

# THE CMTA Report

MARCH/APRIL  
2015

Information on Charcot-Marie-Tooth Disorders for Patients, Families, and the Scientific Community ★ [www.cmtausa.org](http://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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## Sanofi Research Lab Completes Initial Screening of 1.8 Million Compounds in a CMT1A Cell Model

BY SUSAN RUEDIGER, CMTA DIRECTOR OF DEVELOPMENT

In the world of Sanofi, a major healthcare company headquartered in Paris, France, and of its rare disease affiliate, Genzyme, headquartered in Cambridge, Massachusetts, the Tucson Compound Library is highly acclaimed. The library includes more than 2 million compounds that can be tested to identify treatments and cures for many diseases. What's even greater than the library, though, is the team of Tucson researchers committed to finding drugs to treat rare diseases.

The CMTA's recent partnership with Genzyme unlocked access to the Tucson Library, where on February 20, the team completed an initial screen of more than 1.8 million compounds in a CMT1A cell model developed in the labs of Drs. John Svaren and James Inglese, both CMTA investigators.

On February 25, I had the pleasure of visiting the lab and meeting the team behind the CMTA's partnership with Genzyme to search for treatments for CMT1A: Paul August (Biology Department Head), Paul Wright (Project Team Lead), Patti Willson (High Volume



From left to right: Patti Willson, Paul Wright, Elaine Powers, and Paul August from Sanofi-Tucson with Susan Ruediger

Biology), Karen Green (Drug Design) and Elaine Powers (Biology).

For three weeks, Patti had used robotics to inject each of the 1,586 tiny wells in a series of well plates with CMT1A assays, then with luciferase, the enzyme

that makes fireflies glow. The compound screen is designed to detect the down regulation of PMP22, the duplicated protein that causes the nerves in CMT1A to demyelinate. After three tedious weeks of running

(continued on page 2)



Branches benefit from visiting professionals... See page 14

## INSIDE:

New Center of Excellence.... 3

Things You Can Control..... 8

Finding Your Balance..... 10

New Board Members..... 18

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## SANOI

(continued from page 1)

the screen with hundreds of well plates, the data was translated through a computer program into readable graphs.

Patti and Paul walked me through the lab just as the screen was wrapping up. Seeing the CMT1A well plates and the robot that had just finished injecting compounds into tiny CMT1A cells in the search for our treatment was exhilarating.

But even more exciting was running to Patti's desk to see the output from the screen, the actual data in graphic form. This showed the amount of luciferase glow for each of the tested compounds—the brighter the glow, the more PMP22 in the cell. We looked for outliers in the grid, the dimmer points below the norm signifying lower amounts of PMP22 as a result of the compound. At first glance, there were thousands of candidates!

Patti and the team will spend the next six months carefully reading the results of this screen, looking for compounds that may lower PMP22. Patti and Karen will double-team to whittle down the list of candidates from 1.8 million to 30,000 to 5,000. They will repeat the more refined screen to find lead candidates—compounds that seem to be the most effective at lowering the PMP 22 with the least amount of toxicity to the cell.

**The ultimate goal for our partnership with Sanofi-Genzyme is to identify compounds to stop CMT in its tracks.**

## WORDS TO LIVE BY

**PMP22** is Peripheral Myelin Protein 22. The duplication of PMP 22 causes CMT1A. The deletion of PMP22 causes HNPP, another type of CMT. This protein is unique to the peripheral nerves. The CMTA's goal is to reduce the amount of PMP22 in CMT1A to hopefully stop, or even reverse, the demyelination of the nerves.

**Demyelination** is when the protective coating (the myelin) deteriorates. This happens when there is too much PMP22. When the nerve loses its myelin, the nerve speed slows and the strength of the signal is weakened. This causes loss of sensation and movement in muscles that are affected.

**Luciferase** indicates the amount of PMP 22 in each cell. When a cell is combined with a compound that may lower PMP22, the cell dims. Conversely, if the PMP22 is elevated, the cell glows more brightly. A lead candidate for CMT1A will cause the cell to dim.

Once a handful of lead candidate drugs are identified, they will be turned over to Elaine, whose job is to prove that these drugs can remyelinate nerves. In Elaine's words, "I love to remyelinate nerves!" to which I exclaimed, "I love it when you remyleinate nerves, especially mine!" We giggled, knowing that Elaine herself may never actually remyelinate my (or any human's) nerves, but her work could prove that our lead candidate drugs can work. The results of her findings could potentially lead to human trials and Food and Drug Administration approval of these compounds.

The ultimate goal for our partnership with Genzyme is to identify compounds to stop CMT in its tracks, perhaps even reverse it. Meeting the team committed to this work made the collaboration between the CMTA and Genzyme real to me. And they were thrilled to meet a person with CMT1A:

They asked about my symptoms, my family history and my thoughts about being a mother with a genetic disease. They asked what CMT feels like physically, emotionally, and mentally. I wanted them to know why their work is so important and matters so much in making this world a better place to live.

Paul, Paul, Patti, Karen and Elaine all ended the day knowing that their work was for the greater good. I left knowing that every dollar raised for our Strategy to Accelerate Research (STAR) was advancing our vision toward a world without CMT. I called my mother that afternoon with excitement and enthusiasm, and told her that with partners like Sanofi and with the support of the CMT community, we will beat CMT!

If you want to help us achieve these goals, please make an investment in STAR. Your monthly or annual gift will help us further our research and achieve results faster. Visit [www.cmtausa.org/donate](http://www.cmtausa.org/donate) to give today. ★

## CMTA RECOGNIZES NEW CENTER OF EXCELLENCE: Fairview Maple Grove Medical Center

The CMTA has recognized a new Center of Excellence (COE) at the University of Minnesota's Health Specialty Clinic at the Fairview Maple Grove Medical Center. Like the CMTA's other 16 COEs, the new center provides a multidisciplinary approach centered around the CMT patient's needs. Its goal is to improve patients' quality of life by providing resources and adaptations aimed at maximizing function and mobility. In addition to seeing a neurologist, patients have the opportunity to meet with an occupational therapist, a physical therapist, a genetic counselor, an orthotic specialist and a health care service coordinator from the Muscular Dystrophy Association (MDA), which provides clinical and research services to people with CMT as well as other nerve and muscle disorders. Centers of Excellence are vetted by the leaders of the CMTA's Scientific Advisory Board, Dr. Michael Shy and Dr. Steven Scherer.

Consultations at the Fairview Maple Grove Medical Center CMT Clinic can be scheduled by calling Melissa Diaz, the RN Care Coordinator, at 763-898-1075 and leaving a detailed message with name, date of birth, reason for visit and the best number for a return call. A member of the clinic will be in touch before the appointment to gather other vital information. The clinic will need all pertinent records, including previous consultation



*Sitting from left to right: Melissa Diaz, care coordinator; Dr. David Walk, neurologist and clinical director; Joline Dalton, genetic counselor. Standing, left to right: Paul Xiong, orthotist; Lisa White, occupational therapist; Melissa Stucki, MDA representative; Sandy Swanson, physical therapist.*

notes, any genetic test results and EMG/nerve conduction study results. These can be faxed to 763-898-1323, attention Dr. Walk/CMT clinic.

New patients will be scheduled with all members of the

multidisciplinary team. The initial visit will take approximately four hours. Because subsequent appointments are catered to each patient's individual needs, follow-up appointment length is variable. ★

### CANCER DRUGS NOW LISTED AS HIGH RISK

Three drugs used to treat cancer—paclitaxel, docetaxel and cabazitaxel, collectively known as the Taxols—have been moved to the high-risk category for people with CMT.

- **Paclitaxel** injections are used to treat advanced cancer of the ovaries, breast, non-small cell lung cancer, and Kaposi sarcoma, a cancer of the skin and mucous membranes that is commonly found in patients with AIDS.
- **Docetaxel** injections are used to treat breast cancer, non-small cell lung cancer, head and neck cancer, gastric (stomach) cancer, and prostate cancer.
- **Cabazitaxel** injections are given together with a steroid like prednisone to treat men with metastatic prostate cancer. It is used in patients who have already been treated with other medicines that did not work well.

***If you have CMT, alert your doctor that these medications may pose a high risk to you before taking any of them.***



## CMT & Me

BY DR. STEVEN SCHERER, CMTA ADVISORY BOARD CO-CHAIR

I have been part of the CMTA for many years. It is a consuming and fulfilling relationship that has brought me into a world of people who are making a difference for CMT. My week is a good example of what this means to me.

On Thursday, I gave a talk on CMT in a graduate student course at the University of Pennsylvania (Penn). I provided three examples of how knowing the genetic cause of CMT illuminates the path to finding a treatment. First, I explained that CMT1A is fundamentally caused by too much PMP22 in the myelin sheath, and that the CMTA is funding the scientific solutions to fix the fundamental problem. The students were interested, even surprised, to learn that a patient-led organization would fund science.

Second, I described how some mutations of PMP22 and MPZ cause a severe neuropathy (Dejerine-Sottas neuropathy), and one of the students made a very reasonable suggestion—“knocking down” the expression of the mRNA that encodes the bad mutation would be a potential treatment!

Third, I told them that people who have recessive mutations in the gene that encodes the voltage-gated sodium channel Nav1.7 feel no pain, and that this single discovery has motivated a huge effort by pharmaceutical companies to find drugs that can selectively block this channel. If such a

drug is developed, it should revolutionize the treatment of neuropathy pain.

Finally, one of the graduate students presented a paper from Dr. Florian Eichler’s lab, describing how eating extra serine, an amino acid, might be able to reverse the levels of toxic lipids that are thought to cause a rare form of CMT (HSAN1A). I had met with this student on Monday to help her prepare, and she did a good job. I was pleased—I had been able to engage the students in a topic I care for deeply, and they learned something.

On Wednesday, Thursday and Friday, I saw patients, several of whom have CMT. One was an unaffected family member who came to help the rest of her family members determine the cause of their CMT. She was a wonderful person and it meant a lot that she thanked me for our efforts.

The second person was a woman from a family in whom I suspect a novel mutation in MPZ causes CMT. The patient told me that her mother had been seen at Penn more than 20 years earlier and was thought to have developed an “idiopathic neuropathy” at age 50, but now two of her children have developed a similar neuropathy at a similar age. When I got back to my office, I tracked down some of her mother’s records and confirmed what she had said.

All the way home I dwelled on how marvelous it is that one can now find the causes of CMT



**Dr. Steven Scherer, director of the CMT Center of Excellence at the Perelman School of Medicine Hospital of the University of Pennsylvania**

that previously eluded us. My colleagues did everything that was possible in 1993, and the accumulated knowledge about CMT and technological advances in performing genetic tests will enable me to give this family an answer in 2015. This example illustrates that suspecting a cause of CMT is one thing, but proving it requires real effort on the part of the family, the health care professionals—Shana Merrill, a genetics counselor, played a key role in this case—and the scientists, many hours by many people for just this one family!

The third patient was guided to me by Amanda Young, a member of the Bucks County CMTA Branch. This patient had adult-onset CMT and more questions than I had answers. I hope that I can find the cause and lessen the burden of her disease: We had a good start, but I couldn’t get it all done in the hour that we had together.

My other “CMT moment” this week involved a Penn undergraduate who found me because his brother has CMT. He is going to work in my lab this semester, studying the pathology of the “CMT2A rat” that has the Arg364Trp mutation in the *Mfn2* gene. The CMTA funded the creation of this rat, and scientists at PsychoGenics (funded by the CMTA) found that CMT2A rats develop abnormal gait and balance, just like people with CMT2A. Last summer, Dr. Joel Li, a senior scientist in my lab, showed that the rats develop a robust neuropathy by 8 months of age—my personal scientific highlight of 2014! Having a robust and authentic animal model of CMT2A is key to

learning how MFN2 mutations cause CMT2A, and an essential part of developing a treatment for this form of CMT. My lab will participate in this important work.

These are just some examples of the many ways that I work with the CMTA. I lead a team at Penn that includes Shana Merrill (a genetics counselor), Jess Richardson (my administrative assistant), Lois Dankwa (a part-time clinical researcher and a future physician) and Will Motley (an MD/PhD student who is passionate about CMT, and who I hope will continue as a neurologist). My group’s efforts to find new causes of CMT also involve many wonderful colleagues at Penn and around the world,

especially Dr. Stephan Zuchner at the University of Miami and Dr. Michael Shy at the University of Iowa. I thank the MDA and the CMTA for supporting the CMT Center of Excellence at Penn, which enables my clinical work. Finally, I want to acknowledge the people who have CMT—I do it for them.

One last thought comes to mind as I write this: “Now is the time.” People who have CMT, as well as their families and friends, need to be involved. Their voices need to be heard by their elected representatives. It is their time, effort and money that runs and funds the CMTA. Anyone who doesn’t know the cause of his or her CMT should get to a CMT Center of Excellence without delay. ★

## The Littlest Fundraiser

Emily Goodwin, now 11, was diagnosed with CMT Type 2 in June 2012. On December 26, 2012, she went in for the first of two surgeries. She was in a wheelchair for months, but her smile never faded. The following year, Emily went in for another surgery. She healed much faster the second time because her left foot wasn’t as bad as her right. Emily walks much better now, thanks to the surgeries and to her AFOs. While finding the right shoes to fit over her AFOs is a challenge, she wears them with pride and especially likes the fact that people think she’s a soccer player when she wears shorts.

Since her surgeries, Emily has been trying to come up with an idea to raise funds for CMT research. She knew she didn’t want to do a bake sale, and a car wash was out because she gets fatigued so fast. In December 2014, she was making a Christmas present for a friend when a lightbulb went off: She could raise money by selling the decorative lamp shades she was making. She soon extended her product line to include lamps, coasters, hot plates, napkin holders, and stools made of wood from the trees around her family’s home in

New Hampshire. She made a mini-catalog and started showing it to family and friends, resulting in \$200 in sales the first day. She now has some \$300 in new orders, but the snow has kept her from finding the wood she needs to fill them. Come spring, though, Emily will once again be hard at work making lamps and lampshades and raising funds for CMT research.



Emily Goodwin, 11, with her product line



## ASK AN EXPERT

### Dr. Michael Shy Responds to Genetic Testing Questions



*Dr. Shy is the chairman of the CMTA's Scientific Advisory Board and the director of the University of Iowa CMTA Clinic.*

#### **How do I know if I'm eligible for clinical trials?**

Recruitment is actually a challenge for most clinical trials. When we get to that stage, we will be reaching out in every way possible to recruit participants. For example, when there is a trial for CMT1A, we will contact patients with CMT1A who have come through our clinic, and we will work with the CMTA to publicize the trial. We will use our consortium to get out the word. We will reach out to patients in any way we can, and given the reach of the Internet, I suspect all will know about the trials. Being enrolled in the database is not a requirement to be eligible for a trial. There might also be exclusion criteria. For example, also having a diabetic

neuropathy might confound results. The main requirement will be having the correct genetic disease for the trial.

#### **If I didn't receive a confirmed diagnosis from a genetic test, will I be notified if a confirmation is found?**

Yes! As soon as a match is found, you will know. If a clinic orders genetic testing on a patient, it is the clinic's responsibility to inform the patient when a diagnosis is found. If the tests are done through a commercial lab such as Athena, GeneDx or Invitae, then results typically come back within a few weeks. If the tests are done through research protocols such as those we perform in collaboration with the University of Miami, the results may take more than a year.

#### **If I received an unconfirmed result, will I be notified when a new matching mutation is found?**

If particular mutations in a gene have not been previously identified as causing disease, then the lab may say that it is uncertain

whether the mutation causes disease. Practitioners at the Centers of Excellence may be able to interpret the test results.

#### **If I was tested a few years back and the tests were inconclusive, should I get tested again? Should I get tested every two years?**

It depends on how long ago the testing was done. Testing done in 1998, for example, is out of date since many more genes are now commercially available. The answer to the question of whether one should get tested every two years is more complicated. It depends on where the testing was done and how many candidate genes were screened. Next-generation sequencing panels done through GeneDx or Invitae may screen 40-50 genes, and these probably don't need repeating after just two years. Whole-exome sequencing screens 20,000 genes. Results from these tests can be complicated and take years to figure out. Hits are only found in about 20 percent of these cases.

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# Taking Advantage of Teachable Moments

BY PETER I. WARFIELD, MD, MPH, FAAP

When I was about 8 years old, I was diagnosed with CMT. I have to admit that having CMT wasn't something that made me proud. In fact, I tried my hardest to fit in and to pretend that I didn't have it. I was a slow runner, but somebody had to be last. I tripped more than other kids, but we can't all be graceful. It took cycling for me to ever consider myself an athlete.

As I grew up, I was continually challenged by questions and comments from interested and curious people. Why do your feet look like that? Are you limping today? One of my favorite comments was when I

passed a friend while bicycling on a steep hill, and he shouted, "I've seen better legs hanging out of a nest!"

My response to these social challenges was usually to deflect with a quip like, "Oh, that's just my crazy feet," or "No, I just walk funny when I'm tired," or "Whatever, I dropped you on that hill! Were you even moving?" I think now that I could have responded in a more powerful way that would have had a more lasting and positive effect.

Now, as a father and a pediatrician, I am constantly

searching for those teachable moments when the timing is just right and a child (or adult) asks just the right question and is genuinely interested in the answer. It is how a single breakfast conversation with curious kids can cover medicine, macroeconomic concepts, architecture and sports. These moments occur with great frequency, but we often miss them because we are embarrassed, busy, unprepared or unwilling to invest in an answer.

As people who care about CMT, we need to jump at those teachable moments as opportunities to educate and to raise awareness about CMT. The

**As a father and a pediatrician, I am constantly searching for those teachable moments when the timing is just right and a child (or adult) asks just the right question and is genuinely interested in the answer.**

truth is, our witty comebacks and deflections only work for so long. CMT is a slowly progressive disease and we can't hide it forever. Eventually, people notice our differences so we may as well embrace them. Be ready with short and long explanations of what CMT is and why you are the way that you are. Tell people that there is an organization working toward finding a cure for this disease and that real progress is being made. Then get their emails for our fundraisers!

These teachable moments typically come at the most unex-



CMTA Board Member  
Dr. Peter Warfield

pected times. Unfortunately, it is often when we meet a new doctor or health professional. Health professionals should know about CMT, but given the rare nature of the disease, they don't always recall the details. Rather than getting frustrated about this, take the opportunity and jump on the teachable moment! Explain that there are many different types of CMT. Be sure that they know that no two patients with CMT are exactly the same. While the same theories of treatment apply, the specific interventions (e.g., exercises, physical therapy interventions, occupational therapy interventions) will differ with each patient. The health care provider will appreciate your patience and you will have a more productive interaction.

Explaining CMT to people who have never heard of it results in increased awareness. Increased awareness leads to increased funding, and increased funding will result in a cure. Then what will we talk about? ★

# The Things You Can Control

BY BETHANY MELOCHE, DIRECTOR OF SOCIAL MEDIA



I don't always feel in control of my life and CMT doesn't make it any easier. I was diagnosed with CMT at the age of 13. When my health started going rapidly downhill two years later, I found myself focusing on what I couldn't do. It didn't help. So I started trying to focus on things I could control. It turns out, even with CMT, a lot is still within our control. First and foremost, we can control the things we know. Here are five things I've found worth knowing:

## #1: HOW TO GET HELP

I've learned not to depend entirely on the knowledge of medical practitioners. The average doctor may not know all that much about CMT. Most doctors are generalists. I decided to focus on becoming an expert in one thing, my own CMT. This was something I could control.

One of my biggest resources has been the CMTA's website, [www.cmtausa.org](http://www.cmtausa.org), where I have connected with my local CMTA branch and the clinicians at a CMT Center of Excellence. Members of your local branch are likely to be in the know on the best clinicians in your area, and can provide great recommendations for neurologists, physical therapists, podiatrists and more. If you have medical

questions about CMT, you can also email the CMTA at [info@cmtausa.org](mailto:info@cmtausa.org) and they will have an expert answer your question. There's also lots of support to be found on the CMTA's Facebook group at [www.facebook.com/groups/CMTAssociation](http://www.facebook.com/groups/CMTAssociation).

## #2: THE LINGO OF AN ORTHOTIST

My orthotists are very important people in my life. Several common vocabulary words come up over and over again for CMT patients, and it is worth taking the time to learn them. The best way to learn is to ask questions during the appointment. If you want to get a head start, Google these terms and look under Images:

- Plantarflexion v. Dorsiflexion
- Inversion v. Eversion
- Pronation v. Supination

The goal is to be informed so that you can communicate your needs effectively and get the best quality care.

## #3: CMT PAIN AND PAIN MANAGEMENT

A couple of different types of pain are associated with CMT. Some people experience joint pain or pain from bone deformities in their feet. But more often than not, the pain I hear other people describing is the sharp, shooting, burning type of pain, usually in the limbs. This is called neuropathic pain.

The CMTA's website has two great articles about neuropathic pain that you can find in the Free Info Kit under the Resource Center:

- Neuropathic Pain in Charcot-Marie-Tooth Disease by Dr. Greg Carter
- Managing Neuropathic Pain by Dr. Steve Scherer

## #4: SURGERY—WHAT, WHEN, AND WHY

You should also know a bit about the surgical options for CMT—what they are, when you might have them and why. Surgery is not a miracle cure, and each person is different. For me, surgery meant the difference between walking and not walking. Dr. Glenn Pfeffer, an orthopedic surgeon and member of the CMTA Advisory Board, gives a great overview of the surgical options for CMT patients on the CMTA's YouTube account in a video called "Orthopedic Surgery: A Step in the Right Direction."



Bethany underwent 10 procedures in each foot over the course of two surgeries. The procedures included calcaneal (heel bone) and 1st metatarsal osteotomies, tendon transfers of the flexor digitorum longus and posterior tibialis, and a gastrocnemius release.



**#5: NUTRITION**

Symptoms caused by deficiencies in calcium, Vitamin D, and iron can mimic those of CMT. Know the difference:

**Calcium:** People with CMT tend to be at a greater risk of bone loss due to a lack of exercise and muscle loss, and they have a greater risk of bone fractures because they're also more likely to fall. Adequate calcium is crucial to having strong bones. Consult your physician or a registered dietician about how to know if you are getting enough calcium.

**Vitamin D:** Vitamin D deficiency can cause a lot of problems,

including weak bones, fatigue, depression and a weak immune system. A lot of people are deficient in Vitamin D, but luckily, unlike calcium, it's really easy to test your Vitamin D levels. Ask your doctor to test your levels! If you're prescribed a supplement, make sure to re-test after supplementation to ensure you're getting and absorbing enough.

**Iron:** One of the biggest symptoms of iron deficiency is fatigue, something that people with CMT definitely don't need. If you aren't eating a lot of iron-rich foods like spinach or red meat, and especially if you're

unusually tired, have your doctor check your iron levels. Remind your doctor to check your storage levels (Ferritin), as you can be symptomatic if your iron stores are low. Get a documented deficiency analysis before supplementation, and only take as much as you need. Too much iron is just as bad as too little.

**CONCLUSION:**

Carl Jung said, "I am not what happened to me. I am what I choose to become." By taking control of what you know, what you eat and how you spend your time, you can choose what you become. ★

## WHAT'S ON YOUR MIND? ASK DAVID.

**Dear David,**

*I have a relatively mild form of CMT and recently found out that my 16-year-old son has it as well. He is asymptomatic apart from some ankle weakness but is beginning to ask questions about CMT and his future. I am a worrier, and before I saw a CMT specialist I made the mistake of searching the Internet and focusing on the worst-case scenarios I found there. I just want my son to have as normal a life as possible and experience everything he can without worrying about himself. What should I do?*

**David replies:**

I remember at 18 years old knowing something was not quite right with me, going to a doctor by myself and being diagnosed with CMT. I made the

mistake of looking it up in books—this was pre-Internet—and being completely freaked out by what I read. I was the only one in my family with CMT so there was no one to relate to, and my parents were too self-involved to ask any questions. But I had the good fortune to find a wonderful, warm, caring neurologist who was able to ease my fears and concerns. It made all the difference in the world.

Children are often very attuned to their parents' emotional state, so before you share anything with him, check your own feelings and attitudes about CMT and make sure you are feeling centered. Feeling centered is not about being in denial. It is more about being able to convey a calm, practical

and hopeful demeanor. A good CMT specialist can help you with this. The comforting demeanor of my original doctor stays with me to this day. Knowing about CMT is important, but so is teaching your son that having it is not the end of the world. Make sure he learns how to take care of himself and that practical steps like exercise and keeping his weight down can make a real difference in his quality of life. Help him see that the fact that he might have some physical limitations down the road does not mean he cannot experience a full and rewarding life. Teaching your son that his value as a human being and the experience of feeling loved does not depend on the strength of his ankles is your most important job. ★



**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](mailto:info@cmtausa.org).

## Finding Your Balance

BY GREG STILWELL, DPM

Those of us with CMT have a challenging relationship with gravity and balance. Type 1 CMT—with its slowed nerve conduction velocity—means that sensory input from your feet up into your brain is delayed. On slick ground, your foot may move out from under your center of gravity before your nervous system can send information to realign your body and prevent a fall. While balance can be affected by your eyes, ears, head/neck position, and even breathing, this article will focus on the most common CMT-related causes for poor balance.

Integration of upper and lower body is important to increase balance. Building a strong core means using the pelvis as the axle, or center, from which the trunk and extremities move. Building a strong core means more than just doing sit-ups. It means developing fluid and graceful motion that can easily adapt to unexpected drop-offs, ice or other dangerous terrain changes.

Exercises that train the trunk and arms to work harmoniously with your legs and feet are effective methods to increase your balance. Yoga therapy can be helpful because the asanas, or poses, encourage your body to “reconnect” functionally—a right arm with a left leg, for example. This oppositional energy concept comes from the dance world and movement therapy specialists. Imagine

being able to help your foot drop by controlling the twist in your pelvis and lifting through your spine as you walk.

Nordic walking poles are an effective method for learning body awareness. Using these semi-flexible poles as front legs will enable you to feel the origin of your limp or other gait abnormality. You can then build offsetting strengths in other regions such as your spine and shoulders.

Many people with CMT have legs of differing lengths. One leg might be shorter because the bone is actually a different length (anatomic), or it can be caused by a tight muscle group or a pelvic twist that affects balance and gait patterns. Scoliosis and other back abnormalities can affect your balance. Nordic walking poles have been a great help for my own scoliosis and balance issues. The support of the poles promotes strength and conditioning—and outdoor exercise is hard to beat.

The high arched foot commonly found in CMT is typically rigid and not particularly yielding or flexible enough to promote graceful balance. This is where mild rocker shoes can be of benefit. It’s one of those seeming paradoxes: A little de-stabilization with the rocker can increase balance as the body is asked to respond to the small continuous motions induced by the shoe.

A highly conforming foot orthotic can cradle your foot



and toes while still providing some counterbalance to the rolling out (supination) that most high arched feet endure. New padding materials on an AFO or foot orthotic can also increase balance by providing more sensory cues with which the brain and proprioceptive systems may interact.

A multi-density sock, made from various hollow fibers such as bamboo, hemp, or polypropylene, not only cushions and protects the tips of toes and boney prominences on the bottom of your foot, but may also increase sensory feedback to allow body adjustment and maintain balance.

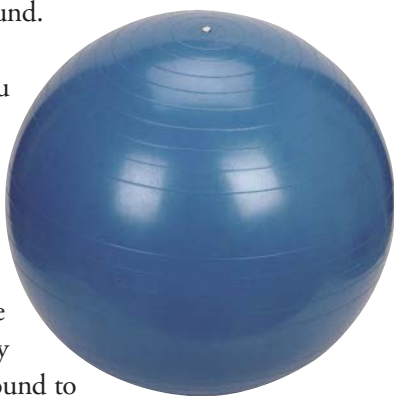
The study of balance is evolving away from using just a cane or a single crutch. Those of us with CMT are in a wonderful position to begin exploring new and innovative ways to create balanced bodies and a more graceful gait. ★

## Exercises to Help Balance

**STAIR WORK:** Find somewhat narrow stairs where you can reach both hand rails simultaneously. Practice standing in the middle of the tread, and lightly touch each rail while stepping up slowly and gracefully, keeping your upper body tall and eyes looking upward at the risers above you. The slower you climb the stairs—in a controlled fashion—the better.

**EXERCISE BALL:** Find a size (usually 55cm or 65cm) that allows you to sit with your thighs parallel to the ground.

Place your hands slightly behind you on the ball and practice moving the ball with your pelvis (sit bones or ischial tuberosities), while your feet are firmly planted on the ground to react to the moving ball.



**CLOSET ROD OR WOOD DOWEL:** Also known as the rod upon which you hang your clothes, these are cheap and fun to use as a balance or “hinge” point to lift one leg, lean to one side, or even close your eyes and pretend to dance with the vertical pole. You know what they say about pole dancers—see for yourself.

**SUSPENSION TRAINER SQUATS:** TRX™ is the most common brand, but other generic systems are available. Place elbows in the padded hand loops, and with hands gracefully spread on the straps above you, practice tiny squats (maybe only 15-20 degrees of knee bend). Be aware of your heels pushing into the ground and your “sitz” bones pushing back and downward. Play around with different foot positions or single legged squats for variety.



**MINI-TRAMPOLINE REBOUNDER:** Use your walking poles along each side of the round tramp, and while in stocking feet use this flexible support surface to shift weight back and forth. Keep your elbows straight and feel how your shoulders begin to lift your spine and ribs while you begin to transfer weight from one foot to another. Yes, it’s exercise, but it’s supposed to be fun.

**GYROTONIC™ METHOD:** Find an instructor near you for private sessions. Spiraling, arching and curling movements are taught that readily translate to daily balance activities. Pilates equipment offers a beautiful way to expand your range of motion, strength and balance. Mat classes aren’t recommended—instead ask your instructor about equipment with names like the Reformer, the Wunda chair, and the Cadillac.

**WATER MOVEMENT THERAPY:** Get a pair of hand paddles for swimming and stand in shoulder-depth water. Fan your hand paddles back and forth in the water to keep your feet off the pool floor, then swivel your pelvis side to side and front to back. Feel how your legs and feet want to grow longer, stronger, and more willing to give you better balance on dry land too.







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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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### Occasion (if desired):

- Birthday     Holiday     Wedding  
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Send acknowledgment to:

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

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

VISA     MasterCard     American Express

Card # \_\_\_\_\_

Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_

### Gift Given By:

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

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

\_\_\_\_\_

## CMTA Member Spotlight: Jim Moneyhon

When Jim Moneyhon finds something he likes, he sticks with it. Hired by the Navy at the age of 22 to work at the Naval Weapons Lab in rural Dahlgren, Virginia, James has remained in the same job, in the same building, for the last 46 years. A physicist by training and a tinkerer by nature, Jim has found a number of unique ways to work around his CMT and continue working at a job he enjoys in a town he has never found a reason to leave.

Born in the Philadelphia suburbs and educated in Gettysburg, Pennsylvania, Jim moved to the tiny town of Dahlgren right after college. When he met a local girl and they decided to tie the knot, the natural location was the base chapel. A few years later, Jim and his wife were the proud parents of six boys and girls (three biological and three adopted).

Jim was about 45 and working on a ship at sea when he first noticed the symptoms that were later diagnosed as CMT. He found himself constantly walking in small circles in an effort to maintain his balance, an unusual dance that no one else on board seemed to be performing. A visit to a series of doctors, including an ENT and an orthopedist, eventually led to a neurologist and resulted in a diagnosis of CMT Type 2.

In the years since his diagnosis, Jim has found a number of ingenious ways to work around his disease. In the late 90s, Jim attended a disability exposition in Chantilly, Virginia, and pur-

chased a device called an EZ Chair. Essentially a wheelchair with pedals, the EZ Chair was maneuverable, comfortable, lightweight, and could be easily folded and stored. Jim describes it as a “lifesaver.” In a job that required a lot of travel, the EZ Chair could be used to carry a laptop and a briefcase, and on an airplane it could be easily folded and stored. The pedals also offered a great form of exercise.

Sadly, the EZ Chair is no longer manufactured, but Jim has taken extraordinary measures to keep his two chairs up and running. When an airline employee accidentally broke the chair’s front axle, Jim was able to build a temporary splint with parts from Home Depot. Later, his oldest son took it to an aluminum welder who fixed and reinforced the broken portion of the chair. Jim recently rode his chair into a meeting of the Baltimore CMTA Branch, where it was an immediate object of great interest. Jim reports that it attracts women and children “like driving a Camaro.”

In addition to the EZ Chair, Jim has a number of devices that make his life with CMT much easier. These include Hikker brand hiking poles (available on Amazon.com)—to which he added Pace Maker rubber tips for increased stability and traction, the Pocket Dresser (which has several button hooks and an attachment for managing zippers), and, to help him with eating, he has a Rocking T-Knife for cutting food. He carries a pair of Gerber pliers with him

on his belt—they’re spring-loaded, and are good for picking up and gripping things that he can’t manage otherwise due his lack of manual dexterity. Another tool that he has found quite useful is a pair of Black & Decker electric scissors (sadly no longer made). Jim’s wife is an avid reader and always keeps her eyes peeled for other products that Jim might find helpful.

Jim uses Version 12 of Dragon Naturally Speaking software at work and is learning the intricacies of Version 13 at home. Although he says he hasn’t yet learned to utilize all of its capabilities, Dragon has been a great help in transcribing his written notes, since his handwriting is not particularly legible.

After experiencing several instances of stumbling and falling while on naval ships, Jim no longer visits them at sea. But he still finds his work with the Navy and the Department of Defense interesting and important, and he has no immediate plans for retirement. (His wife jokes that they will carry him out of his office in a pine box.)

If, like Jim, you have any special tools or gadgets that help get you through the day, please share them with the CMTA by emailing Bethany Meloche at [bethany@cmtausa.org](mailto:bethany@cmtausa.org).

—Clark Semmes



CMTA Member  
Jim Moneyhon

**IF YOU KNOW SOMEONE** who would be a good subject for a CMTA member spotlight, please contact Clark Semmes at 410-350-4812 or [clarksemmes@gmail.com](mailto:clarksemmes@gmail.com).



## CMTA BRANCH NEWS

### • North Alabama CMTA Branch

Two representatives from Allard USA spoke at the January 29 meeting of the North Alabama Branch. Rodney Vaden and Buzz Hanie from Allard USA told the 18 members in attendance about the benefits of bracing, provided samples and answered questions. Members also discussed an upcoming fundraiser and September awareness month projects.

### • Arizona CMTA Branch

The Arizona CMTA Branch reports a great meeting in January with seven people in attendance. The guest speaker was Mark Werner (*pictured on page 1, contents box*), a certified prosthetist/orthotist with 25 years of experience. He is the co-founder of Arise Prosthetics LLC, which personalizes services to improve people's mobility. Mark demonstrated types of orthoses, including the posterior leaf spring and the Allard Toe-Off, AFOs that help support the leg muscles and stabilize the feet. Werner emphasized the importance of people communicating their needs to their orthotists and of orthotists listening to and spending time with their patients.

### • San Diego, CA CMTA Branch

The San Diego CMTA group had an extensive discussion of braces and orthotics at its last meeting. The consensus seemed to be that Scripps Memorial Hospital Encinitas provides the most in-depth analysis in determining options for orthotics. One member recommended

Swiss Balance in Santa Monica for orthotics and braces, and another suggested Hangar Orthotics in San Diego. The brands discussed were Allard orthotics and Phatt braces. The San Diego Branch's next meeting is in April, specific date TBD. Tara George, the CMTA's West Coast Regional Branch Manager, will be the speaker.

### • Denver, CO CMTA Branch

The Denver CMTA Branch had its first meeting in a new location in Golden, Colorado, in January. Thirteen members (including one new one) discussed local resources for the CMT community. Much of the discussion centered on a neurologist new to Denver, Dr. Vera Fridman of the University of Colorado Hospital, who has seen a number of branch members. She was described as young, very knowledgeable and enthusiastic about working with CMT. One member described his visit to Fridman, who is heavily involved with Dr. Shy and the CMTA, as one of the most enjoyable and informative visits he has ever had with a specialist. Every patient visit benefits the CMT community at large by providing a larger body of people with CMT to be examined. Like the other branches and the national organization, the Denver Branch is compiling a resource guide and asked members to recommend local neurologists, podiatrists, orthotists, physical therapists and occupational therapists.

### • Sarasota, FL CMTA Branch

Two GeneDx representatives delivered a very informative presentation to 24 attentive members of the Sarasota, FL CMTA Branch on January 17. Diana Tulley covered genetics and testing for CMT, and Kristian Brinkmann advised members about applying for testing and covering the costs. Some members feel it is important to be tested for family planning or to advise their children and grandchildren. Knowing our CMT type also helps if we want to participate in certain CMT research studies. Members also shared information and resources with each other. For example, two members had new non-slip flooring surfaces installed in their home to help prevent tripping and falls.

### • Atlanta, GA CMTA Branch

Four new families joined loads of familiar faces in a tremendous turnout at the January 17 meeting of the Atlanta CMTA Branch. Branch leader Susan Ruediger started the meeting by laying out important calendar dates for the coming year: On March 21, Allison Childress will present a physical therapy exercise video focusing on the feet; on May 16, the meeting will focus on driving with CMT and using hand controls; on June 20, the branch will break into three focus groups, each led by a trained therapist, to talk about having CMT, kids (with and without CMT) and care givers; on Aug 15, there will be a STAR

(continued on page 16)



## BRANCH LEADER SPOTLIGHT

## Dale Lopez, Chicago Area

Dale's journey with the CMTA started 10 years ago when she noticed that her son Tyler, then 9, was running a little funny around the bases at his Little League game. That single observation turned into multiple doctor visits and, finally, a diagnosis of Charcot-Marie-Tooth.



Dale Lopez and her son Tyler

Not knowing what CMT was or where to turn for help, she searched the Internet and found the CMTA. After reading about the CMTA's research efforts, she attended a Chicago-area fundraiser, where she met Patrick Livney, Elizabeth Quелlette, and other CMTA board members. She says their dedication and drive gave her hope that a treatment or cure will be found.

Like most parents, Dale wanted to do whatever she could to help her son so she started her own fundraising event through the CMTA's "Circle of Friends." That was nine years ago and she has done a fundraiser every year since, raising an astounding \$120,000 in total. She says the CMTA has been there every step of the way, helping in every way possible.

Dale has lived in the Chicago area her entire life. While she might be mistaken for a professional fundraiser, she's been in the information technology business for 35

years, earning a degree in computer science while working as a fashion model. To counter the effects of working behind a computer all day, Dale plays the washboard and tambourine in her husband Dan's band, the Sole City Juke Band. She and Dan have been married 23 years and have two sons, Tyler and Danny.

Dale's first event was a simple walk around a local park. Dale asked her family and friends to sponsor her and Tyler. To their surprise, almost everyone they contacted not only sponsored them, but they showed up to walk as well.

The next year Dale and Dan decided to do a benefit along with the walk. The walk took place in the morning and the benefit in the evening. The benefit included food, live music (with Dan's band and other musicians who donated their time), and raffle baskets of donations from local businesses. The event was such a

big success that the crowd overflowed the room they'd rented.

For the next few years, Dale continued to organize the walk and benefit, renting larger venues each time. She formed a committee of family and friends to help solicit donations, make raffle baskets and work the night of the benefit. She found getting donations a

particularly eye-opening experience, and was amazed at the willingness of local businesses, professional sports teams and restaurants to help.

More than 300 people attended Dale's most recent benefit in September 2014, which featured more than 45 raffle baskets and over 50 silent auction items. She says she couldn't have done what she's done without the help of her family and friends in organizing and attending a night that everyone has come to anticipate with enthusiasm.

Today, 19-year-old Tyler attends Moraine Valley Community College in Illinois. He had two reconstructive surgeries on his left foot while in high school and still managed to make the golf team his first two years. He's been brace-free since the surgeries. Tyler will probably have surgery on his right foot this year, but it won't stop him from walking with Dale in the event he inspired. ★

## CMTA BRANCH NEWS

(continued from page 14)

presentation and a neurologist; the annual picnic at Stone Mountain takes place at a date TBD in September, possibly incorporating a “Walk and Roll”; and on Oct. 17, a psychologist will talk about coping techniques.

Susan also gave an extensive presentation about STAR, noting that there was a major breakthrough with 2A in 2014 as the laboratory models were characterized and confirmed, and that the CMTA hopes to see 1A human trials in 2015.

Asked why drugs found for 1A won't necessarily work for other types of CMT, Susan explained that while all CMT types have same nerve outcome (peripheral neuropathy), the causes for each are different (e.g., too much of a type of protein for 1A). The cause drives the drug development. There was also discussion on retesting, which is not needed if Dr. Shy (and the Inherited Neuropathies Consortium, including Stefan Zuchner at University of Miami) have your blood/genetic data. They'll advise as new types are found. Your data must be in the INC center. Visit [www.rarediseases-network.org/INC/about/](http://www.rarediseases-network.org/INC/about/) to learn more and enroll.

### • Baltimore, MD CMTA Branch

A dozen members of the Baltimore CMTA Branch did chair yoga under the watchful eye of physical therapist Kristin Mowry on January 25. Mowry, from the Kent Island Health and Wellness Center, has a doctorate in physical therapy and is also a certified nutritional consultant and certified holistic health counselor. Kristin didn't just talk about nutrition, she brought a huge pot of vegetable soup to the meeting to warm and nourish attendees. Kristin also demonstrated a series of yoga moves for members, with modifications for those who needed and/or wanted to remain seated while doing them. According to Kristin, almost any exercise or yoga move can be modified to make it suitable for people with CMT: The key is modification.

Kristin also emphasized the importance of presenting a clear picture of CMT to any new physical therapist or doctor. She

suggested giving any new provider one write-up on CMT in general and a second write-up on individual abilities and restrictions. The branch also welcomed four new members at its January meeting: Jim Moneyhon, Steve Simms, Linda Miller and Lynn Thomas! Posting the meeting on Facebook was a great way to reach new people.

### • Indianapolis, IN CMTA Branch

Peter Cook from Cook's Fabrication was the guest speaker at the Indianapolis Branch meeting on January 24. He did a great job teaching the group about different types of orthotics/braces. After his presentation, group members discussed having as future guest speakers a physical therapist, a neurologist, a podiatrist and a dietitian. Next up is Michelle Hayes, Midwest Regional Branch Manager for the CMTA. In addition to the presentation, a new member shared his experiences with Edelweiss Equine Therapy Center ([www.horses4therapy.org](http://www.horses4therapy.org)).

### • Southwest Michigan CMTA Branch

The branch met on January 16. Four members were present, including one new member, who had many questions about CMT that the group was able to answer. Topics included CMT diagnosis, hereditary factors, genetic testing, treatment, CMT clinics and living with CMT.

### • Las Vegas, NV CMTA Branch

Dr. Glenn Pfeffer, an orthopedic surgeon at Cedars-Sinai Medical Center in Los Angeles, spoke to the Las Vegas CMTA Branch on February 21. Pfeffer, who has more than 25 years of surgery experience with CMT patients,

(continued on page 18)

## WARNING: CMTA RELEASES YOUR NEW FAVORITE PAIR OF SWEATPANTS

Ever consider revamping that pair of 10-year-old sweats in your closet? We're not talking about your “favorite” pair, just the ones that have seen better days!

The CMTA is delighted to announce a new item of CMTA apparel—CMTA Sweatpants Est. 1983. They will keep you warm on frosty nights, act as a napkin while you're eating popcorn and watching a movie, and, most importantly, represent an important cause you feel strongly about.

The sweatpants are 50 percent cotton/50 polyester, made with an air jet yarn that creates a smooth, low-pile surface. They have a covered elastic waistband and a slightly tapered leg with an open-bottom hem draw cord.

Help support the CMTA by buying a pair of these incredibly comfortable and fashionable sweatpants. They just might be your new favorite pair.



To order the CMTA Sweatpants, visit [www.cmtausa.org/est1983](http://www.cmtausa.org/est1983).  
Price: \$30 Sizes: S, M, L, XL, 2X, 3X.  
Price includes shipping inside the USA. Add \$10 for international orders.





## CMTA BRANCH NEWS

(continued from page 16)

gave a terrific presentation and said he is available to present for other West Coast groups that have a projector.

### • New Mexico CMTA Branch

Eighteen people turned out for the February 7 visit of the CMTA's three representatives: Jeana Sweeney, Michelle Hayes and Tara George. Jeana Sweeney presented an excellent program, discussing CMT symptoms in

general, as well as all of the major types of CMT being covered by CMTA research and the research status of each one. Jeana also talked about the pros and cons of genetic testing, including the pro that knowing one's CMT type allows for inclusion in the registry at [rarediseasesnetwork.epi.usf.edu/inc](http://rarediseasesnetwork.epi.usf.edu/inc). Having more people with CMT in the registry may help with fundraising since people often donate to causes that affect more people. It was also noted that genetic test-

ing costs go way down when a person is tested for only one type of CMT. If it's known that a person in the family has 1A, for example, then others in the family need only be tested for that type. The next meeting of the New Mexico CMTA Branch is Saturday, May 11.

### • Research Triangle Area CMTA Branch

The RTP Branch challenged all other branches to a contest to see which one can raise the most money from its members for

## NEW BOARD AND ADVISORY BOARD MEMBERS

*The CMTA is happy to welcome new members to the Board of Directors and the Advisory Board, both of whom are related to current Board members:*

**CHRIS OUELLETTE** is the Executive Vice President of Operations and Service at Alpha Analytical, an environmental analytical testing laboratory in Massachusetts that employs more than 300 people. He has extensive experience in business operations, strategic planning, production and quality management, and executive leadership, and he plans to put it all to work for the CMTA. Chris's engagement with CMT began when his nephew Yohan was diagnosed with CMT1A in 2000. Chris's sister, Elizabeth, is Yohan's mother and Vice Chair of the CMTA Board. As a result, his focus is to proactively develop and support initiatives that will increase CMT awareness, enhance the everyday lives of those with CMT and someday find a cure for CMT. In 2014, Chris initiated the first annual Cycle 4 CMT event in Vermont, which raised more than \$70,000 in support of the CMTA's STAR program. His goal is to conduct this event annually, and he has a vision of taking it to a national level. Chris looks forward to actively supporting the ongoing fundraising efforts of the CMTA and all initiatives that complement the mission and vision of the association.



**AMY WARFIELD, PT, DPT, NCS**, is a physical therapist at the MedStar National Rehabilitation Hospital in Washington, D.C. She received her Master's Degree in Physical Therapy from Ithaca College in New York and her Doctorate Degree in Physical Therapy from A.T. Still University in Arizona. Amy is also certified by the American Physical Therapy Board of Specialties as a Neurologic Certified Specialist (NCS). She is an adjunct faculty member at the University of Maryland School of Medicine in the Department of Physical Therapy and Rehabilitation Science. Amy previously practiced clinically at the University of Rochester in New York and the Kennedy Krieger Institute in Maryland. In each clinical setting, she has enjoyed working with pediatric and adult neurologic rehabilitation patients at different stages of their care. Amy's husband, CMTA Board member Dr. Peter Warfield, and two of her three young children have CMT Type 1A. Watching her kids and husband struggle with the everyday challenges of CMT motivates Amy to make a positive difference in understanding the optimal management of CMT across the lifespan.



# CMTA MEMBERSHIP, PUBLICATIONS & ACCESSORIES ORDER FORM

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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
- Access to the CMTA's Online Community, including access to CMTA Branches and Discussion, Circle of Friends and CMTAthletes groups
- An information kit and a 10% discount at the CMTA store
- Bimonthly delivery of *The CMTA Report*, (electronic and/or hard copy)
- The *CMT Facts* series (electronic 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

CMT research. At its January meeting, the NC RTP Branch collected \$350 to be used for research. The RTP Branch brainstormed ways to help the CMTA raise awareness to about CMT. The huge success of the ALS "Bucket Challenge" was cited, and members were asked to come up with a challenge for CMT that can go viral.

#### • Dallas, TX CMTA Branch

The branch held a potluck meeting on January 17 with 25 members in attendance, including eight new members. They discussed the Dallas STAR Research Update to be held on March 21. They also shared stories and resources and talked about fundraising and a September Walk 4 CMT.

#### • Vidor, TX CMTA Branch

The Vidor, TX Branch held its inaugural meeting on Sunday, February 1. Fourteen people shared snacks and stories and discussed future guest speakers, including a physical therapist or occupational therapist. They also discussed the upcoming Dallas Star Research event on March 21 and plans for an Awareness Month walk, bike or swim. Members also took part in a raffle and two lucky winners went home with beautiful embroidered fleece throws that said "Charcot-Marie-Tooth: Funny Name....Serious disease."

#### • Southeast Wisconsin CMTA Branch

Eleven members of the Southeast Wisconsin Branch shared stories, encouragement and treats at a meeting at The Fine Art Gallery on January 31. Two new members traveled all the way from Green Bay. They shared gadgets and ideas that have helped them along their way. Thanks to a generous donation from one member, the group plans to mark September's awareness month with the lighting of the rings atop Mitchell Park Domes. ★

## JOIN THE CMTA:

<b>Subscription Membership</b> <input type="checkbox"/> \$30/year <input type="checkbox"/> \$80/3 years <b>STAR Membership</b> <input type="checkbox"/> \$100/year <input type="checkbox"/> \$270/3 years	<b>Choose your newsletter format</b> <i>(check one or both)</i> <input type="checkbox"/> PDF <input type="checkbox"/> Print				
		QUANTITY	COST		TOTAL
			Regular Price	STAR Member Price	
The Patients' Guide to Charcot-Marie-Tooth Disorders [CD Format]			\$10	\$8	
CMT Facts IV			\$10	\$8	
CMT Facts V			\$15	\$12	
CMT Facts VI			\$15	\$12	
My Child Has CMT			\$5	\$5	
Teaching Kids about CMT...A Classroom Presentation (DVD/1 hour)			\$10	\$8	
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		
Be a STAR Wristbands			\$1.50 each*		
Be a STAR Necklaces (Includes battery)			\$5 each*		
Washable CMTA Tattoo (Pack of 5)			\$1 per pack		
CMTA Pin			\$3 each		
CMTA Brochure & Neurotoxic Drug Card			FREE		
<b>Donation to the CMTA (100% Tax-deductible)</b>					
<b>Shipping &amp; Handling (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)</b>					
*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.)

Money Order                       American Express       MasterCard       VISA

Card Number: \_\_\_\_\_ Expiration Date: \_\_\_\_\_

**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)  
Gold salts  
Ixabepilone (Ixempra)  
Leflunomide (Arava)  
Metronidazole/Misonidazole  
(extended use)  
Nitrofurantoin (Macrochantin,  
Furadantin, Macrobid)  
Nitrous oxide (inhalation abuse)  
Perhexiline (not used in US)  
Pyridoxine (mega dose of  
Vitamin B6)  
Stavudine (d4T, Zerit)  
Suramin  
Thalidomide  
Zalcitabine (ddC, Hivid)

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

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

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

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

# THE CMTA Report

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.