

THE CMTA Report

SEPTEMBER/OCTOBER
2015

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



OUR MISSION:

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

OUR VISION:

A world without CMT.

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Gait Measurement Key to Treatment Decisions

BY JAMES NUSSBAUM, PT, PHD, SCS, EMT

Charcot-Marie-Tooth (CMT) disease affects those diagnosed (and those not yet diagnosed) in many different ways. Many people with CMT have weakness in their lower legs, which can limit balance, gait and overall mobility. Doctors caring for patients with CMT do not always refer their patients to physical therapists (PTs).

While neurologists, physiatrists and the members of the medical community in general often fear that recommending resistance exercise to improve

strength in patients weakened by CMT may exacerbate the neuropathy, this author feels strongly that appropriately prescribed and progressed therapeutic exercise may help many people with CMT, and the purpose of this article is to implore the patient and provider population to measure function and the physical characteristics that impact function. Thankfully, many physical therapists incorporate objective outcome measures into their assessments. Unfortunately, not



all patients with CMT are evaluated and treated by PTs.

The focus of this article is to stress the importance of utilizing spatiotemporal 2D gait characteristics in patients with CMT.

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How to Talk About CMT

BY JONAH BERGER



It is one thing to travel through this life with the unstable feet and uncertain balance of CMT. It is another thing altogether to share that experience with others. In fact, based on personal experience and chatting with my fellow CMTers over the years, I think sharing the path openly is one of the greatest challenges set before all of us.

There is a real challenge to being abnormal in our society, which so values normality. There is a pressure to conform and a stigma attached to anything that makes us different. The irony is

that the things that make us different are the very things that make us great. Life with CMT teaches us wisdom, humility and grace. It makes us stronger from surviving the challenges. And it shows us the appreciation of true ability. We don't take strength for granted in this tribe!

How then do we talk about it? How do we get it out? How do we share it with others?

Three thoughts:

1 Be brave. You need a lot of courage to open up about this personal challenge. It is scary at first, but I assure you that the more you do it, the

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HALF-DAY PATIENT/FAMILY CONFERENCE SET FOR WINDY CITY IN OCTOBER

The CMTA will hold a half-day Patient/Family conference in Chicago, Illinois, on Sunday, October 18, 2015. The conference will take place from 10 a.m. to 2 p.m. at the Sheraton Suites Chicago Elk Grove.

Dr. Michael Shy, head of the CMT Center of Excellence at the University of Iowa, will kick off the program, followed by presentations from some of the most prominent minds in the fields of CMT research and treatments. CMTA CEO Patrick Livney will present the latest exciting research news.

This event provides a tremendous opportunity not only to hear but to interact personally with these experts. Registration is just \$25 per person (non-refundable) and includes a light breakfast beginning at 10 a.m.

Discounted rooms are available at the Sheraton Suites Chicago Elk Grove at 121 Northwest Point Blvd, Elk Grove Village, IL 60007. To secure the conference rate of \$109, call 847-290-1600 by September 17 and make sure to mention "CMTA." Complimentary parking is available in Elk Grove Village, a major suburb in Chicago's northwest corridor only minutes away from the famous Woodfield Shopping Mall and Arlington Park Race Course. The hotel is easily accessible from Interstate 90 and is just eight miles from Chicago O'Hare International Airport (ORD).

The Patient/Family Conference will also feature exhibitors offering valuable information and a variety of suggestions and products to assist people affected by CMT with mobility, alternative pain management and exercise.

Don't delay. Register now for this informative and interactive conference. You can do so online at www.cmtausa.org/event/chicago or you can mail a check made payable to the CMTA with "Chicago, IL PFC" in the memo line. The deadline for registration is October 4.

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HOW TO TALK ABOUT CMT

(continued from page 1)

easier it becomes. Human beings are curious by nature. That is why people stare at our leg braces or the way we walk. So FEED their curiosity with information. Teach them and send them down the road with the knowledge to replace their silent judgments.

2 Practice your speech. Rather than making it up on the spot, have an explanation ready for when the topic comes up. I explain that CMT is a slowing down of the messages from the brain to my muscles. That the nerves aren't able to get the messages through fast enough or clear enough, so over time my muscles get weaker. I try to stay

away from scientific talk. Keep things simple. Then I always leave them with a statement about why it could be worse.

Let people see that you are facing your challenges. Seek out the people who are obviously curious or watching you and be the initiator. Go right up to them and explain what you have—especially to kids. They are so open. Help keep them that way. Teach them to learn about differences and not to fear them.

3 Remember that everyone has special needs of some kind or another. Every single person walking this Earth is dealing with the burden of challenges they'd like to put down. Whether you can see their challenges or not, they are there. Everyone is nervous to talk

about them. And everyone feels better when they have the chance to get it out and be understood.

When I first started to wear leg braces in my twenties, I wore jeans even in the summer to cover up my differences. Over time, I realized that I was only fooling myself. You have to be who you are. It is the only way to live happily. Having CMT is hard enough and the burden of keeping it to yourself is a waste of energy. Get it off your chest. Teach others about CMT, learn about the unique challenges that others face. This world would be a better place if we learned to celebrate our differences. Figure out where your current comfort zone ends and go beyond it. The benefits of being open are worth the effort, I promise you! ★

MEASURING GAIT

(continued from page 1)

In English, this means measuring the way people walk—looking at the values of certain aspects of gait compared to expected values and the comparison of right versus left, or symmetry indices. In our PT and OT clinics in New York City, we focus on three specific gait values. Step length is the distance each foot travels before setting back down. Normal is ~55–70 centimeters for each foot. Single limb support is the percentage of time each leg is solely bearing body weight during gait versus one entire gait cycle. Normal is to spend approximately 40 percent on the right leg, 40 percent on the left and 20 percent of the time on both legs, in double stance (actual norm is 38.5–40.5 percent).

Lastly, we place a premium on gait speed, or how quickly one walks when walking at a normal comfortable pace. Normal is ~110–140 centimeters per second. At ProHealth & Fitness PT OT in Manhattan (www.prohealthptot.com), we use a laser gait analysis system to measure step length and gait speed to a tenth of a centimeter and single limb support to a tenth of a percentage point. Our software allows us to take a constant average of each patient's performance and compare how people do over time with different interventions, such as braces, medications and therapy. Having the ability to objectively measure how people walk is invaluable when trying to see if people are functioning better or worse over time. This allows us

to look at facts versus opinions.

Measuring patients' abilities with valid and reliable objective tests is a primary component of how we evaluate our patients. Some of the common measures of function utilized in our clinics include lower extremity functional strength (sit to stand in 30 seconds), balance and mobility (Timed Up and Go, Berg

Everyone with CMT should be evaluated to establish baselines...

Balance Scale, Dynamic Gait Index), and ambulation endurance (six-minute walk test). Many of these tests are considered gold standards and should be utilized with many patient populations. Specific gait parameters (measured using 2D spatiotemporal gait analysis), allow skilled therapists to look into the exact components of each patient's gait and enable us to try to treat some of the underlying impairments and pathologies.

Some patients with CMT wear orthotics to help with foot

and leg position, enhance safe walking or provide energy return during ambulation. Whether to wear orthotics and what type of orthotics to wear are questions often discussed between providers and those with CMT. Utilizing objective measures, particularly gait parameters, to measure changes in gait with and without braces, can help them answer those questions.

Everyone with CMT should be evaluated to establish baselines and monitor changes good and bad over time. Evaluation is often covered by insurance providers, and, using these baseline measures, decisions on new braces versus old, different shoes and, of course, the effects of different therapeutic interventions can be made objectively. Measurement is key. It is important to establish baselines at any point, even if someone was diagnosed 10 years ago, and to assess how CMT and interventions impact functional parameters. Find a good PT today, and get measured! ★



Author James Nussbaum is a member of the CMTA Advisory Board and the Clinical and Research Director of ProHealth & Fitness PT OT in New York City.

GET A WARM FUZZY!

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

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

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

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

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



2015 CMT Awareness Month Biggest, BEST Ever

We'll have a full and complete report on Awareness Month in our next issue, but with the addition of 32 All-Star Events, it promises to be the biggest and best ever. All across the country people will be walking, riding, and swimming "4CMT." Thanks to our wonderful members, proclamations from cities and states recognizing September as CMT Awareness Month are pouring in—we'll have a complete tally in the next issue. Another amazing group of CMTers will be sporting blue hair in September, part of the "Go Blue 4CMT" campaign. We thank you one and all for helping to make this the most successful Awareness Month start in our history. It's not too late to be a part of Awareness Month even if you're not willing to dye your hair blue. Get started TODAY by visiting our interactive Awareness Month pinboard at www.cmtausa.org/am2015.

One of our favorite parts of Awareness Month is the CMTA STAR Awards, which celebrate the energy and enthusiasm with which people with CMT live life. Recipients are nominated by friends and family, and the awards are presented during our Awareness Month. This year's winners are profiled below.

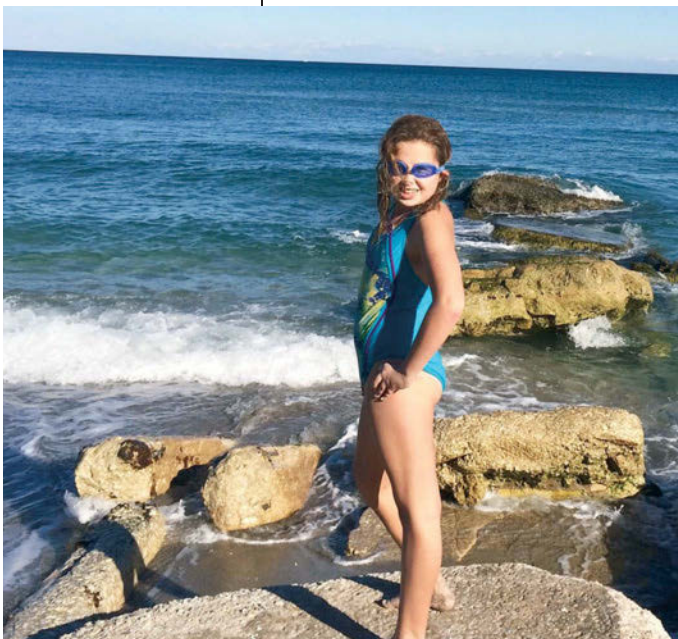
The "Shooting Star" Winner: Anne Marie Levenson

*Nominated by
Lee and Jen Levenson*

Anne Marie Levenson, 11, stands alone once again. The teams have been chosen. In land sports, she is always picked last.

Anne Marie wonders: "Why do we still use this cruel method of making teams?"

**Shooting Star Anne
Marie Levenson**



Answering her own question, she thinks: "These experiences are a blessing in disguise because they teach me to be empathetic, sympathetic and compassionate."

Affected by Charcot-Marie-Tooth disease, Anne cannot run well or fast. Her hips feel like they are being stabbed by hot daggers deep inside. She cannot jump either. Her hands and feet are weak. They lack normal coordination. Anne doesn't blame her classmates. She is not bitter. Anne was diagnosed when she was 18 months old. She underwent an open reduction of a congenitally dislocated hip, common among CMTers. At age 4, teachers noticed she had fine motor difficulties. But Anne Marie counts her blessings. She's had many understanding, helpful and caring teachers at Lake Worth Christian School. Mrs. Wendy Teitsma is an educational therapist there with whom Anne formed a special bond. Her handwriting has improved year after year.

Anne thinks to herself, "These symptoms hinder my

ability to help my team. Walking, running and even writing are difficult for me. But I will do my best and in the water things are much different. In the water I'm an athlete."

Anne is an excellent competitive swimmer. She competes as a Paralympian for the South Florida Paralympic team. Although she cannot run one mile due to pain, she swims up to two miles during her training workouts. Swimming a mile is the equivalent of running about six miles. It's very tough and it is good for almost every muscle group, improves coordination and builds up the cardiovascular system.

Anne loves the staff at Aquacrest pool where she trains. Alex, Paul and the guards all encourage Anne. Plus they are healthy, wholesome role models. Anne achieved junior lifeguard status with CPR and lifesaving techniques.

Coach Anita Wolk says: "Her strokes and her speed are impressive. And Anne continues to improve. She is very dedicated. I believe Anne has a bright

future for success with the Paralympic team. But she will win just by competing and trying as is the case with all athletes.”

We are proud of Anne Marie as a heroic person who overcomes adversity and shows us the way to turn challenges into chances to be our best.

The “I’m a Star” Winner: Branch Hunsaker

*Nominated by Melissa Arakaki
 Wasatch Front, UT CMTA
 Branch Leader*

would like to nominate R. Branch Hunsaker for the 2015 “I’m a Star!” award.

A Wyoming native, Branch was diagnosed with CMT2A at a young age, and grew up in a household with other family members also living with CMT. He was fitted for his first pair of AFOs at Shriner’s Hospital in Salt Lake City. An orthotist at Shriner’s took the then-16-year-old Branch back into the lab to show him how orthotics and prosthetics were made. He was



“I’m a Star” winner Branch Hunsaker

sold, and has made it his career to make orthotics and prosthetics for people in all walks of life, including himself and his family members.

After graduating from high school and serving an LDS mission, Hunsaker attended a community college in Wyoming. He then headed to Dallas for the Prosthetics-Orthotics Program at the University of Texas Southwestern Medical Center. Branch had planned on returning to Shriner’s, but decided after completing school that he wanted to work with a wide variety of patients. After a resi-

dency with Hanger Clinic in Salt Lake City, he was tapped to open a satellite office once a week in Provo, Utah. The location grew so popular that Branch is now managing it full-time.

In 2014, Branch traveled to Micronesia on a humanitarian trip to help fit people with custom orthotics and prosthetics, and in 2015 he did the same in Tonga. I believe that Branch’s compassion toward others with disabilities, as well as his willingness to serve and help others, make him the perfect candidate for the 2015 “I’m a Star!” award. ★

ORANGE AND BLUE: WHAT CAN YOU DO?

As many of you know, orange and blue are the CMTA’s colors. We’d like to see how creative you can get with these two colors. Office cupcakes with orange and blue? Sending your favorite loved one living with CMT orange and blue flowers? Only you know!

We want to see photos! Post them on Facebook (<https://www.facebook.com/CMTAssociation>) or email them to us at info@cmtausa.org. The more creative you get the better. Why? Because the person who gets the most creative will win a CMTA package full of fun and helpful products (including a free \$100 STAR membership)!

To find out how to Go Blue, visit <http://www.firstgiving.com/CMTA/GoBlue4CMT>.



**WE DOUBLE DARE YOU
 TO GO BLUE FOR CMT**

RAISING FUNDS

Comedy
for a Cause
Fundraiser

Some 60 Sonoma County residents laughed “4CMT” at a benefit performance of “The MAMA-Logues, a Comedy about Motherhood” on July 16. CMTA staffer Sharon Bello took to the stage with four other local thespians to raise funds for CMT research and entertain the audience with a showcase of readings from comedy blogs and pop-song parodies conceived by cast member Laurie Levy.

Fourchette Restaurant, in Petaluma, California, was the stage for the night. The 90-minute show began with a parody of Lorde’s song “Royals” aptly named “Rested,” chronicling the lack of sleep that faces new moms. Blog performances included “Dear Fetus” followed by “The Facebook Mom,” “Monkey Baby,” “I Finally



MAMA-Logues (clockwise from top left): Kate Fiebusch, Sharon Bello, Selena Polston, Nancy Rush, Laurie Levy.

Swore at My Teenage Daughter,” “Thanksgiving Conversations with My Mother” and more. Audience members laughed and shared knowing nods and glances throughout the show, which ended with a raucous parody of Lady Gaga’s “Bad Romance” titled “My Bad Mom Pants.”

Immediately following the show, Sharon, who is also the North Bay Area, CA CMTA Branch Leader, explained to the audience what CMT is and how

it affects the 2.8 million people who have it. She thanked everyone for attending and made sure they knew that their dollars were going directly to research to find treatments and an eventual cure for CMT.

The evening also included a silent auction and raffle with donations from Aveda, Kindermusik, local salons, a hobby shop, an amusement park, a winery, a photographer, the local

theater, a wellness product company, Cold Stone Creamery and more. “What is CMT?” pamphlets were displayed on the tables so attendees could learn more about CMT while waiting for the show to begin and during breaks. The restaurant offered nibbles and Hook & Ladder winery donated three cases of wine.

Altogether, “The MAMA-Logues” raised more than \$1,800, putting smiles on the faces of everyone involved!

Vittorio’s Friends
Circle Around Him
Once Again

More than 140 people attended the Third Annual Vittorio’s Circle of Friends Fundraiser in Gloucester, Massachusetts on July 18, raising \$25,000 for CMT research. Since joining the CMTA in August 2012, Vittorio and his

Vittorio poses with his Circle for an end-of-night selfie.



F O R A C U R E

friends and family have raised more than \$112,000 for research and a treatment for CMT.

The evening's theme of DNA was on display in T-shirts and test tube candy, representing the fact that Vittorio still doesn't know his CMT type despite being tested for more than 80. A secondary theme was sharks: Guests wore foam shark fin hats, a giant inflatable shark hung from the ceiling and the "Jaws" theme song played as Vittorio walked up to give his speech.

The evening was filled with friends and family and all of them helped out. One of Vittorio's uncles recorded the entire night while another one spent the entire evening cooking. His friends read the winning auction items, his little cousins picked the free door prizes and his Noni won "Fandango" tickets! The 50/50 raffle was more than \$1,000, the biggest in three years.

Vittorio says he feels "lucky to be a part of such a caring and supportive group," which is why he always ends the night with a group photo. ★

TAILGATE FUNDRAISER RAISES \$500 FOR CMT RESEARCH

The smell of bratwurst filled the summer air as CMTA summer intern Rebecca Silverman hosted a tailgate fundraiser before the June 26 Brewers game in Milwaukee. Seventy people—University of Wisconsin-Madison students with their friends and families, as well as some Chicago CMTA Branch members—partied in a large parking lot surrounded by other tailgaters with the dome of Miller Park in the background.



Michael Silverman (left) and Mark Wolpoff, both 11.

In addition to the brats, the group enjoyed salads, cupcakes, and Ian's mac and cheese pizza, a favorite of UW-Madison students.

While some enjoyed the food, others participated in traditional tailgating games. Parents played against their children in an epic cornhole tournament, and the college kids taught the adults how to play flip cup. Not surprisingly, the parents lost every round.

Everyone received a CMTA wristband and many wore T-shirts designed for the event, prompting questions from the surrounding tailgaters. The group was having so much fun at the tailgate that no one wanted to go into the game, but when they did the scoreboard greeted them with the words "Welcome Charcot-Marie-Tooth Association!" Not only was the tailgate a success, raising \$500 for CMT research, but the Brewers won!

DONATIONS WERE MADE TO THESE CMTA "CIRCLES"

VITTORIO'S FUNDING THE FIGHT

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Trionic Veloped Goes Off-Road

BY SUSAN REILLY

When I heard about the Trionic Veloped, my first thought was yes, I've seen walkers with big wheels before. I had, but I'd never seen anything like this. I call it my off-road walker. It will travel down a gravel road, across a grassy field or on a hiking trail. For someone with balance and mobility problems, the Veloped is a game-changer. For the first time, I am able to walk across grassy fields with my grandchild and even take a hiking trail that is commensurate with my ability. I only wish I'd had one of these when I was a child!

I was diagnosed with CMT in kindergarten. Even at that early age, my drop foot was already well along and I was having trouble walking on any

ground that wasn't smooth or paved. As I went through grade school, I avoided walking on grass, uneven ground or buckled pavement because it was guaranteed that I would at some point twist my ankle and fall. In those days there was no Americans with Disabilities Act and almost nothing was accessible. There were no accommodations for school or any other activities. Walking was an exhausting chore and the long school hallways seemed endless. While doctors told my parents that CMT was a painless disease, I had crushing pain down the front of my legs.

So I got along the best I could. I went camping and did what I could to avoid falling. I restricted my movement. I didn't

go certain places where I knew the ground would be very uneven. As time went on, I didn't go many places at all because my legs tired easily and it was scary to think I might get somewhere and not have a place to sit down. By this time I had braces, so the ankle twisting was not as much of an issue, but uneven ground was difficult due to my balance issues. I tried a walker, but kept tripping over it when I hit a sidewalk crack. I called it my tripper! I tried a cane but that only kept my body anchored on one side.

Now enter the Trionic Veloped!

For all the off-road benefits the Veloped offers, it's even better in the city. Those sidewalk cracks are no match for Veloped, which makes walking around the neighborhood a joyful stroll rather than a frustrating stop-and-go experience. It rolls along easily, allowing the users to look around and enjoy the walk rather than scanning the sidewalk for cracks and other disruptions.

The Veloped has a basket with ample room for a water bottle or a lunch or even some groceries if you take it shopping. There is a comfortable seat so you never have to look for a bench or chair when your legs are tired. The handlebars easily raise and lower to accommodate a person's height.

One feature I particularly like about the Veloped is the ease of pushing it over a curb. Thanks to the two front



Susan Reilly with her trusty Trionic Veloped

wheels—one on the ground and the other suspended on a spring attached to the first wheel—a small push will pop the walker up over a curb without any lifting. It makes walking around town or a shopping mall or public buildings possible for a person with balance issues and muscle weakness. The Veloped folds up, and if it is still too big

for the trunk or car space, the wheels pop off with an easy press of a button. They pop back on just as easily.

I take my Veloped everywhere. I took it on a trip to Alaska several years ago. It was a great help getting around on tours of old mining camps and glaciers. I don't think I'll ever travel without it again. I recently

took it with me on a plane for the first time and discovered it was easy to check at the gate with all the strollers. I popped the front wheels off at the gate and carried them on the plane. This is one dandy walker, off-road, in the city or across the world.

To find a U.S. distributor for the Swedish-made Veloped, visit www.trionic.us/. ★

Etsy Shop Sells CMT Goods, Donates 10 Percent to CMTA

CMTer Amy Ryan is the proprietor of a shop called AmyWonderland on Etsy.com. Amy has always loved creating art and crafts and spends nearly every pain-free moment she has holed up in her office doing what she loves—working with her hands. Amy makes unique hats, hair bows, and other things to sell in her online shop. In an act of remarkable generosity, she donates 10 percent of her gross monthly income to the CMTA's STAR initiative.

To help mark Awareness Month, Amy has created a brand new line of hats and hair bows in the CMTA's signature colors of orange and blue. She'll donate 50 percent of those gross sales to STAR. Amy doesn't just spread awareness about CMT in September, though. She spreads awareness 12 months a year, mentioning CMT in every item description she creates for her shop, talking about



Amy's shop is located at: www.AmyWonderland.etsy.com

it on various online message boards, and speaking up when someone points out that her feet and hands move differently than other people's do. Amy says she has received lovely messages from strangers who take a moment of their time to say, "I had never heard of this disease until I read about it in your shop. I'm going to go take a look at the website now."

It has taken Amy a while to learn how to start a conversation about CMT. At first, she

was afraid it would seem like she was asking for pity. But as she began to talk to people about CMT, she realized that the main focus of the conversation is usually about the disease rather than the individual. She has found that speaking in an open, honest, and friendly manner encourages people to take a genuine interest in what's she's saying.

Amy says that while her shop and personal donations may be small, taken together with the efforts of others they are powerful. "Every little conversation we have brings us one step closer to a greater goal," Amy says, "improving quality of life for patients and finding a cure for Charcot-Marie-Tooth disease."

Monthly coupons for Amy's shop can be found on her Facebook business page at www.facebook.com/AmyWonderland

CMTA Member Spotlight: Aron Taylor

BY CLARK SEMMES

Born into a music-loving family, some of singer/songwriter Aron Taylor's earliest memories are of listening to Led Zeppelin and Pink Floyd albums in the living room of his home in Parsons, Kansas. While still in grade school, Aron discovered hip-hop and was soon reciting lyrics that reminded him of tongue twisters or nursery rhymes.

In second grade, Aron's parents noticed that he ran with an awkward gait. They took him to the doctor, who diagnosed him with Charcot-Marie-Tooth disease.

*When I was just a tyke
My momma saw me running
in the street
And something didn't look right*

In fifth grade, Aron was fitted with plastic leg braces. They pinched when he played kickball and he tried to remove them, but his teacher stopped him. That same year Aron had surgery on his legs and he entered sixth grade in a wheelchair. When the surgeon finally removed the casts from his legs, Aron's leg muscles had atrophied. The doctor told him that the muscles would never return. This encounter forever destroyed Aron's opinion of doctors, and he hasn't worn braces or seen a doctor about his CMT since.

Aron suffered a lot of anxiety and self-consciousness as a result of his CMT, and frequently wondered if people were staring at him and noticing that he was "different." But despite his anxieties, Aron never lost his love of



music, and by eighth grade he was writing his own songs.

*Feeling isolated on an island
Took a pen and started writing*

Desperate to produce his own music but unsure what equipment he needed, Aron one day dialed 411 and asked for the number for a "DJ store in New York City." To his amazement, this gambit worked and he soon possessed a catalog of musical recording equipment. Aron bought his first equipment and went into production. In 1998, he released a CD that he created in its entirety, from cover art to printing. He sold it around Parsons and neighboring towns. In 2002, he produced his first professional album entitled "Ridiculous Beats Presents: BOOM!!! Midwest Ballaz," that is still available on iTunes (<https://itunes.apple.com/us/album/ridiculous-beats-presents/id65109674>). In 2010, he released "Lovefest," a hip-hop/rap album with 21 of his own songs.

In 2013, Aron decided to look inward and began writing songs about overcoming obstacles, including his own. While his previous work was frequently sar-

castic and tongue-in-cheek, the new music was more serious and focused on delivering a message. The effort produced Aron's finest work to-date, including a song entitled "The Life You Love," in which Aron sings candidly about his own battle with CMT.

*Ya gotta get up and get to it
Overcome your tears and
make no excuses*

While Aron is hopeful that his music might one day become a full-time job, he is practical enough to have a good career already in place as an IT professional at a law firm. Recently engaged, he is looking forward to his wedding in October. Aron has had his share of falls and injuries, but he finds that staying active is the best prescription, and that staying fit not only minimizes falls but reduces the injuries he suffers when the inevitable falls occur. He walks a lot, lifts weights and recently lost about 15 pounds. Aron is a big fan of the CMTA's various forums on Facebook and believes they offer great advice to both those with CMT and those living with someone who has CMT.

More information on Aron and his music can be found on www.ridiculousbeats.com. He also hosts two weekly online radio shows on a website called LawrenceHits.com. One of them is called The Hip-Hop Happy Hour (H4), which airs at 6 p.m. CST every Wednesday. The other is a show on Thursdays at 6 p.m. CST called Ridiculous Rock (R2) and features mostly classic rock. ★

**Dreams do
come true,
but only with
help from YOU.**

*Without YOU there can be no research.
Without YOU there can be no treatment.
Without YOU there can be no hope.
Without YOU things will never change.*

Make it PERSONAL.
Make a DIFFERENCE...
In YOUR life and HIS.

www.cmtausa.org/1Amatch

**A CMT1A \$500,000
Challenge Grant**

Thanks to the efforts of one CMTA member family, all contributions made to the CMTA's STAR program for CMT1A between July 1 and September 30, 2015, will be matched dollar for dollar up to \$500,000.



My Gift to the CMT1A Match

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

- \$25
- \$50
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Detach and mail to:

Charcot-Marie-Tooth Association
PO Box 105
Glenolden, PA 19036



My Brother, My Hero

BY AUDREY MORRIS, 13

On your way into a movie theater, you notice a man and his son. They both walk with a distinctly different gait from anyone you've ever met, and you watch as the boy trips and falls. Instead of acting concerned, the man doesn't even help him up. He looks accustomed to this, like this happens often, like it could easily be him on the ground. You're wondering what's wrong with them when the man says, "Remember it's not about how hard you fall, it's about the fact that you get back up."

That man is my father, and that boy is my brother, Alex. Charcot-Marie-Tooth disease runs in my family, specifically CMT2E. CMT damages the nerves in the hands and feet, resulting in muscular atrophy.



Author Audrey Morris and her brother Alex

It slowly wears down your body and makes you weak. Most people with CMT, even young people, aren't athletic, but my brother didn't let that stop him. He even played football from the age of 9 to the age of 18. He was on the varsity team for two years and was arguably the worst player, but he stuck with it. He went to every practice, and while he sat on the bench for most of the game, he was the heart of that football team. He was the one the players looked up to, the one they most admired. The high school created an award just for him for being the person who most inspired the rest of the team. My brother not only inspired his football team, he inspired me.

Alex, now 25, was 12 when I was born and he cared about me from the moment I arrived. He was willing to do anything to keep me happy, even if that meant babysitting me and holding me when I cried. He's been my hero from the moment I could put a thought together.



Even though he wasn't always a perfect kid, he was always a great brother. Learning how rough he used to be reminds me that we're all human and that it's OK to make mistakes as long as you own up to them. My brother has always been the best person in my life and whenever I need help, I ask him. When I need to talk to someone, I talk to him. When I have done something wrong, he's the only person I'm not afraid to tell. He loves me for who I am. He'll stand up for me whatever the cost. He gets me. He knows what I'm going to say way before I say it and he can tell with just one look at me how I'm feeling. In many ways, we're the same person inside and for that I thank God every day. ★

6TH ANNUAL STAR FUNDRAISER TO BE HELD OCTOBER 26 AT NEW YORK'S ESSEX HOUSE

The Sixth Annual New York CMTA Event will be held at the glamorous hotel Essex House on Central Park South on October 26, 2015, from 6:30 to 10 p.m.



The evening promises to be the best so far, with a buffet dinner, entertainment by mentalist Oz Pearlman, music and an auction with items such as concert tickets, sporting event tickets, trips, jewelry and memorabilia. Most importantly, there will also be an update from the CMTA's STAR research team on the progress made this year.

Proceeds from the event will help fund the CMTA's search for a treatment and ultimately a cure. Individual tickets are \$300. Sponsorship opportunities are also available. Visit www.cmtausa.org/event/nystar/ to learn more.

A Special Thanks to all Federal Employees!

Thank you very much for your past support of the CMTA through the Combined Federal Campaign. In total, 2015 contributions amounted to more than \$12,000, allowing us to continue to meet our mission every day. As you know, the CMTA has three focus areas: Improving the quality of life for those with CMT by providing resources and information; increasing awareness about CMT; and funding research for the development of treatments for all types of CMT. Our progress includes:

- Creating 80 Branches throughout North America, providing local resources for those with CMT
- Building our social media presence and interacting with more than 20,000 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 2016 giving year. The CMTA has been named as one of the “Best in America” as certified by Independent Charities of America. The CMTA is also approved as a national charity for the 2016 giving year. Our CFC number is 10597. ★

WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,

I live in a small rural town and have never spoken to anyone outside my family about my CMT. I am fortunate that my husband is empathetic and helps with chores around the house. I have a small group of friends at church who have never asked what's wrong with me although they are well aware that I have a strange gait. I am 54 years old and find myself getting increasingly angry that no one seems interested enough to approach me to ask any questions. How do I manage my feelings towards my "friends"?

David replies:

Don't assume that your friends don't care about you just because they have not asked you any questions about your CMT. I find that many people, even those who are close to us, are hesitant to invade what they consider our personal space.

On the other end of the spectrum are the people who seem to have no boundaries at all and can be incredibly insensitive in the way they approach our personal challenges. In other words, many people are just plain awkward when it comes to delicate subjects.

I found that when I stopped identifying my CMT as a “problem” and saw it as simply another aspect of what makes me who I am, I was less shy about bringing CMT up when it seemed like the elephant in the room. Joining a CMT support group and meeting others with similar challenges helped enormously. I pushed myself to speak about it because I discovered that the more I spoke to others with CMT, the less alone I felt. I hadn't even admitted to myself how alone I had become. I had convinced myself that I

was okay not speaking about such a major part of my life.

September is CMT Awareness Month, a great time to use the energy of your anger and become pro-active by taking some CMT pamphlets to church to educate others about CMT. I know it takes courage to “come out,” but this will help you feel strong.

There is power in honesty and being courageous can erode the silent shame of feeling different. Helping spread awareness is a way of connecting to others and to something much larger than ourselves. You will be helping others to accept their challenges as well. Remember that what is hidden and unexpressed takes up a lot of room in our minds and releasing our feelings about life with CMT can make room for other things. ★



David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. Write to David at info@cmtausa.org.



THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS:

IN MEMORY OF:

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MISSY WARFIELD— *Happy Birthday!*

The Dougherty Family

AMY WONDERLAND

Ms. Amy Ryan

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.

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In honor of (person you wish to honor)

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- Birthday Holiday Wedding
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CMTA BRANCH NEWS

• Central Alabama

Marc Savelis from GeneDx presented a slideshow on genes and the different types of CMT at the July 18 meeting. He also discussed GeneDx's special CMTA rate for gene testing. The group will hold its Walk4CMT on

September 19 at Veteran's Park, starting at 9:30 a.m.

• North Alabama

Fourteen people attended the branch's summer meeting at St. Florian Park. Todd Oyen talked about vitamins and nutrients that may help increase energy,

prevent muscle wasting, and aid in heart and nerve health. The group will hold a walk at St. Florian Park on September 19.

• Denver, CO

Branch members enthusiastically discussed the CMTA's push for

(continued on page 16)

CMTer Killed on D.C. Subway; Community Loses a Star

Tragedy struck the CMTA community on July 4, 2015, when CMTer Kevin Sutherland, 24-year-old son of CMTA Branch member Doug Sutherland, was killed in a senseless act of violence. Riding the Washington, D.C. subway on his way to a July 4th celebration, Kevin was stabbed by an individual reportedly attempting to steal his cell phone. The suspect, Jasper Spires, 18, was caught on surveillance footage and left a bag with identification at the scene of the crime. He has been arrested and charged with Kevin's murder.

Doug and Theresa Sutherland of Trumbull, Connecticut, are understandably grief-stricken by the loss of their only child but are attempting to focus on all the wonderful things Kevin accomplished during his short life and all the people he touched.

The son of two engineers (electric and software), Kevin

mastered the Linux operating system at the tender age of 13 and volunteered on a help desk line where he dispensed advice to people all over the globe. His parents often wondered if the people receiving the advice knew their guide was barely in his teens.

Diagnosed with CMT Type 1A when he was around 4 years old, Kevin rarely allowed his disease to affect his goals. Although he was a slow runner, at a young age he played T-ball and studied karate. His interests later shifted from athletics to computers and then politics. At the age of 15, Kevin met Congressman Jim Himes (D-CT) and began working on his campaign. He later interned in Himes' Washington office. While in college at American University, Kevin served as student government secretary for two years. After



Kevin Sutherland

college, he worked for The Lone Star Project, a political research organization that worked to get Democrats elected in Texas. Last April, he began work at New Blue Interactive, an organization that works with politicians on constituent outreach.

According to Doug Sutherland, Kevin "exemplified a lot of CMT patients in both his perseverance and his desire to find a productive career." Theresa speculates that Kevin's CMT may have contributed to his "enormous capacity for empathy and his desire to help others." According to Doug, Kevin was hopeful that progress would be made on combating the disease before he was more severely affected, and he always wore his CMTA wrist band to show his support for the organization.

At Doug and Theresa's request, the CMTA has created a site for anyone wishing to make a donation in Kevin's honor (www.cmtausa.org/kevin).

CMTA BRANCH NEWS

(continued from page 15)

state proclamations declaring September CMT Awareness Month. Talking specifically about the request for a proclamation in Colorado, it was noted that 2,142 Colorado residents have CMT.

• Hartford, CT

Eleven members met on June 23 to talk about a wide range of subjects that included genetic testing and the importance of being tested to be included in clinical trials and resulting treatments. Members talked about both of the CMTA's genetic testing partners—GeneDX and Invitae. Specifically, they talked about Invitae's 34-gene panel for

CMT, which takes three weeks and costs \$1,500, and which may be covered by insurance. One member said his recent testing with GeneDX only cost him \$100 after insurance. STAR handwarmer "rewards" were passed out to those who participated in last year's Bowlathon or made donations to the CMTA last year. Members were also treated to a session of chair yoga by certified instructor Sarita Nanda.

• Sarasota, FL

Meeting on June 27, the group discussed a variety of subjects, including recommendations for beneficial exercises, such as tai chi, Pilates, and yoga; handling "the CMT shuffle" (difficulty with balance) in social situations; discussing CMT for the first time with family, friends, coworkers, and acquaintances; the onset and progression of symptoms with and without pain; suggestions for equipment, such as different types of AFOs, canes, walking sticks, walkers, power scooters, and wheelchairs; and using the blue Notification Card that alerts TSA in airport security that a person has a disability and might need a different screening procedure.

• Chicagoland North

The branch welcomed two new members, Jim Valentine and Sy Ahmed, to its July 18 meeting. Sy is going to lead some meetings in the northwest suburbs at the Streamwood Public Library. The "Reach for the STAR's Walk & Roll for the CMTA" will take place at 10 a.m. on Saturday, September 19, at Lake Katherine's Nature Center & Botanic Garden in Palos Heights.

• Fort Wayne, IN

Eight members attended the July 19 meeting at the DeKalb Health Community Hospital. Psychotherapist Linda Tonkel spoke on managing the emotional stress of a chronic illness, stressing the importance of sleep, the need to focus on what one can do and dealing with the loss of function.

• Iowa City, IA

Meeting on July 25, 10 people talked about physical therapy, exercise, stretching, strength, balance, surgery, medication, bracing, numbness and Dr. Shy's Clinic at the University of Iowa. The group also discussed their ages at diagnosis, their siblings' reactions to their diagnoses, negotiating stadiums and similar facilities, how the public reacts to CMTers when they fall, how to describe CMT to others, dealing with ice, dealing with stairs, and the Half-Day Patient/Family Conference set for October in Chicago.

• North Iowa

Members met on June 20 to talk about the challenges of daily living and how to deal with them. They also talked about their fundraiser at Buffalo Wild Wings, which was recently featured in a radio interview promoting the event.

• Baltimore, MD

The branch's June 7 meeting featured genetic counselor Shawna Feely, who traveled all the way from Iowa to speak with the CMTA Baltimore and Easton branches. Shawna gave an amazing presentation on the genetics of CMT and generally dazzled everyone with her vast knowledge of CMT and other genetic

(continued on page 18)

CHECK OUT OUR TV SPOT

In the spring of this year, the CMTA launched a Public Service Announcement, or PSA, about CMT. We're asking you to post and share this video on social media and/or contact

your local broadcasting company to see how you can go about sending our TV or radio PSA their way.

Both the TV and radio spots were created with a grant from the Pennsylvania Department of Education and played throughout the state. It created tons of excitement and awareness.

Our hope is to have this spot played throughout the country, but we can't do this alone—we need YOU! Contact Jeana Sweeney at jeana@cmtausa.org for the links to the files you need to get the piece aired.



We're Network SuperSTARS

CMTA Branches

AL—Birmingham Area

Central Alabama CMTA Branch
Bethany Tongate
205-533-8558

AL—North Florence

North Alabama CMTA Branch
Tina Smith
256-366-5273
Todd Oyen
256-810-6582

AR—Benton Area

Central Arkansas CMTA Branch
Lisa Jones
501-776-5364

AZ—Phoenix Area

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CA—Los Angeles Area

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CA—Los Angeles Area

Los Angeles, CA (South)
CMTA Branch
Alani Price
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Tara George
412-607-5193

CA—North Bay Area

North Bay Area, CA CMTA
Branch
Sharon Bello
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CA—Sacramento

Sacramento, CA CMTA Branch
Holly Stevens
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CA—San Diego Area

San Diego, CA CMTA Branch
Jordan Thomas
619-549-0872

CA—South Bay Area

San Francisco Bay Area
CMTA Branch
Ori Bash
408-829-4562
Tau O'Sullivan
408-796-7141

CO—Denver Area

Denver, CO CMTA Branch
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CT—Hartford

Hartford, CT East CMTA Branch
Roy Behlke
239-682-6785

CT—North Haven

Southern Connecticut
CMTA Branch
Lynne Krupa
203-288-6673

DC—Washington, DC

Washington, DC CMTA Branch
Steven Weiss
Kimberly Hughes
301-962-8885

FL—Naples

Naples, FL CMTA Branch
Roy Behlke
239-682-6785

FL—Sarasota Area

Sarasota, FL CMTA Branch
Rachel Rivlin
941-870-3326

FL—Tampa Bay Area

Tampa Bay, FL CMTA Branch
Vicki Pollyea
813-251-5512
Edward Linde
813-712-4101

FL—West Palm Beach

South Florida CMTA Branch
Phil Lewis
561-630-3931
Eileen Martinez
561-777-8471

GA—Atlanta Area

Atlanta, GA CMTA Branch
Susan Ruediger
678-595-2817
Katerina Marks
404-372-3158

IA—Iowa Area

Iowa City, IA CMTA Branch
Jeffrey Megown
319-981-0171

IA—North Iowa

North Iowa CMTA Branch
Michael Groesbeck
641-512-1718

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Branch
Dale Lopez
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IL—Norridge Area

Chicagoland (North) CMTA
Branch
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Sy Ahmed
847-912-1062

IL—Springfield Area

Central Illinois CMTA Branch
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IN—Fort Wayne Area

Fort Wayne, IN CMTA Branch
Aimee Trammell
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Priscilla Creaven
260-925-1488

IN—Indianapolis Area

Indianapolis, IN CMTA Branch
Nancy Allen
317-459-8773
Patricia Wood
317-345-2254

KS—Wichita Area

Kansas Area CMTA Branch
Karen Smith
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KY—Ashland, KY

Ashland Tri-State CMTA Branch
Debra Foster
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LA—Louisiana

Louisiana CMTA Branch
Paul DiMaio
985-234-9013

MA—Boston

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Mimi Works
617-913-4600
Jill Ricci
978-887-1014

MD—Baltimore

Baltimore, MD CMTA Branch
Clark Semmes
410-350-4812

MD—Easton

Easton, MD CMTA Branch
Missy Warfield
Seth Warfield
410-820-0576

ME—Portland Area

Portland, ME CMTA Branch
Mary Louie
207-450-5679

MI—Kalamazoo Area

Southwest Michigan CMTA
Branch
Jori Reijonen
269-341-4415

MN—Central Minnesota

Central Minnesota CMTA
Branch
Jo Smith
612-807-4729

MN—Minneapolis Area

Greater Minneapolis CMTA
Branch
Marilyn Menser
320-522-0871

NC—Asheville Area

Asheville, NC CMTA Branch
Ruth Ann Carroll
203-981-3738

NC—Durham Area

Research Triangle Area, NC
CMTA Branch
Margaret Lee
919-359-6003
919-656-2948 (cell)

NC—Wilmington Area

Wilmington, NC CMTA Branch
Laurel Richardson
814-404-8046

NE—Hastings Area

Hastings, NE CMTA Branch
Levi Stanger
402-705-4358

NE—Lincoln Area

Lincoln, NE CMTA Branch
Karri Hood
402-641-0443

NJ—Central New Jersey

Central New Jersey CMTA
Branch
Mark Willis
732-252-8299
Jacqueline Donahue
732-780-0857

NJ—Morris County

Morris County, NJ CMTA
Branch
Alanna Huber
973-933-2635

NM—Albuquerque Area

New Mexico CMTA Branch
Gary Shepherd
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NV—Las Vegas Area

Las Vegas, NV CMTA Branch
Virginia Mamone
702-343-3572
Jerry Cross
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NY—Buffalo Area

Buffalo, NY CMTA Branch
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Most CMTA Branches
can be accessed via
the CMTA Online
Community at
www.cmtausa.org.

CMTA BRANCH NEWS

(continued from page 16)

diseases. Shawna works directly with leading CMT neurologist Dr. Michael Shy at the University of Iowa CMT clinic.

• Southwest Michigan

Nine members at the July 16 branch meeting heard a presentation by Zachary Ostrowski, a certified pedorthist and president of Select Orthopedic Supply. He answered many questions about proper footwear, orthotics and custom orthotics, AFOs and foot care for individuals with CMT.

• Buffalo, NY

Twenty-four people, including family members and other supporters, attended the first ever meeting of the Buffalo, NY branch on May 7. Attendees shared their stories of personal struggles and small triumphs with the disease. A few people displayed various kinds of braces that are available. All discussed the limited resources in the area. Three committees were established—Resources, Governmental Policy, and Medical—and the group explored possible fundraising opportunities. The importance of clinical trials will be one of the topics at

the August meeting along with the much-anticipated visit of Jeana Sweeney, CMTA Director of Community Services.

• New Mexico

Seventeen members attended the New Mexico branch's summer meeting, which featured a Skype presentation by Dr. Glenn Pfeffer, a prominent foot and ankle surgeon at Cedars-Sinai in Los Angeles. Dr. Pfeffer has worked with a great many CMT patients over the years and is quite an expert in CMT foot and ankle situations and treatments. Dr. Pfeffer is willing to give the presentations to other branches as well. The branch followed the Skyping instructions developed by Branch Leader Gary Shephard, who warned that groups will need a location with either high quality wi-fi bandwidth or a hardwired circuit. Following Dr. Pfeffer's presentation, the group discussed developing a local provider list that includes surgeons, podiatrists, physical therapists and neurologists.

• Cleveland, Ohio

Branch members met at Panera Bread on July 22. After enjoying dinner together, they discussed CMTA happenings, including the branch's new initiative—

motivational partners. Group members who sign up will be motivational partners to one another. The group also played CMT Jeopardy and talked about its Walk4CMT, to be held on September 19, and an anonymous donor who will match donations up to \$1,000.

• Vidor, TX

Kelly Millard from Allard USA addressed the branch meeting on August 9. She brought in several types of AFOs and left a list of local orthotics companies that carry Allard products. She also donated some medals for the Zombie Walk scheduled for September 26.

• Dallas, TX

Melissa Alderdice from GeneDx showed branch members how to fill out the testing application, answered insurance questions, talked about the company's financial assistance program, and explained the benefits of testing. The group discussed its All-Star Walk, a short walk to be held on September 12 at South Lakes Park in Denton. The group also learned that thanks to Kathy Connell, the CMTA's PSA is being played on KBUS in Paris, Texas. ★

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Turn your silver into gold! If you've got change for lunch or change for the vending machine, you can make a change in your future.

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We're asking you to set out a jar and put your change in it for a month. Then, count that change and donate at least that amount to your future!



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BECOME A CMTA SUBSCRIBING MEMBER OR STAR MEMBER TODAY!



What do your membership fees pay for? The CMTA provides high-quality services for people with CMT today while developing treatments for tomorrow.

The CMTA's programs include:

- ★ The 17 CMT Centers of Excellence—clinics at top-rated universities that specialize in CMT,
- ★ Eighty CMTA branches in North America that meet quarterly or bi-monthly,
- ★ Two patient/family conferences per year where CMT experts and families come together,
- ★ Monthly webinars with CMTA Advisory Board members sharing their expertise,
- ★ Valuable printed guides like the CMT Guide to Orthotics and the CMT Survivor's Guide,
- ★ Exercise videos featuring a physical therapist living with CMT1,
- ★ Youth outings at patient/family conferences that give children with CMT an opportunity to connect with their peers,
- ★ Facebook groups that allow people to connect globally, and
- ★ An online emotional support group where people with CMT can share experiences, issues and insights.

Sustain the CMTA with your annual membership. With your support, the CMTA can direct more individual donations to STAR to deliver the first treatments for CMT.

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		Regular Price	STAR Member Price	
The Patients' Guide to Charcot-Marie-Tooth Disorders [CD Format]		\$10	\$8	
CMT Facts IV		\$10	\$8	
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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)
Gold salts
Ixabepilone (Ixempra)
Leflunomide (Arava)
Metronidazole/Misonidazole
(extended use)
Nitrofurantoin (Macrochantin,
Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of
Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:

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

Negligible or doubtful risk:

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

THE CMTA Report

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WHAT IS CMT?

- ▶ CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- ▶ CMT may become worse if certain neurotoxic drugs are taken.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT can, in rare instances, cause severe disability.
- ▶ CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ▶ CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ▶ CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ▶ CMT does not affect life expectancy.
- ▶ CMT is sometimes surgically treated.
- ▶ CMT causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- ▶ CMT has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- ▶ CMT is usually inherited in an autosomal dominant pattern, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- ▶ CMT Types that can now be diagnosed by a blood test include 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN.
- ▶ CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.