankle wraps from Walmart and watched where she walked. She went to an orthotist and got plastic braces, but they hurt and she stashed them in her closet, where they reside to this day.



Allard braces allowed Virginia to dance again. Allard representative Jeff Smith brought a demonstration pair of ToeOffs to the crowded coffee shop where they were meeting. She loved them so much that when Jeff encouraged her to take them out to the parking lot for a test, she briefly considered fleeing with them.

Within a year, Virginia was not just walking with braces, she

(continued on page 31)

**SCHWANN CELL**

(continued from page 21)

we want to know how to turn it on to initiate the repair process.”

The nature of the top-level gene-silencing system suggested drugs that might remove the silencing mark from the genes in question, and Svaren says he’s identified an enzyme that may “remove the brakes” and deliberately activate the repair program when needed in response to injury.

Even if the drug tests are promising, years of experiments

will be necessary before the system can be tested in people. Furthermore, as Svaren acknowledges, “many factors determine how well an axon can regenerate. I am not saying this single pathway could lead to a cure-all, but we do hope it is an important factor.”

Svaren says it’s not clear how the current finding on peripheral nerves relates to damage to the brain and spinal cord, where a different type of cell cares for neurons. There are some similarities, however. In multiple sclerosis, for example, cleanup must precede the

replacement of damaged myelin.

Ultimately, the study could open a new door on regeneration, even beyond one key sector of the nervous system. “We have thought of the Schwann cell as a static entity that was just there to make myelin, but they have this latent program, where they become the first responders and initiate many actions that are required for the axon to regenerate,” Svaren says. ★



*David Tenenbaum is with University Communications at the University of Wisconsin-Madison.*

## CMTA APP: HERE’S THE SQUEEZE

In early 2016, the CMTA introduced its mobile app, designed to help connect CMTA advocates and assist them with fundraising and reaching donors. Today, almost 1,000 people have downloaded the app, using it to stay current on CMTA news and events, keep the latest version of the neurotoxic medications list at their fingertips and create and share donation pages.

The CMTA app was created to help in everyday fundraising as well as event fundraising. The goal of the app was to make it easier for advocates to collect donations. App users can also share donation pages by creating their own fundraisers or joining existing fundraisers. They can even take in-person credit card donations to the CMTA right on their phones! The CMTA app also includes an incentive-driven program, known as the LemonAid Stand, which awards users with LemonAid points for every dollar in donations they collect. Advocates can track their points, goals and fundraisers and redeem their points for awesome CMTA prizes on their LemonAid profile. Advocates should also watch for special promotions when they can earn more points for the work they’re already doing to support the CMTA.

Advocates have always been creative in coming up with ideas and possibilities to increase donation totals. CMTA and the app developers are always willing to assist advocates in their efforts. Advocates can contact the CMTA app developers through the app (select “Report an Issue” to send an email directly to the developer support team) or by reaching out to CMTA branch managers for support and assistance in custom fundraisers.

If you have not yet downloaded the CMTA app, you can find the app by searching CMTA in the Apple App Store ([appsto.re/us/u3IM8.i](http://appsto.re/us/u3IM8.i)) or the Google Play Store ([play.google.com/store/apps/details?id=com.lemontreegrowth.lemontreegrowth](http://play.google.com/store/apps/details?id=com.lemontreegrowth.lemontreegrowth)).





# CMTA MEMBERSHIP, PUBLICATIONS & ACCESSORIES ORDER FORM



## VIRGINIA

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was running with them. In February 2013, she entered her first race, the 5k Las Vegas Color Run. As she crossed the finish line, she flashed back on the hopelessness she felt on getting her diagnosis. After the race, she sent a picture of her crossing the finish line to everyone at Allard, leading to her selection as an Allard ambassador.

Today, Virginia is the Las Vegas Branch leader and one of 13 co-captains of Allard's TeamUP, the first national team composed of people who all live with foot drop. From a triathlete, to a marathoner, and a teacher to a wounded veteran, each member has a unique story and different cause of foot drop, including CMT, MS, muscular dystrophy and spinal injury. Virginia runs in about five races per year.

Her favorite race is still the Las Vegas Color Run, a paint race in which participants are showered with colored powder as they run. Runners are encouraged to wear costumes and in recent years Virginia and her daughter have dressed up as hula girls, hippies and super heroes.

Recently the members of TeamUP travelled to Sweden for an Allard event that included ballroom dancing lessons. The lesson was Virginia's first and she says she was "nervous but up for the challenge." She had a wonderful partner who made her laugh as he taught her some moves. She says that while she might need braces to dance, she feels "lucky and blessed to be able to enjoy the little things that mean the world." It might take her a little longer, or she might have to do it differently, but she finds the joy in life. If you take her advice—"See everything as if it's your first time, listen with your heart, wonder like a small child, and dance like no one is watching"—you just might find the joy too. ★

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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)  
Bortezomib (Velcade)  
Cisplatin and Oxaliplatin  
Colchicine (extended use)  
Dapsone  
Didanosine (ddI, Videx)  
Dichloroacetate  
Disulfiram (Antabuse)  
Eribulin (Halaven)  
Fluoroquinolones  
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  
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### **Uncertain or minor risk:**

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# THE CMTA Report

The Charcot-Marie-Tooth Association

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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.