

THE

# CMTA Report

SPRING 2016

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**Marcia Semmes** *Executive Editor*  
**Karlyn Rosen Aires** *Designer*  
**Dana Schwertfeger** *Contributing Editor*  
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**Email the CMTA at**  
**info@cmtausa.org**

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# CMTA CEO Patrick Livney to Run Spartan Obstacle Race for STAR

BY TRICIA (LIVNEY) HIRSCH

**IN ANCIENT GREECE,** the Spartans were a warrior people known for their discipline, bravery and tenacity.

On Saturday, April 9, my brother—CMTA CEO Patrick Livney—will need each of those traits as he and his team fight to cross the finish line of his first Spartan Sprint, a 3.5-mile obstacle-laden race through mud and root-filled fields. Like everything he does, he's doing it to benefit the CMTA and its STAR research program.

Over the past few years, my family has traveled across the

country to participate in mud runs from Spartan Sprint Races to Tough Mudders. These races range from 3.5 to 15 miles and include obstacles like traversing creeks, climbing cargo nets, running up slick quarter pipes over 15 feet high and cage crawling through mud pits under barbed wire. Mud races are about teamwork and building bonds of trust rather than competition. The idea is to take some risk, overcome fears, experi-

ence an adrenaline rush and spend the day outside with family and friends for a worthy cause.

At each race, we have been inspired by watching wounded warriors and others with physical disabilities conquer these grueling races with assistance from their family and friends. It occurred to us that we should rope Patrick into this wild and crazy endeavor. It took a year to cajole him into committing and he did so only on the condition that the event would focus on fundraising for STAR rather than on him. Of course, we felt like the two were not mutually exclusive. We are now a team of

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**SPARTAN**

(continued from page 3)

20 strong who will support Patrick safely across the finish line of the Spartan Race in Concord, North-Carolina. Close family—including my husband and three children, Pat's wife and daughter, and our brother and his wife and children—along with friends and trainers will ensure that Patrick does not break an ankle and that laughter accompanies every obstacle. It is guaranteed that we will be washing mud out of our hair, or off of our scalps, as the case may be, for weeks after the race!

The training takes enormous physical and mental grit—and even more determination. The past few months of training have been transformational for Patrick. His world fell apart in 1976 when he was diagnosed with CMT at age 16. His life as a competitive athlete ended abruptly and there was little medical information about the disease available. His anger towards life in general and no one in particular defined him

for a long time. His balance and walking abilities weakened, but he never considered wearing braces. Despite his CMT, Patrick became successful, started a wonderful family and joined the CMTA about 10 years ago, channeling his anger into passionate and tireless dedication to finding a treatment and a cure for millions around the world living with CMT.

In preparation for the Spartan Race, Patrick trains three to four times per week, focusing on his core and ab strength with P90X2, weightlifting and cardio. He has lost 11 pounds by eating more protein and fewer sugars and carbs. For now, he walks on the treadmill with a target heartrate and then jumps on the elliptical to combine both arm and leg exercise. As race day approaches, he will expand his training to include



Training for the Spartan

more rigorous terrain to simulate the obstacle course. Pat freely admits that he's concerned about having adequate grip strength for some obstacles and the possibility of breaking an ankle. But, Spartan that he is, those concerns are fueling him, not

stopping him.

Once Patrick agreed to train for the race, he realized the timing was right—physically and emotionally—to be fitted with new AFOs. He chose custom Noodle carbon fiber braces by Kinetic Research, fitted by Sean McKale of Midwest Orthotics, to begin his new journey. For my family, it was really emotional watching him walk with his new braces for the first time. Seeing the improvement in his balance and gait was overwhelming. The braces have increased his mobility by 25 percent, his confidence has skyrocketed and his overall energy level has increased.

We are so proud to be a part of this challenge with Patrick and hope that you will join the team by donating to STAR on his behalf. For a better understanding of our mission and what the Spartan Race is all about, we invite you to watch a short YouTube video produced by Patrick's nephew at [www.youtube.com/watch?v=XEiNf21-CC4](http://www.youtube.com/watch?v=XEiNf21-CC4). Patrick has a lofty fundraising goal of \$500,000 to benefit STAR. You can make a donation to support his efforts at [www.firstgiving.com/cmta/spartan](http://www.firstgiving.com/cmta/spartan). For us, this event will bring together Patrick's family and friends from around the country, and we would love to see many of you at the finish line. ★



Support Patrick Livney's efforts at  
[www.firstgiving.com/cmta/spartan](http://www.firstgiving.com/cmta/spartan)

## CELEBRATING CMTAthletes

# Disney Princess and Athlete Cynthia Lawrence

In 2015, I ran the race of my life—the Disney Princess Half Marathon.

I didn't realize it then, but it may have been my last race. My ankle started bothering me when I was training for the race—the same ankle I injured years ago, a really bad sprain that took a year to heal. During training, pain returned. And it never went away.

I saw an ankle specialist who diagnosed me with chronic ankle tendonitis. He said that although surgery could be an option and might give me temporary relief, the fact is that my ultimate underlying problem would still be there. That problem is CMT. The structure of my foot is altered, and my ankle muscles are weak. As a result, I have tendonitis and pain. But this hasn't stopped me from trying to stay active and healthy.

I started 2016 thinking this might be the last year I run races. I signed up for the Princess 10K at Disney in February, and I am a part of a relay team doing the Oregon Wine Country Half Marathon in August.

Doing a race at Disney is always risky for a slow runner. They have cut-off times and enforce them with runners wearing balloons (the balloon ladies) who run at the back of the pack. If you fall behind the balloon ladies, you might get swept off the course, officially not permitted to finish.

I was lucky at the 2015 Princess Half Marathon. Jude

Burton, another runner with CMT, ran with me. Jude kept me focused on finishing and helped me keep the negative voices out of my head. You know those voices. The ones that tell you to quit, that you are too slow, that you can't do it. I am eternally grateful to her and proud that I finished my dream race.

But the 2016 10K was a different story. I lined up to start the race—and it was freezing. I was nervous and by the time I started I couldn't feel my feet. By the second mile, the balloon ladies had caught up with me, and by 2.75 miles I was taken off the course.

Not finishing a race is hard. It's hard not to feel like I failed and when people tell me that I am strong and brave for even starting, I get angry. Sure, I fight my injuries and go out and train and get it done. I register for and start races. Most people would never do these things. But the people who tell me that I am strong and brave don't understand life with CMT. This is what it's all about.

I know that there is currently no cure for CMT. That said, I want to always remain active and ready for a treatment when it comes, whether through running, swimming, spinning, Pilates or weight training. I know everything is adaptable in some way and there are a ton of ways to push and challenge myself. I also know that



*Cynthia Lawrence after the 2015 Disney Princess Half Marathon*

my failures, setbacks and challenges drive me.

What will my next goal be? I'm not sure. I am going to take a break and figure out where I am going and how I will get there. Maybe it's time for me to try to conquer one of my oldest goals.

Maybe it's time for me to learn how to ride a bike. ★

*Cynthia is a photographer specializing in maternity, newborn, baby and family photography ([www.cynlawrence.com](http://www.cynlawrence.com)). She has two amazing kids (ages 7 and 5) and a husband who keep her extremely busy. In her free time, she tries to sew, knit and paint. She is a member of the South Florida CMTA Branch and moderator of the CMTAthletes Facebook group ([www.facebook.com/groups/cmthletes/](http://www.facebook.com/groups/cmthletes/)). And she loves college football.*

## CELEBRATING CMTAthletes

# Karen Brown and the Making of a Triathlete

The moment I crawled, braceless, out of the sandy-bottomed channel where I'd just completed a 200-yard open-water swim was the moment I became a triathlete.



Karen Brown, biking, cheered on by son Emmett

Rather than accept help and be disqualified, I overcame my fear of failure, my fear of looking silly and my excuses for giving up and I finished the race.

The open-water swim was just one leg of my first mini-triathlon (200-yard swim, four-mile ride, one-mile walk), which I completed in Phoenix in 2015. The water was supposed to be 80 degrees the day of the event so I didn't worry about surface chop or buying a wetsuit. It turned out to be 70 degrees: I was numb with cold, unused to the chop, ignorant of how to swim straight in open water and struggling to breathe. To compensate for the current favoring my stronger side, I pushed my weaker side so hard that I somehow shifted my top rib out of position, causing significant pain. About 75 yards in, I didn't see how I could make it through the swim, let alone the whole race. I had trained freestyle but had to swim the last 125 yards sidestroke because that was all I could manage. And then when I finished the swim, I realized I couldn't walk out of the sandy-bottomed channel without my braces. So I

crawled. Today, I'm still braced from thigh to toe, but I don't feel disabled anymore. I'm a triathlete! This is how I did it.

I became an athlete rather late in life. I wasn't diagnosed with CMT1A until I was 25, and injuries and poor medical advice led me to live my first few decades with extreme physical caution. I began training in my early 40s from a rather sedentary starting position. Ironically, while CMT used to be the reason I stayed on the couch, now it is the reason I stay active. Not only am I discovering how much I really CAN do, but I'm improving my balance and getting stronger, which helps in my everyday life. My CMT is my greatest motivation to stay active. Without it, I sincerely doubt I would ever have considered a triathlon!

For me, finding a great swim coach and physical therapist/trainer has been immeasurably helpful in the swim and run legs. Because I am more consistent with training when others are expecting me at certain times, I take a competitive swimming class at the local community college. I'm also working with a

biomechanical physical therapist/certified athletic trainer to improve my core strength, stability and gait and to learn to RUN—I was only able to walk in my 2015 race. When I finish with PT, I'd like to continue the work with a personal trainer, using 5K races to measure my walking/running improvement between triathlons (one a year, I think). Just getting out there and riding regularly, as well as seeking out additional hardware (an athletic knee brace), has helped me most on the bike. In May 2016, I will be doing my first full sprint distance triathlon.

I find I have to be the tortoise when it comes to my training—slow and steady. My gains are harder-won and more easily lost than those of my “healthy” friends. I get injured more easily and take longer to recover, so it is all about pacing myself and finding a level of activity where I am challenged but not pushed so hard that fatigue derails me. My favorite resource for training and motivation is the CMTAthletes group on Facebook. What a community of support and inspiration! To build a real-life community of support and accountability, I created a Circle of Friends on the CMTA website and asked my friends and family to give to CMT research in support of my triathlon. That gave me a cheering section and helped raise funds for research. It would have been so easy for me to back out of the race midway, when my self-doubt tried to take me out, but knowing that people I love had already put up their money in support of ME kept me on track.

**Ironically, while CMT used to be the reason I stayed on the couch, now it is the reason I stay active.**

When I began this adventure, I discovered a number of people in my life who didn't believe I could actually reach my goal. Some even thought I was delusional to try. I learned how important it is not to let other people tell you what you believe about yourself, even if those people love you and are well-intentioned. Surround yourself with people who believe in you.

At the same time, give yourself permission to modify your goals based on your training experiences.

I started out in pursuit of a longer triathlon, and only after months of preparation did I realize I was shooting too high for a first contest. I wanted to quit, really, because I felt so defeated. And I'm grateful that with the support and encouragement of a few dear friends, I stayed in it and shifted my goal to a shorter race. It doesn't mean I won't hit that longer goal in time—only that I wasn't ready for it YET. And that's okay. Goals are important because they give us something to



work toward, but in truth the timelines are irrelevant. It's the journey that makes us athletes.

My advice for others is to do what you love, and find a way to use that passion to challenge yourself. Train consistently, but be kind to your body because pain does not equal gain for CMTers. Be a tortoise! ★

*Karen Brown is a wife and mom above all else. She also shares her home with her two latest rescue dogs and a tank full of frogs and fish. Karen loves to sing, bake, read, write, and make artsy crafty things in her spare time.*

## MONTHLY GIVING BLANKET GREAT FOR PICNICS!

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

- ★ A monthly gift of \$15 helps the CMTA's 70 branches hold regular meetings in North America.
- ★ A monthly gift of \$30 helps the CMT Centers of Excellence to provide high-quality care in 20 clinics worldwide.
- ★ A monthly gift of \$50 helps the STAR Scientific Team work toward the first treatment for CMT.

When you make a monthly gift of \$30 or more at [www.cmtausa.org/monthly](http://www.cmtausa.org/monthly), you'll receive a CMTA blanket.\*

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



*\*Please allow 6-8 weeks for delivery.*

## MEET YOUR CMTA ADVISORY BOARD

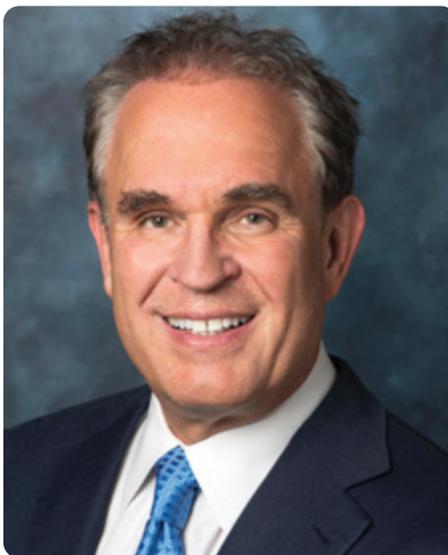
### Dr. Glenn Pfeffer

**B**ased at Cedars-Sinai Medical Center in Los Angeles, Dr. Glenn Pfeffer is one of the leading orthopedic foot and ankle surgeons in the world. His primary clinical and research interest focuses on reconstruction of the foot and ankle. One of his current research projects involves an unprecedented approach to the surgical correction of cavovarus deformity in CMT patients using computer modeling and 3-D printing. An expert on Charcot-Marie-Tooth disease, Dr. Pfeffer is a valued member of the Cedars-Sinai CMT Center of Excellence and the CMTA Advisory Board.

Dr. Pfeffer received his bachelor's degree from Yale University and his medical degree from the University of Pennsylvania, where he did his surgical internship and orthopedic residency. He completed two fellowships, one in foot and ankle surgery at the University of Texas, Houston, the other in hand and microvascular surgery at the University of California, San Diego. After completion of his training, he served overseas for six months with Project Hope as a volunteer orthopedic surgeon.

Dr. Pfeffer's interest in CMT dates back to 1987, when he first went into practice. A young woman with a cane came to his office and asked if he could help her walk more normally. She told him that out of embarrassment she had never been on a date or shown anyone her feet. "Her feet were badly

deformed," Dr. Pfeffer recalls, "twisted inward and forcing her to walk on the sides of her ankles. I had never seen anything like it." She explained that she had Charcot-Marie-Tooth disease, a condition that he knew little about. Anxious to help this young woman, Dr. Pfeffer quickly learned all he



could about CMT. Eventually he was able to surgically correct her feet so that they were flat on the ground and she walked on her soles. He had changed her life, but she had also changed his.

Some of Dr. Pfeffer's CMT expertise can be attributed to his very personal understanding of the issues, which comes from his own foot problems. As a youth, he had pain in his left foot and saw many doctors in New York City, who told him there was nothing wrong with him. A good athlete, he was held back from being great by the nagging pain in his foot. "No one could help me," he explains, "so I learned to

live with my problem, accepting it as normal." It wasn't until years later, after his foot and ankle fellowship, that Dr. Pfeffer diagnosed his own problem as a tarsal coalition, a condition where the bones in the back of the foot are fused together. He has always been against fusions for CMT patients, largely because he doesn't want patients to end up with a foot like his. In 2004, Dr. Pfeffer had surgery on his foot, but it was too late to restore motion. His experience taught him the importance of early surgical intervention and gave him a vivid glimpse into the world of those suffering from CMT and the misdiagnoses they receive.

Dr. Pfeffer says that the majority of patients he sees do not need surgery. Most patients can be helped with custom braces or a specialized physical therapy program. Surgery, however, plays an essential role when a patient has a foot that is not flat on the ground during walking. He believes the CMTA is a remarkable organization due to its commitment to research and its interest in helping people with immediate needs, including surgery. "With the help of the CMTA, there will one day be a cure," he reflects, "but until then there are a lot of people for me to help." ★

*Dr. Pfeffer is the director of the Foot and Ankle Center at Cedars-Sinai Medical Center, co-director of the Charcot-Marie-Tooth Program, and co-director of the Cedars-Sinai/USC Glorja Kaufman Dance Medicine Center.*

# Flying Through the Fear

BY ORI BASH

I am not now and have never been a thrill seeker. I have always been more of the risk-averse type. But a little over a year ago, at the beginning of 2015, I embarked on a campaign to overcome my strong inclination to avoid risk. And in December 2015, I finished the year off with a bang with an indoor skydiving experience. It was the thrill of a lifetime.

Indoor skydiving is the simulation of freefall conditions in a vertical wind tunnel. Essentially one is floating on a cushion of air, replicating the feeling of flying.

To me, though, indoor skydiving was about more than seeking a thrill. It was about something grander. My risk-aversion tendencies were deep seated, and my CMT diagnosis in 2007 at the age of 28 only made those tendencies worse. I cut out many physical activities out of fear of failure and hurting myself and also to avoid the emotional pain of experiencing first-hand that I couldn't perform such activities anymore. I knew that this attitude was crippling and that it had to change.

Over time, I worked on myself and became more accepting of my CMT. I re-jiggered my mental state. I reset my expectations for performance and adopted a "willing to fail" mentality, reframing challenging activities as growth opportunities and praising myself for pushing my own boundaries. I also adapted to some of my physical limitations with aids like AFOs (leg braces) and implemented a new and moderate exercise routine.

At first I worried whether a skydiving experience would be too much for someone with CMT.

I asked myself: "Can I do it?" "How will CMT hold me back?" "Could I be putting myself in harm's way?" "Will my AFOs get in the way?" "Can I get in and out of the air tunnel?" I am so glad that I had the courage to participate because it was so much fun, and my CMT did not restrict me in any way.

After a short training session with a video and an opportunity to ask questions, I changed into my flight suit and helmet. A flight instructor reminded me of hand signals for communication while flying and helped me step into the tunnel and assume the "super-

I reset my expectations for performance and adopted a 'willing to fail' mentality, reframing challenging activities as growth opportunities...

man" body positioning for safe flight. (My AFOs did not hinder this in any way.) I was assured that the flight instructor would stay by my side during the entire time to ensure my safety. As the adrenaline rush of the first few seconds began to wear off, I thoroughly began to enjoy the flying sensation.

And when my two minutes of flying were over, I was helped out of the tunnel without a glitch.

I am proud that I pushed my boundaries and I want others to experience this amazing feeling. That's why I created the "Skydive

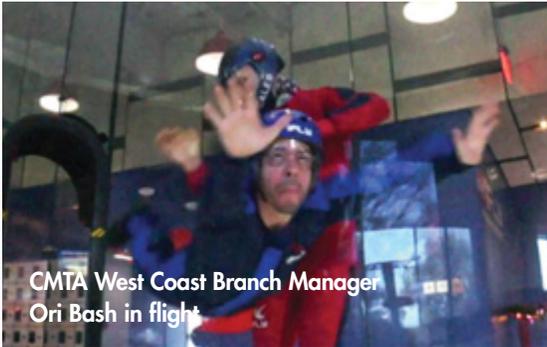
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**FLYING**

(continued from page 9)

for the CMTA” concept. The fundraiser is simple and easy. Just raise \$1,000 (or more!) and you



CMTA West Coast Branch Manager  
Ori Bash in flight

and three of your friends can soar like eagles with an indoor skydiving experience. The folks at iFly brag that indoor skydiving can be done from the age of 3 to 103! Now, I can brag that it can be done by people with CMT and other physical disabilities! For more info about an indoor skydiving experience, check out [www.iflyworld.com/what-to-expect/](http://www.iflyworld.com/what-to-expect/). iFly locations are listed at <https://www.iflyworld.com/find-a-tunnel/>.

I would love to help you craft your story for the FirstGiving page ([www.firstgiving.com/CMTA/sky](http://www.firstgiving.com/CMTA/sky)

diver) and also with composing your e-mail campaign and other marketing/promotional efforts. Please contact me for more information about the fundraiser at [ori@cmtausa.org](mailto:ori@cmtausa.org).

Don't miss out on this great opportunity to challenge yourself—whether with the physical aspect of indoor skydiving, with being open and raising awareness of CMT, or fundraising for the CMTA. I can't wait to hear about your experience at iFly! Thank you for helping the CMTA continue on its mission of “A World Without CMT”! ★

# O Happy Day!

Facebook friend Nicole Rachel recently asked her friends: **“If by a miracle there were a cure for our disease, what’s the first thing you’d do?”** We loved the answers!

*Walk without looking where I am stepping.  
Take a hike across Ireland.*

**Run! Jump! Stand on my toes to get something down from a high shelf!**

*Run. I'd run until I puked and then run some more.  
And I'd probably never wear shoes again.*

**Travel the world! Climb all the pyramids I could!**

*I would put on a pair of stilettos  
and run up and down the steps*

**Buy another motorcycle and feel the wind in my face again.**

*Oh yes, simple things  
I took for granted—  
beautiful shoes, work,  
and DANCING....*

*I would buy a pair of heels, find the coolest tutu  
and run a marathon, then go to Disney World and  
have fun until I literally could not walk any more.*

*I'd put on some high heels and a dress and go dancing.  
I've never been able to wear heels and never been able  
to dance. It looks like so much fun!! I would love to be  
able to just slip on a dress and have beautiful legs.*

**Go on a long dangerous hike in the woods  
on uneven surfaces and not look down.**

*I'd walk barefoot on the beach,  
then run through the waves,  
jumping over them and run and  
run and run! Sometimes I dream  
I'm running, and then all of a  
sudden my CMT disappears!*

**Go outside barefoot!**  
*Summer, feel the grass between my toes,  
winter feel the cold from the snow.  
Oh how I miss the little things.*

*I'd like to go to medical school and  
ride a skateboard between classes.*

*I would run for hours, buy the highest stripper heels  
I could find, go dancing all night long, and go to a  
rock concert because I wouldn't have to worry  
about standing without support anymore.*

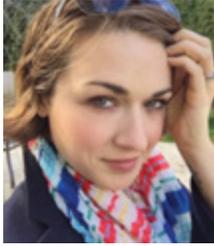
*I would fall down on  
my knees and thank  
Heavenly Father for  
sending all of us  
a MIRACLE.*



# I Have a Disease I Don't Talk About, But I Think I Might Start

BY KASEY JONES TONSFELDT

I have CMT. My brother has it. My mother too. My uncle had it and so did my grandmother. It would be hard to guess that anything is wrong or different about me. I seem normal—fit even. And I am, but with a caveat.



only as a way of undermining its power, explaining why I'm injury-prone or balance-challenged, and giving people an opportunity to engage and be curious.

It is extremely rare that anyone is. My mention of CMT is usually met with silence. A missed beat before the conversation continues.

The symptoms are things that most people wouldn't really notice or wouldn't take seriously. I fall a lot. I trip over things. My ankles just buckle because I'm standing wrong. I have a tough time using ballpoint pens now and only write with felt tip, just like my mother. I'm a slow runner and running hurts. I'm not terribly coordinated. I'm clumsy. Without deeper context, this stuff isn't remarkable. Some people think it's comical because they don't know that it's not. Hell, some people who know something is wrong still think it's funny and make jokes about it. And despite the sting, the hurt that just lingers, I don't correct them.

I don't blame anyone for that. It's tough to know what to say and most people opt to say nothing at all. It does mean that I rarely have an opportunity to discuss what's lurking in the back of my mind—that every year, I will grow weaker and I will struggle more with the little things—holding a pen without my hand cramping, injuring myself and not realizing because I simply don't feel pain like I should, wearing impractical shoes, trying a new sport—especially if anyone's watching ... the list goes on.

I come from a suck-it-up-and-deal family. We don't complain publicly and we don't brag. We don't parade our weakness around for others to see, and we don't flaunt our good luck. We are not victims or victors. We don't use the inevitable misfortunes of life to gain sympathy, and we don't use privilege or success to build ourselves up. We keep our heads down. We work hard. We try to be good, honest people.

This week I went to Oregon Health and Science University's neurology department. The visit was incredibly tough. It was my very first as an adult because for what I have, there's no cure, no treatment, nothing. If you know you have it, there's pretty much no point in seeing a doctor at all. There is literally nothing they can do for you, so I've never gone. But I wanted to ask what happens if I have kids (even though I already knew), so I went.

The struggle makes me human and the perseverance makes me strong.

The first doctor knew almost nothing about CMT. She tested my reflexes, the strength of my fingers, my hands, my wrists, my toes, my feet and my ankles. My toes, my feet and my ankles collapsed against the pressure behind her hands. She banged her little hammer against the back of my ankles, but there was no muscle jerk or reflex. She asked me to stand with my feet together and close my eyes, I tipped this way and then that. She smacked her little metal tool against her hand, holding the end against my skin, asking me to tell her when the vibration stopped. Most of the time I could. Sometimes I couldn't even feel that it had started.

Still she told me my symptoms were so mild I probably didn't have it. I asked about my potential children—she didn't know. And then she said we were done, to get dressed, schedule some follow-up testing and go home. Then she left.

Moments later the attending doctor—the neuropathy specialist—came in. He took one look at my increasingly gnarled, bony feet with their high arches and did a quick strength test of my ankles. He smiled at me and shook his head and I knew he knew. I fought back tears.

He knew what I was going through and he knew how wrong his colleague had been. How thoughtless she had been to

(continued on page 12)

## ARE YOU A CMTA ALL-STAR?

The CMTA is looking for dedicated individuals to host CMTA All-Star events. These are coordinated events that bring people in your community together to Walk 4CMT, Cycle 4CMT, or Swim 4CMT! Our goal is to have them all over the country. By becoming CMTA All-Stars, you and others in your community can come together to raise critical funds for the CMTA's drug discovery program, STAR.

If you're interested in hosting a CMTA All-Star event in your community, you'll have the support of the CMTA and a lot of fun in the process! Are you ready to make a difference? If so, contact Jeana Sweeney at [jeana@cmtausa.org](mailto:jeana@cmtausa.org) to have an All-Star information packet mailed to you.



### STARTING TO TALK

(continued from page 11)

diminish my experience while giving me even an inkling of hope that I might not have this. That it might not get any worse.

He rattled off the myriad of symptoms he guessed I was experiencing.

**You can't wear heels anymore, huh?** No. No I can't.

**Do you trip a lot?** All the time.

**So all those scars on your feet and knees and legs are from falling?** Yep.

**You'll need to be careful. Now is about the time you'll start hurting yourself without knowing it because you just can't feel the pain like a normal person.**

I broke my foot last summer and proceeded to walk, workout, run sprints, everything for two weeks. The fallout lasted months.

I felt my chest tighten.

*Someone understood.* The things I thought I'd been feeling weren't imagined. They're real and for someone like me, they're normal. Someone was actually asking

me questions and understanding the answers. I didn't have to cater to his discomfort or force a smile.

It was such a relief.

But it was also a punch in the gut.

This is real. This is happening. And it's only going to get worse. There's no treatment. There's no recourse. This is only the beginning.

As you might imagine, my appointment was followed by tears and worries and sadness. And that was followed by reminders that my mother is nearly 70 and still active, vibrant and beautiful—even with the braces on her legs. This isn't fatal. This isn't even paralyzing. It's a constraint, a limitation, a proverbial cross to bear, and there's actually some good in that. Those are the things that give us *depth, empathy, gratitude and perspective*. In the end, I know that the CMT has made me a kinder, gentler, more compassionate person.

The struggle makes me human and the perseverance makes me strong.

Today, I'm still a little raw. Still a little distracted. I'm not ready to talk about what this

means for any potential kids in my future because I just don't know how I feel yet. I am ready to talk about everything else though.

I need people to understand that when I joke about being clumsy, it's a way to deflect the pain and embarrassment I feel at struggling to do normal things. It's not an invitation to joke about it too.

I need to be able to process that this is getting worse, that it will continue to get worse, but that it's all stuff I can handle. I need to remember that the way I process things is by talking about them. Getting them out. Saying them aloud. Staying quiet and tough isn't working. And it's lonely as hell.

I'm not 100 percent certain what all of this means. I still don't want people's sympathy or their pity. I don't want to be a downer. But I do want to be honest. So for now, I'll just focus on that. ★

*Kasey, 33, is the co-founder of a business growth agency, Young Lions Collective and the founder of a new company that helps women become entrepreneurs. She is also the co-founder of PDX WiT, Portland's largest women in tech group. When she's not founding things, she is also a fitness nut, a wife, and a mother to three furry four-legged children.*

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

Dear David,

*My beautiful 11-year-old daughter was diagnosed with CMT about a year ago. Until recently, she seemed to be doing well, apart from occasionally tripping and not having much strength in her lower extremities. We are thinking of some mild bracing, but I am worried that she will not do well looking a little different from her friends. She is rather shy and doesn't always stand up for herself.*

*David replies:*

Although I appreciate your concern about your daughter feeling different and wanting to protect her from getting hurt, it is important to allow her to experience some discomfort. This will help her develop the necessary psychological strength to manage her feelings throughout her life.

Although she is at the age when "fitting in" is a priority, there is no time like the present to reinforce for her that her CMT is not something to be ashamed of, but that it is simply her uniqueness, in the same way that every child is different in some way. It will probably require many conversations stressing the theme that different does not mean worse, just different. Don't hesitate to involve her teachers. For example, you could suggest to them having a day celebrating everyone's uniqueness. Of course this would need your daughter's consent. Studies show that when non-disabled children are exposed to these differences, they develop a greater sensitivity, not only to others who are different, but to their own differences as well. Encourage your child to verbalize her feelings whenever possible, even if you have to initi-

ate the conversations.

Praise and point out her strengths, and, of course, include her in everything, even if you need to modify some activities so it is easier for her to participate. Please keep in mind that she is also observing your own reactions to her CMT so it is important that you are absolutely honest with yourself and that you do your own work in accepting that your child is not perfect.

Your daughter might have to learn to advocate for herself, but you can give her a great start by showing her how much she is loved just for being herself. The earlier in life she can accept and



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

love herself, the easier it will be later on. As we all know, a perfect body does not make a perfect life. The habit of comparison is epidemic in our society. We learn this very early and carry it our whole lives.

Teaching a child to put comparison aside and love his or her uniqueness is a tough task but well worth it. ★

*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.*

### FLUOROQUINOLONES MOVED TO MODERATE TO SIGNIFICANT RISK CATEGORY

The CMTA has moved all fluoroquinolone antibacterial drugs from the "Uncertain or Minor Risk" category of its Neurotoxic Medications list to the "Moderate to Significant Risk" category.

The U.S. Food and Drug Administration (FDA) in 2013 required that the drug labels and Medication Guides for all fluoroquinolone antibacterial drugs be updated to better describe the serious side effect of peripheral neuropathy. This serious nerve damage potentially caused by fluoroquinolones may occur soon after these drugs are taken and may be permanent.

The risk of peripheral neuropathy occurs only with fluoroquinolones that are taken by mouth or by injection. Approved fluoroquinolone drugs include levofloxacin (Levaquin), ciprofloxacin (Cipro), moxifloxacin (Avelox), norfloxacin (Noroxin), ofloxacin (Floxin), and gemifloxacin (Factive). The topical formulations of fluoroquinolones, applied to the ears or eyes, are not known to be associated with this risk.

Dr. Louis H. Weimer, professor of neurology at Columbia University Medical Center, said that the FDA's decision to raise the risk status of fluoroquinolones was controversial and the evidence supporting it weak, but that it's better to err on the side of caution.



## NEW CENTER OF EXCELLENCE AT CONNECTICUT CHILDREN'S MEDICAL CENTER

**D**r. Gyula Acsadi, PhD, is the director of the new pediatric CMT Clinic and Center of Excellence at the Connecticut Children's Medical Center. The CMT Clinic provides comprehensive diagnostic evaluation and treatment by a team that includes Dr. Acsadi, Dr. Kristan Pierz, a highly experienced orthopedic surgeon, a nurse coordinator, a dedicated physical therapist, an occupational therapist and an orthotist.



Dr. Acsadi is a board certified neuromuscular specialist and a professor of pediatrics and neurology at the University of Connecticut. He formerly worked with Dr. Michael Shy at Wayne State University and served as co-principal investigator for the Inherited Neuropathy Consortium NIH grant.

The CMT Clinic collaborates closely with the pediatric Center for Motion Analysis of Connecticut Children's Medical Center, directed by kinesiologist Sylvia Ounpuu, who provides comprehensive assessments of gait abnormalities. The information gained from this analysis is crucial in the treatment (e.g. surgery and bracing) decision-making and documents changes in disease progression, resulting in a better understand of the walking difficulties in CMT. The Pediatric CMT Clinic team published the gait findings in *Gait and Posture* in 2013, and a review on "Pediatric CMT" in the June 2015 issue of *Pediatric Clinics of North America*.

The team members of the Pediatric CMT Clinic are very excited to be part of the Inherited Neuropathy Consortium and hope to further advance the research in CMT to the benefit of their patients. The clinic is located at 505 Farmington Ave., Farmington, Connecticut, close to the Medical School. Clinic hours are the second Wednesday of the month and appointments can be made by calling Nanci Stolgitis, RN, at 860-837-7500.

It's "App" to make you very happy!

Get the CMTA app today... and start making lemonade out of lemons

[www.cmtausa.org/app](http://www.cmtausa.org/app)

## New CMTA App Puts Website in Your Back Pocket

**W**e understand your need to have information at your fingertips. If you have ever been in a doctor's appointment and wished you'd remembered to print out and bring the CMTA's Neurotoxic Medications list, or you've been in the middle of telling a friend about your super cool fundraiser for the CMTA and wished there were some way to collect a donation from them right then and there, then the new CMTA App is for you!

The CMTA's new app for iPhone and Android allows you to create custom fundraising pages that you can share with your friends right from your phone. And for every dollar you raise for the CMTA, you will earn points that you can cash in for fun CMTA prizes and apparel!

The app also allows you to stay up-to-date with critical information for any CMT patient. Read the latest CMTA news, access the Neurotoxic Medications list and always have the CMTA website in your back pocket—literally! The app is currently available in North America, Europe, New Zealand and Australia.

# The *Ins* and *Outs* of CMTA Webinars

BY BOB CHRISTENSEN

CMTA webinars are presentations conducted by members of the CMTA Advisory and STAR Boards, along with other institutions and corporations that help those affected by CMT. While a tremendous amount of research continues into the search for a treatment for CMT, the webinars focus on the practical side of living with CMT.

I need those practical tips because I have CMT 1X. In my family, we have our very own “brand” of CMT; no one else has our exact mutation. I’ve known something was wrong since I was about 4 or 5 years old when my parents had custom orthotics built for my shoes. Back then, it was really hard to find someone who knew what CMT was. But with the help of the CMTA and a vibrant community of practitioners and volunteers who help get the word out, that’s now getting better.

My family members are not the only ones who are unique. There are more than 80 types of CMT and people’s symptoms vary widely with each. There’s no one-size-fits-all approach, and it’s hard work to figure out the best treatment for each of us. The CMTA webinars can be a powerful resource in your approach to managing your own, or a loved one’s, CMT. Webinar presenters have a wide variety of backgrounds and experience in working with CMTers. Even if you think you’ve heard it all before, the variability of CMT leaves room for unique and different solutions to our problems.

I have the unique opportunity to chat with each presenter, both before and during webinars, and I

realize their dedication to the work they do. They know and understand so much about how this disease affects us all, and each brings a unique set of skills to those who choose to listen. And yeah, it’s all free!

In the past 12 months we’ve had webinars on bracing and surgery, which might be expected. But we also got into the details with a full webinar on hand surgery to enhance function in children. We discussed how to face the daily challenges of living with CMT with some very practical and uplifting talks by people who have it. We’ve been brought up to speed on going back to school with CMT and how to work with teachers, peers and schools. We’ve focused on the care of pediatric patients and physical therapy specific to that audience. We’ve learned about specific foot problems to be on the lookout for, and so much more. I encourage each of you to visit the webinars page on the CMTA website at [www.cmtausa.org/webinars](http://www.cmtausa.org/webinars) and make use of this resource. I also encourage you to let us know what’s on your mind so we can host a webinar on a topic important to you, or one we have not yet considered.

So, how do CMTA webinars work? First, you’ll need a web browser and you’ll need to register before the webinar begins. The webinar web page has all the information you need. Each webinar is approximately one hour long and generally runs from 8-9 p.m. ET on a weekday in mid-month. The webinar generally starts with an introduction from a moderator—most recently this has been me. After a brief introduc-

tion, including instructions on how to ask questions, the presentation begins. Throughout the webinar I watch and listen to both the chat and questions windows, help with technical issues, and get your questions to our presenter(s).

Presenters then go through their slides/videos/images, etc., taking questions as they go. This gives viewers the chance to ask about what they’re seeing and to



get a deeper understanding of the topic at hand. Our presenters are always very generous with their time and try as best they can to answer all questions. If we don’t get to all the questions as we go along, there is normally a 10- to 15-minute period at the end where we review and answer further questions.

So, hats off to those who work with CMT patients on a daily basis. I cannot say enough about the dedication of those I work with on these webinars. The diversity of topics is fantastic. The personalities are enjoyable. And I believe tremendous value is being added to the CMTA community. I hope you’ll find some time to join us ... we’ll enjoy having you in on the conversation. ★

To see the schedule of upcoming webinars or view recorded webinars, please visit [www.cmtausa.org/webinars](http://www.cmtausa.org/webinars).

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## CMTA REMEMBRANCES

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

### Honorary Gift:

In honor of (person you wish to honor)

\_\_\_\_\_

Send acknowledgment to:

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

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

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

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# FREE SHOES FOR STAR MEMBERS!

All new STAR members receive a free pair of shoes from Aetrex. Continuing and renewing STAR members receive 50 percent off every pair ordered online.

*Tips for placing a successful order:*

- When ordering your free pair of shoes from Aetrex, please have only the free pair in the shopping cart when you check out. You can place subsequent orders to receive the 50 percent discount.
- The coupon code for free shoes can only be used once per member and paid membership. The 50 percent discount is only valid for the member holding the membership.
- Aetrex will honor the coupons for free and half-priced shoes for Aetrex shoes only.\*
- The coupons are valid when ordered online at [www.aetrex.com](http://www.aetrex.com) or by calling their customer service line at 1-800-526-2739.

Thank you for your support as a STAR member. Not a STAR member? To upgrade your Subscription membership to a STAR membership, please call Kim at 1-800-606-2682.



*\*Aetrex Worldwide is unable to offer discounts on Apex Shoes.*

## Looking for the Perfect Shoe for Spring?

The CMTA is pleased to announce a partnership with Foot Solutions, a health and wellness specialty retailer with more than 100 stores staffed with pedorthists and certified fitters. Foot Solutions offers footwear and orthotics to support your feet and help relieve symptoms related to CMT.



Members of the CMTA will receive:

- A 20 percent discount on any custom orthotics, all made in the USA,
- A 10 percent discount on the purchase of shoes and products,
- A free computer foot scan, and
- A fitting analysis to ensure the proper fit and function of footwear.\*

Most Foot Solutions stores have trained pedorthists on staff who have been educated in advanced shoe-fitting, shoe modifications and foot orthotics that accommodate the feet and allow for comfortable and stable ambulation. They are also familiar with CMT and associated lower extremity problems.

After a thorough analysis of the feet and gait, they will fit the

correct shoe for your lifestyle. They can accommodate your needs, whether determined through a doctor's prescription or determined by you!

Foot Solutions carries a variety of shoe brands including Aetrex, Finn Comfort, P.W. Minor and Brooks. They carry athletic shoes, casual shoes, dress shoes, boots and sandals, many of which accommodate in-shoe and ankle-foot orthotics.

To find a participating store near you, please visit [www.cmtausa.org/footsolutions](http://www.cmtausa.org/footsolutions), or visit [www.footsolutions.com](http://www.footsolutions.com) for more information.



*\*A thorough foot exam will take 30 minutes.*



# CMTA Branches

Most CMTA Branches can be accessed  
online at [www.cmtausa.org/branches](http://www.cmtausa.org/branches)

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256-366-5273  
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708-499-6274

### Norridge Area

Charles Barrett  
224-628-5642  
Sy Ahmed  
847-912-1062

## INDIANA

### Fort Wayne Area

Aimee Trammell  
574-304-0968

Priscilla Creaven  
260-925-1488

### Indianapolis Area

Nancy Allen  
317-459-8773  
Patricia Wood  
317-345-2254

## KANSAS

### Wichita Area

Karen Smith  
316-200-0453

## MASSACHUSETTS

### Boston

Mimi Works  
617-913-4600

Jill Ricci  
978-887-1014

## MARYLAND

### Baltimore

Clark Semmes  
410-350-4812

### Easton

Missy Warfield  
Seth Warfield  
410-820-0576

## MAINE

### Portland Area

Mary Louie  
207-450-5679

## MINNESOTA

### Central Minnesota

Jo Smith  
612-807-4729

### Minneapolis Area

Marilyn Menser  
320-522-0871  
Mark Jeffris  
651-222-4504

## NORTH CAROLINA

### Asheville Area

Ruth Ann Carroll  
203-981-3738

### Charlotte Area

Todd Long  
704-902-4700

Trisha Hirsch  
404-226-1389

### Durham Area

Margaret Lee  
919-656-2948

### Wilmington Area

Laurel Richardson  
910-515-8488

## NEBRASKA

### Lincoln Area

Karri Hood  
402-641-0443

## NEW JERSEY

### Central New Jersey

Mark Willis  
732-252-8299

Jacqueline Donahue  
732-780-0857

### Morris County

Alanna Huber  
973-933-2635

## NEW MEXICO

### Albuquerque Area

Gary Shepherd  
505-296-1238

## NEVADA

### Las Vegas Area

Virgina Mamone  
702-343-3572

## NEW YORK

### Buffalo Area

Chris Warden  
716-870-4425

### Upstate New York

Elizabeth Misener  
David Misener  
518-527-0895  
**Westchester Area**  
Beverly Wurzel  
Frank Wurzel  
201-224-5795

## OHIO

### Cincinnati Area

Jill Stuhlmueller  
513-254-4065

Jo Koenig  
513-607-2822

### Cleveland Area

Heather Hawk Frank  
440-479-5094

Mandy Kimpton  
440-724-1731

### Columbus/ Newark Area

Rebecca Knapp  
740-668-2103

## OREGON

### Grants Pass

Jessica Barton  
541-218-5350 (cell)  
541-846-8525

### Portland Area

Debbie Mchugh  
503-201-7284 (H)  
503-310-7229 (M)

## PENNSYLVANIA

### Bucks County Area

Linda Davis  
Mitch Davis  
215-943-0760

### Chester County

Ashley Caspersen  
484-364-9334

### Harrisburg

Erin Gaul  
(717) 379-7504

### Johnstown Area

J.D. Griffith  
814-539-2341

Jeana Sweeney  
814-269-1319

### Northwestern Area

Joyce Steinkamp  
814-833-8495

### Philadelphia Area

Rhea Malaluan  
267-386-5666

Ronnie Mendoza  
609-670-0870

### Pittsburgh

Carolyn Roberts  
412-363-2811

## SOUTH CAROLINA

### Columbia Area

Elise Bidwell  
803-462-1788

### Greenville Area

Rebecca Lauriault  
864-918-2437

Kitty Hodinka  
610-761-6874

## TENNESSEE

### Hendersonville Area

Brittney Grabiel  
423-213-2336

### Nashville Area

Bridget Sarver  
615-390-0699

Gwen Redick  
256-655-0391

## TEXAS

### Austin Area

Nate Halk  
512-415-6097

Dan Gattuso  
512-516-9161

### Dallas Area

Michelle Hayes  
214-529-3325

### El Paso Area

Veronica Gallegos  
915-203-4391

### Houston Area

Kristin Leard  
713-516-8630

Benjy Hershorn  
832-731-0121

Meredith Wells  
832-264-7312

### San Antonio Area

Kat Tovar  
210-385-1551

### Vidor Area

Angie Beaumont  
281-229-2099

## UTAH

### Orem Area

Melissa Arakaki  
801-494-3658  
Emily Hunsaker  
801-839-9060

## VIRGINIA

### Chesapeake Area

Donna Koch  
757-650-2417

### Fredericksburg

Leigh Van Doren  
540-370-1968

### Harrisonburg Area

Jeanette Thompson  
540-383-6195

Anne Long  
540-568-8328

### Richmond Area

David Collins  
804-730-2918

## WASHINGTON

### Seattle Area

Lynn Ronald  
206-546-8923

Denise Snow  
206-321-1261

## WISCONSIN

### Madison Area

Debi Weber  
608-712-8709

Jessica Wells  
714-333-8031

### Milwaukee Area

Susan Moore  
414-604-8736

## CANADA

### Southern Ontario

Kelly Hall  
519-843-6119

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: Mary Louie, Portland, ME

Mary Louie is a young woman with a lot on her plate. With a full-time job, two young children, and a heavy workout routine, Mary is constantly on the move, leopard braces and all. Despite her busy schedule, Mary finds time to serve as the leader of the CMTA branch in Portland, Maine.

Born and raised in Portland, Mary is part of an athletic family. Her mother, Big Mary, doesn't let CMT stop her from skiing cross-country, hiking and working as a nurse for 12-hour shifts on her feet. Her father, a former skateboarder and sailor, is a member of a group that surfs the coast of Maine year-round.

Growing up with a grandfather and mother who both have CMT, Mary always knew she had a 50-50 chance of having the disease. In high school, she dislocated her knee while playing field hockey, and at the age of 22 she was diagnosed with CMT Type 2. The diagnosis hasn't slowed Mary's

pursuit of athletic achievement. In 2009, Mary took part in the Mount Desert Island Marathon, which winds its way along the outer edge of that beautiful island in Acadia National Park. Registered as a walker, Mary began the course before the runners, but was then passed by nearly all the participants. Eight hours later, as she approached the finish line, Mary was determined not to finish last in the race and passed six people in the last three miles.

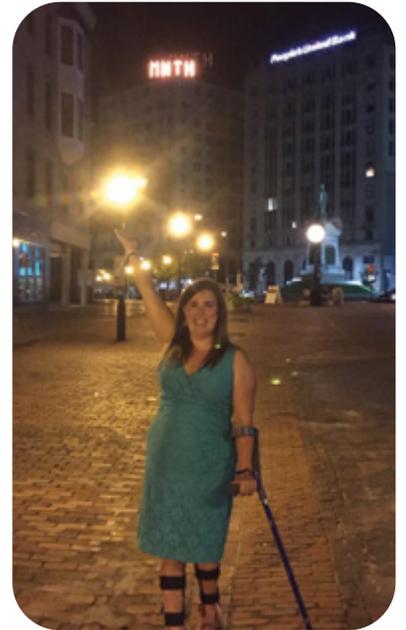
More recently, Mary has focused on swimming and water aerobics. She swims laps at her local pool for an hour four nights a week and does water aerobics two nights a week. In the summer, Mary swims in the annual Peaks to Portland event, a 2.4-mile swim in 60-degree water. The first year Mary took part, she found it quite difficult. The water was black, imposing sensory deprivation, and the currents in the cold water were challenging. But having completed the event four times, Mary is now

more confident of her abilities and looks forward to the next one. Mary will also be swimming in the upcoming Oxford Biathlon, which takes place on May 21. It's her second biathlon. She likened the first one, a one-mile swim in the warm waters of the Tred Avon River, to a bathtub and found the only difficult portion of the race was getting out of the water at the end.

Despite her busy schedule, Mary finds time to care for her 7-year-old daughter, Charleston, and her 5-year-old son, Kieran, with her husband, Rendon. They met at an outdoor science school in California when they were both 21.

Mary also finds time to come up with great new awareness and fundraising campaigns for the Portland Branch. For the past few years, the branch has arranged for the clock tower in central Portland to flash the letters CMT for a 48-hour span of time. During this period, Mary and her group distribute literature and raise awareness about CMT among the residents of Portland.

Whether the passage of time is marked by the completion of laps, the growth of her children, or the big clock in the center of town, Mary is always in motion. She's a great reminder that for those of us with CMT, motion can be medicine and staying active is often the best possible prescription. ★



*Mary Louie in  
Portland, Maine*

### UNIVERSITY OF ROCHESTER LOOKING FOR 1A PARTICIPANTS FOR CRAMP STUDY

Dr. David Herrmann is conducting a research study at the University of Rochester for subjects diagnosed with CMT1A. The pilot study will look at the effectiveness of a medication to help prevent muscle cramps in CMT1A, comparing the number and severity of provoked muscle cramps between the medication and a placebo treatment. There is currently no FDA-approved treatment for these muscle cramps. Participants will be asked to attend four visits over three weeks and keep a diary of their muscle cramping. They will be asked to take medication for two periods of five to seven days each; one period of study medication and one of placebo. The study is blinded, so participants will not know which medication they receive first. Individuals interested in being considered for this study should contact research coordinator Joan Mountain by phone at 585-275-1209.

## Remembering Archy Express Creator Jerry Cross

The CMTA lost one of its most beloved branch leaders on December 14, 2015, when Jerome (Jerry) Cross passed away at the age of 70. The long-time Las Vegas branch leader was known for his wonderful sense of humor, his generous spirit and as the architect, creator and chief engineer of the Archy Express, a homemade train that traveled the country raising funds and awareness for the CMTA.

Born in Los Angeles, Jerry served in the U.S. Air Force before retiring to the small town of Pahrump, Arizona, where he jokingly referred to himself as the Grump from Pahrump. The Grump cobbled the Archy Express together from a riding lawnmower, upside down wheelbarrows donated by the local Home Depot and a whole lot of love and patience. It was named for the CMTA's mascot, Archy the Turtle, which was created by Tina Marie Thomas and brought to life by long-time CMTA employee Pat Dreibelbis. Hand-built by Jerry in his garage, the train ultimately consisted of almost a dozen "turtle cars," with

names like Rod and Tina. It was a magnet to children and adults alike. Charging a dollar for rides, Jerry and the Archy Express raised funds for the CMTA but more importantly served as a tool for introducing people to the topic of Charcot-Marie-Tooth disease.

In 2010, Jerry packed the Archy Express into a rented truck and transported it all the way to Inverness, Florida, for a CMTA event irreverently entitled "Cooterfest." There Jerry was met by Pat Dreibelbis, Dana Schwertfeger, Elizabeth Ouellette, and Jeana Sweeney (dressed as Archy's sister, Tara the Turtle). The event was a roaring success and no one who attended will ever forget Jerry's amazing spirit or the train he created with love and hard work.

Elizabeth Ouellette, acting chair of the CMTA Board, called Jerry an "outspoken advocate for his family, his community and the CMTA" who dedicated his

life to raising awareness of CMT across the country. "Jerry's love of life and warm heart was an inspiration to us all," she said, adding "Jerry will be sorely missed by everyone at the CMTA, but his generous spirit and positivity will live on forever."

Long-time CMTA webmaster Dana Schwertfeger remembered Jerry as the indefatigable leader of the Las Vegas CMTA Branch, as well as the lighthearted purveyor

of dehydrated water and electric long underwear. "Jerry's ability to put a smile on your face and find a warm place in your heart made him a truly wonderful person and great friend," Dana said.

Jerry is survived by his wife Irene, his three daughters, and the undying gratitude of the CMTA community. We will never forget the Grump from Pahrump and the love and generosity he shared with all of us. ★



Jerry was an outspoken advocate for the CMTA.



The Archy Express



# CMTA BRANCH NEWS

## PHOENIX, AZ

Three new members joined seven existing members of the Phoenix Branch for an enjoyable meeting on January 9. Guest speaker Amy Burnside talked about mindfulness, meditation and pain management. She also recommended several books: "Mind-sight" by Daniel Siegel, "Freedom from Pain" by Maggie Phillips, and "Change Your Brain, Change Your Pain" by Mark Grant.

★

## SARASOTA, FL

The Sarasota Branch raised more than \$7,000 at its CMT Walk and Roll at the Sarasota Square Mall on November 7, 2015. Even some of the shoppers at the mall walked with us and donated on the spot. At the branch meeting on December 5, 2015, 100 percent of the members in attendance answered a request to donate and the money was sent to the CMTA for the STAR program. CMTA Advisory Board member David Tannenbaum engaged each of the members of the group individually and spoke about the challenges and methods of dealing with CMT in a positive way.

★

## INDIANAPOLIS, IN

Six members, two of them new, heard Shawn Notarione from Allard address the Indianapolis Branch on January 23. Notarione talked about the benefits of bracing and presented three of Allard's products: the Epsilon, ToeOFF and BlueROCKER. He emphasized the importance of the prescribing doctor making detailed notes about the necessity of the AFO and getting the correct code for insurance—L1932. Shawn works with a number of clinics in Indiana, including SRT, Midwest Ortho, AOI and Hanger Clinic.

★

## IOWA CITY, IA

Occupational therapist Rachel Pins outlined the benefits of OT for the 13 people at the Iowa City Branch's first meeting of the year. Pins, a member of the team at the University of Iowa's CMT Clinic, passed around samples of the materials used to make plastic finger splints and an example of an adaptive knife and demonstrated exercises using thera-putty and household items. The group also talked about silver ring splints and hand stretching. Other topics included bracing types, shoe selection, handicapped-friendly housing, back pain, young people dealing with school/gym, and genetic testing.

★

## NORTHERN IOWA

Meeting on January 23, three members of the Northern Iowa Branch shared new publications and discussed hearing loss in CMT 1A patients, having neurology students sit in on meetings, the new CMTA website and Ask the Experts section, Social Security benefits and more.

★

## LAS VEGAS, NV

Some 20 members of the Las Vegas Branch dedicated their February 4 meeting to late Branch Leader Jerry Cross, who died in December 2015 (see related story p. 20). Members shared their favorite memories of Jerry and heard from Susan Ruediger (CMTA director of development), Michelle Hayes (regional branch manager), and Ori Bash (regional branch manager), who were in town for a conference on orthotics. There was lots of socializing, along with an update on STAR (Strategy to Accelerate Research) and other major initiatives at the CMTA.

★

## ALBUQUERQUE, NM

The New Mexico Branch held its first meeting of 2016 on January 30 with 11 members present. Guest speaker Peg Swisher, an Albuquerque pedorthist with 38 years of experience, discussed proper shoe fitting techniques and why most shoe stores don't do it correctly. She then worked directly with some members to demonstrate correct foot measurements. Santa Fe physical therapist and group member Robin Thompson will talk about exercises for those with CMT at the group's next meeting on April 30.

★

## CHARLOTTE, NC

The Charlotte Branch held its inaugural meeting on January 30, with very special guest speaker Patrick Livney, CEO of the CMTA. Pat gave an amazing presentation on STAR. The group also welcomed Jonathan Gattis from GeneDx, who spoke on genetic testing for CMT. Branch Leaders Trisha Hirsch and Todd Long also announced the upcoming Spartan fundraiser to be held on April 9 (see related story p. 3). Both Todd and Tisha are looking forward to their next meeting on May 7.

★

## CINCINNATI, OH

Nine people attended the Cincinnati Branch's inaugural meeting. Members shared their CMT stories and information about orthotics and braces, neurologists and therapists, genetic testing options, exercises/stretchers and member experiences with the CMT Center of Excellence in Ann Arbor, Michigan. The group plans to have a Facebook page and to compile a directory of medical professionals who are knowledgeable about CMT.

★

## PORTLAND, OR

The Portland Branch met on January 21, and decided to continue meeting at Village Baptist Church and to provide transporta-

tion to those who are further afield. Members plan to increase attendance with a calling tree reminding people of the meeting time and place. Members also heard a report about a successful fundraiser and were strongly encouraged to be proactive in raising funds for research to find a treatment for all types of CMT, not just 1A. Finally, the branch came up with questions for their leader to take to the Leader Conference in Tampa, including:

- 1) Does climate affect CMT symptoms?
- 2) How exactly are the funds raised being used?

★

## HARRISBURG, PA

Personal trainer Carol Agnew was the guest speaker at the Harrisburg Branch's January 17 meeting. Carol, who has MS, shared her story of overcoming her physical and mental hurdles with a positive attitude and a focus on health and fitness. The group is planning a fishing tournament for April 17, with a rain date/backup date of April 24.

★

## AUSTIN, TX

Fourteen people turned out for the first meeting of the Austin Branch on January 14. A representative from Hanger Clinic also attended and discussed having a representative come to a future meeting to provide an overview of AFOs. The group spent most of its time with roundtable introductions and a discussion of members' experiences with CMT. Two attendees were first timers and were excited to meet others with CMT. The group also discussed locations for future meetings, settling on the Yarbrough branch of the Austin Library for its central location and for its chairs without wheels. The final minutes of the meeting focused on discussing the CMTA website and resources available.

★

## SAN ANTONIO, TX

The San Antonio Branch held its inaugural meeting on February 13. Everyone was very excited to finally have the opportunity to meet others like themselves and develop friendships. Although the turnout was small, Branch Leader Kat Tovar is hopeful that word will spread throughout the local CMT community and more people will join.

★

## MADISON, WI

Three members attended the Madison Branch's first-ever meeting on December 2, 2015. They got to know each other and talked about what they would like to see from the group—sharing resources, stories and camaraderie, as well as learning new information. After the New Year, the branch started a Facebook Page and picked up two more contacts, both with elementary school aged children with CMT. They are working on securing a location on the West Side of Madison and plan to alternate between Saturday morning meetings on the West Side and evening meetings at the East Side location.

## NEW VIDEO SERIES: THE BENEFITS OF BALANCE WALKING FOR CMT

We told you last summer about the benefits of adding Balance Walking™ poles to your exercise routine (*The CMTA Report*, July/August 2015, p. 10). They add stability, balance and confidence while you're walking. They also reduce stress on joints—ankles, knees, hips and lower back—by 33 percent. The poles help strengthen the parts of the body not affected by CMT so that they can better compensate for the affected parts.

Visit [www.cmtausa.org/balancewalking](http://www.cmtausa.org/balancewalking) to watch three CMTers demonstrate how their Balance Walking poles increase their stability, balance and confidence, then pick up your pair of Balance Walking poles with a CMTA discount.



### PICK UP A PAIR OF POLES AT 10 PERCENT OFF AND THE CMTA GETS \$30

*Interested in getting Nordic fit? Balance Walking will donate \$30 to the CMTA for each set of poles sold. The CMTA and your body will both thank you! Visit [www.balancewalking.com](http://www.balancewalking.com) and enter the coupon code "CMTA" to get started! A free motivational book is included in your order.*

## DERBY PARTY TO BENEFIT THE CMTA

If you love hats, horses and the CMTA—and happen to be in Lexington, Kentucky, on Saturday, May 7—you are invited to a Derby Celebration at the Stagger Inn, 269 West Main Street #50.

Event organizer Stefanie Rose Miles promises an outdoor patio, plenty of TVs for race viewing inside, friendly wagers, fabulous hors d'oeuvres and drinks, a silent auction and appearances by musical guests.

"Hats, Horses & Hope" is a very personal endeavor for Miles. Her cousin's 9-year-old daughter

was diagnosed with CMT when she was about 3. CMT also runs in Stefanie's husband's family, so the cause is especially important to her.

Stefanie and her cousin grew up in Kentucky, went to school and cheered together, and were valedictorians of their high schools (two years apart). Though Stefanie moved to Tennessee and her cousin remained in the Lexington area, the two became even closer as they got older. Tragically, Stefanie lost her cousin to cancer in June 2015.



Determined to honor the memory of her cousin, who adored the Derby, and support research for her niece's illness, Stefanie came up with the idea of a Derby fundraiser.

"Hats, Horses & Hope" would like to thank

its sponsors to date: Doug Terry Racing, LLC; The Stagger Inn; Burley BBQ (catering); and Hagyard Pharmacy (the official Equine Pharmacy of the USEF).

If you can't make the party, consider throwing your own Derby fundraiser for the CMTA (email [michelle@cmtausa.org](mailto:michelle@cmtausa.org)), or make a contribution in lieu of ticket purchases at [www.firstgiving.com/CMTA/derby](http://www.firstgiving.com/CMTA/derby). ★



**Tickets are \$50 each at [www.firstgiving.com/CMTA/derby](http://www.firstgiving.com/CMTA/derby) (no ticket sales at the door).**



# CMTA MEMBERSHIP, PUBLICATIONS & ACCESSORIES ORDER FORM

## PERSONAL FUNDRAISING PAGES ARE EASY AND EFFECTIVE

Looking for ways to help the CMTA find that first treatment for CMT? How about a fundraiser that requires just a bit of your time, only takes a few minutes to set up and doesn't require you to leave home!

The CMTA's personal fundraising pages provide an easy way for people to run a successful fundraising campaign to help the CMTA fund STAR Research. We make it simple for you to reach out to people in your circle—friends, family, colleagues and acquaintances. Are you too old for birthday presents? Ask your friends and family to make a gift to the CMTA instead. Are you getting married and have all the small appliances and flatware you need? Ask your wedding guests to donate to the CMTA instead. Asking people to make a contribution to CMTA in your honor will greatly enlarge the number of people who support the CMTA—and increase the chances of finding that treatment we all want.

The pages are super easy to create and customize and will provide you with a personal link that you can email/share on all social media fronts. Whether you use only email or are a Twitter/Facebook/Pinterest maven, with a few simple clicks you can create a social media campaign tailored to you.

If you are interested in starting a personal fundraising page, please contact Jeana Sweeney at [jeana@cmtausa.org](mailto:jeana@cmtausa.org) or visit [www.cmtausa.org/fundraising](http://www.cmtausa.org/fundraising).

NAME: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
First MI Last

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

COUNTRY/POSTAL CODE (IF NOT U.S.): \_\_\_\_\_

DAYTIME PHONE: \_\_\_\_\_ EVENING PHONE: \_\_\_\_\_

EMAIL: \_\_\_\_\_

**\*\*\*If you are a STAR member or are joining as a STAR member now, you may purchase publications and accessories at discounted prices. (Some exclusions may apply.) To check your membership status, please call 1-800-606-2682, ext.105.\*\*\***

### Subscription Membership Benefits:

- Online access to valuable information about living with CMT
- An information kit and a 10% discount at the CMTA store
- Quarterly delivery of *The CMTA Report*, (electronic and/or hard copy)

### STAR Membership Benefits:

- All of the benefits of Subscription Membership

#### PLUS

- One free pair of Aetrex Shoes in the style of their choice (new STAR members only)
- 50% off all Aetrex shoes (new and renewing STAR members)
- An expanded and updated copy of the CMT Survivor's Guide
- A 20% discount at the CMTA Store
- One *You're a STAR* auto decal

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		Regular Price	STAR Member Price	
My Child Has CMT		\$5	\$5	
CMTA Titleist Hats Quantity and Color: Blue___ Lt. Blue___ Black___ White___		\$25	\$20	
CMTA T-Shirts <input type="checkbox"/> Navy Blue with white logo) <input type="checkbox"/> White with blue logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
CMTA Shark-0 T-Shirts Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$20		
<b>NEW!</b> CMTA Sweatpants Quantity and Size: Youth XL___ Adult S___ M___ L___ XL___ 2XL___ 3XL___		\$20		
Be a STAR Wristbands		\$1.50 each*		
Be a STAR Necklaces (Includes battery)		\$5 each*		
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CMTA Pin		\$3 each		
CMTA Brochure & Neurotoxic Drug Card		FREE		
<b>Donation to the CMTA (100% Tax-deductible)</b>				
<b>Shipping &amp; Handling</b> (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)				
*Quantity discounts for these items available online				
				<b>ORDER TOTAL</b>

Check payable to the CMTA (US residents only; non-US residents, please use credit card or international money order.)

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

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

## CMT PATIENT MEDICATION ALERT:

### **Definite high risk (including asymptomatic CMT):**

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

### **Moderate to significant risk:**

Amiodarone (Cordarone)  
Bortezomib (Velcade)  
Cisplatin and Oxaliplatin  
Colchicine (extended use)  
Dapsone  
Didanosine (ddI, Videx)  
Dichloroacetate  
Disulfiram (Antabuse)  
Eribulin (Halaven)  
Fluoroquinolones  
Gold salts  
Ixabepilone (Ixempra)  
Lefluonamide (Arava)  
Metronidazole/Misonidazole (extended use)  
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)  
Nitrous oxide (inhalation abuse)  
Perhexiline (not used in US)  
Pyridoxine (mega dose of Vitamin B6)  
Stavudine (d4T, Zerit)  
Suramin  
Thalidomide  
Zalcitabine (ddC, Hivid)

### **Uncertain or minor risk:**

5-Fluorouracil  
Adriamycin  
Almitrine (not in US)  
Chloroquine  
Cytarabine (high dose)  
Ethambutol  
Etoposide (VP-16)  
Gemcitabine  
Griseofulvin  
Hexamethylmelamine  
Hydralazine  
Ifosfamide  
Infliximab  
Isoniazid (INH)  
Lansoprazole (Prevacid)  
Mefloquine  
Omeprazole (Prilosec)  
Penicillamine  
Phenytoin (Dilantin)  
Podophyllin resin  
Sertraline (Zoloft)  
Statins  
Tacrolimus (FK506, Prograf)  
Zimeldine (not in US)  
a-Interferon

### **Negligible or doubtful risk:**

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

# THE CMTA Report

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.