

THE CMTA Report

JULY/AUGUST
2015

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

NIH Lab Tour Exhilarating, Exhausting

BY CLARK SEMMES

At a state-of-the-art laboratory in suburban Washington, D.C., a team of dedicated scientists, some of them hand-picked by the CMTA, is rapidly testing hundreds of thousands of drug compounds on tiny samples of CMT-impacted cells. The scientists work for the National Center for Advancing Translational Sciences (NCATS), in Rockville, Maryland, and they are in the process of identifying compounds capable of stopping the progression of specific types of CMT.

As the list of compounds that show promise as a possible drug treatment for each type of CMT is winnowed down, each candidate's characteristics are carefully examined, and some candidates are eliminated due to their toxicity, stability or other characteristics. Once a final



Robotics room at NCATS

handful of the most promising compounds is identified, animal and human trials can commence. FDA approval for a drug to arrest the progression of CMT1A is the CMTA's first goal, one that gets closer every day.

On a recent tour of NCATS, a group of CMT-

affected individuals and family members witnessed firsthand the remarkable technology and amazing individuals working around the clock to achieve the CMTA's long-sought-after vision of a world without CMT. The tour began with Dr. James

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NIH Funds INC for Four More Years

The National Institutes of Health in June announced \$5 million in renewed funding for the Inherited Neuropathies Consortium (INC) through 2019. The two funding agencies are the National Institute of Neurological Diseases and Stroke (NINDS) and the National Center for Advancing

Translational Sciences (NCATS). INC, which is also funded by the CMTA, is a member of the Rare Disease Clinical Research Network (RDCRN), which facilitates clinical research in rare disorders. INC is an international group of 17 sites, all of which are Centers of

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Charcot-Marie-Tooth Association

OUR MISSION:

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

OUR VISION:

A world without CMT.

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NIH TOUR

(continued from page 1)

Inglese, head of the Laboratory of Assay Development and Screening Technology at NCATS, who provided an overview of the lab's efforts to find a treatment for CMT. Before any compounds could be tested for their ability to arrest a CMT subtype, a model of that type of CMT had to be created, miniaturized and duplicated hundreds of thousands of times to create environments in which to place the candidate compounds. These environments are known as assays, and the center in Rockville partnered with STAR project team members at Dr. John Svaren's laboratory at the University of Wisconsin to create and test these assays. Because NCATS is part of the National Institutes of Health, a part of the federal government, these assays were then made available to CMTA partners interested in testing additional compounds for their ability to halt the progression of CMT. One lab that has taken advantage of this is Sanofi Genzyme, which recently completed testing the 1.9 million compounds in its library for their impact on the CMT type 1A assay.

Dr. Inglese has two post-doctoral students working with him, Trish Dranchak and Brittany Wright. While Trish, a tall blond woman of Russian heritage, focuses her work on finding compounds that impact CMT Type 1A, Brittany Wright, a dark, petite North Carolinian, focuses her work on compounds that impact CMT Type 1B. At our first lab stop on the tour,

most of us expected to see row after row of test tubes, similar to the ones we worked with in our high school chemistry classes. Instead, we were informed that test tubes were largely a thing of the past, replaced by "plates" that each contain more than a thousand "wells." In each well was a tiny sample of PMP22 (approximately 2,000 cells), the compound that is overproduced in people with CMT Type 1A. Each plate costs about eight dollars, a sum that seems trivial until you realize that the center uses thousands of them at a time.

The highlight of the tour was the robotics room. Here, in a glass-enclosed room the size of a semi-trailer, huge robotic arms move trays of plates, rapidly injecting compounds into their tiny wells. The speed with which this process is performed is mind-boggling, and the work goes on 24 hours a day. Managing the robotics during our tour was Pepper Bouney, a lean, heavily tattooed former bicycle mechanic whose skills and dedication mesh perfectly with this job's requirements. He says that working on high-end bicycles for 20 years was great training for the robots. Pepper is on call at all times and is frequently summoned by the robot at odd hours to fix minor snafus.

Once compounds are injected into the tray wells with their tiny samples of CMT, they must be observed to take note of their impact on the disease. This is accomplished through a luminescent "reporter" that is added to the well plates. When a compound impacts the CMT, the reporter begins to glow. Virtually undetectable by the human eye,

the amount of glow is precisely measured by more machines, which then generate spreadsheets of numbers for Trish and Brittany to analyze. Back in the lab, Trish and Brittany showed us a plate that demonstrated the various levels of light and dark that could be attained in the



Compound library at NCATS

wells on a plate. The shades of light and dark on this particular plate had been arranged to form a replication of a head shot of Pat Livney. It was an amazing demonstration of the sensitivity of the tools for measuring compound impacts.

After a full morning of walking all over the NCATS campus, those of us lucky enough to have taken the tour were physically exhausted but mentally exhilarated by the cutting-edge science and dedicated scientists working tirelessly to find a cure for CMT. For me, the tour served as a reminder of the level of effort and size of the costs needed to finally put an end to CMT. For my friends and my family, I took the opportunity to rededicate myself to raising funds to fight for a cure. I hope you will do the same. ★

INC FUNDING RENEWED

(continued from page 1)

Excellence (COE) within the CMTA.

INC's main goal is to measure how various forms of CMT progress over time so that it can determine with clinical trials whether the many exciting candidate medicines being developed by the CMTA alter disease progression. INC is currently building the infrastructure to test these treatments. Anyone who has been seen at a CMT Center of Excellence can help by returning for a follow-up visit as part of INC's natural history studies, which depend on knowing how different types of CMT progress over time.

The consortium also works to develop standards of care for patients with CMT in areas like surgery, exercise and genetic testing and to train the next

generation of CMT scientists and physicians.

INC also identifies new causes of CMT and works with patients in its Patient Contact Registry to ensure that measures of disease severity and progression are relevant to those who actually have the disease, not just the investigators studying it. Anyone who hasn't yet done so is urged to join the Contact Registry online at www.rarediseasesnetwork.org.

CMTA CEO Patrick Livney believes the INC database is critically important to complement the progress and promise STAR holds for an eventual therapeutic. "We need to identify everyone with CMT and know the type they have for eventual clinical trials," Livney said, noting that follow-up visits are critical to map progression of the disease.

Dr. Michael E. Shy, INC's principal investigator, said he is

proud of the consortium's accomplishments in its six years of existence, including the recruitment of more than 7,200 participants into its various protocols, more than any of the other consortia in the history of the RDCRN. According to Shy, INC has published over 160 manuscripts on various aspects of CMT, including various outcome measures used around the world to measure disease severity for adults and children with CMT. It has also identified more than two dozen new forms of CMT and trained a number of young investigators.

Nonetheless, Shy points out, INC still has a lot to do as there are as yet no cures for CMT. Shy thanked the CMTA "for being such a great patient advocacy group" and says he looks forward to continuing the work to develop and test treatments for patients with CMT. ★

CMTA Adds 13 New Branches to Family Tree In First Half of 2015

The CMTA's Community Services team has been on fire this year, establishing 13 new branches in 11 states and bringing the total number to 82.

On the West Coast, the CMTA's own Sharon Bello started up the North Bay Area, CA CMTA Branch in June, giving us two branches in the San Francisco area. Grants Pass, Oregon, also came on board in June, doubling the number of branches in that state.

In the Midwest, there are new branches in Louisiana, Greater Minneapolis, Central Minnesota, Central Alabama, Northern Iowa, and the Ashland, Kentucky Tri-State area, encompassing parts of Central Tennessee, Southern Kentucky and West Virginia.

On the East Coast, there are four new branches—one in Buffalo, New York; one in Harrisburg, Pennsylvania; one in Chester County, Pennsylvania; and one in Chesapeake, Virginia.

The CMTA welcomes all its new branches, branch leaders, and members to the fold. The CMTA couldn't do what it does without them!

If you are interested in starting a branch in your area, please contact Jeana Sweeney at jeana@cmtausa.org.



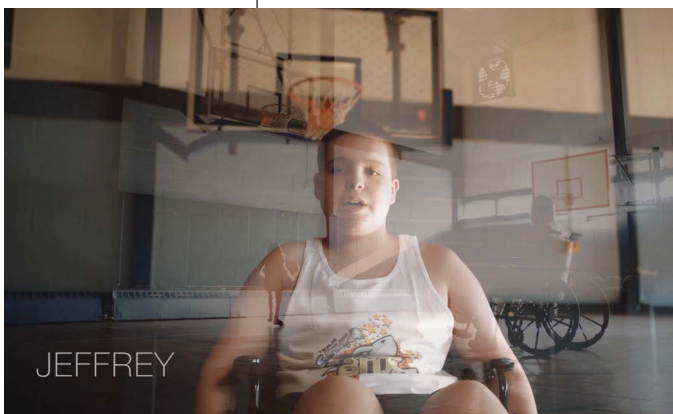
The Making of a Public Service Announcement

BY BOB DEROSA

If you've ever wondered what goes into making a television spot, then wonder no more. Sixty seconds goes by fast, and you'd be surprised how much goes into creating and producing a broadcast spot. I'd like to take you on a journey of what's involved.



RYLEE



JEFFREY



ALEXANDRA

The CMTA recently produced a PSA with a grant from the state of Pennsylvania. The CMTA, and Jeana Sweeney in particular, worked hard to secure the grant and asked if I would help develop an idea for the spot. There were some requirements we had to follow, in particular that the PSA couldn't solicit donations.

THE IDEA: Brainstorming led to a consensus that we would base our story on the CMTA's wildly successful shark T-shirt graphics. But how? By carrying a common theme throughout all the scenes—that everyone who has CMT has felt the bite of Charcot-Marie-Tooth. We wanted to be authentic, so all of the individuals we used have CMT. We wanted diversity, folks of all genders and ages. We wanted it to be serious and passionate, sympathetic but not saccharine. We wanted to show real people not letting the bite of CMT prevent them from leading their lives their way. We used many close friends from the CMTA community in New Jersey. They weren't just good—they were amazing. And why wouldn't they be? They live their lives with CMT—Courage, Motivation and Tenacity, to quote Tampa Bay Area, FL Branch Leader Ed Linde.

THE SCRIPT: We came up with a script that required no teleprompter, relying on the passion in our actors' eyes and the conviction in their voices. The line

was "I felt the bite at age___." Every scene had a shark in it—a subtle but strong reference to the payoff and the name Charcot-Marie-Tooth. Repetition in the dialogue and a visual of the shark establishes a strong connection to the viewer, who wonders "What Bite?" Who are these diverse people and children, and what is this all about? This is called a misdirection. When timed and executed properly, it locks the audience in and they are compelled to stay tuned for the payoff. When watching the spot, take notice of the subtle references to the CMTA—the basketball and golf shirts, the close up of the golfer's wristband, and the shark pointing towards the CMTA logo.

THE SETS: We used three locations and five sets for the 30- and 60-second spots, all shot in one day. The golf scene was challenging. We don't really have green golf courses in January in New Jersey. The solution was a golf simulator environment. First we went to Dicks Sporting Goods. They told us to write to corporate. Corporate wrote back and said we had to arrange at the store level. Finally, a terrific young lady at the Wayne store arranged for us to shoot at 8 a.m. on a Saturday.

The basketball scene was next up. With youth leagues everywhere, getting a court on a Saturday morning was nearly impossible. We first tried the YMCA in Passaic, New Jersey,

where I worked out when I was young. It wasn't a great neighborhood then, and it's even seedier now. But we needed a location and since our event was during the day, we figured we'd be OK. Fortunately after more scouting, the Boys and Girls Club of Garfield came through for us. The shot took two hours and we were out before bingo started.

The bedroom scene, living room scene and paint studio were all shot at my close friend Angelo's photo studio. We built each set in the same day.

There are many generous people and businesses out there. Every place gave us their facility for free.

THE PROPS: The golf shirts and basketball jerseys were printed with the shark logo. The toys

were purchased as props. The bed was actually an air mattress. We built the French doors and hung curtains. The painting was a canvas print that we painted over.

THE SHOOT: Everyone involved worked tirelessly, including the crew, which did the job for a fifth of the first estimate. It

You can view the spot at
www.cmtausa.org/psa

started with a pre-shoot meeting on Thursday. I met with the film director, head of photography and his assistant. They were totally in sync with the creative vision of the spot.

We started Saturday morning at 8 a.m. and ended at 7 p.m. The team consisted of me, Jeana, the director, the videogra-

pher, his assistant, lighting director, sound director, the first grip, and our talent.

POST PRODUCTION: With more than 200 voiceovers to choose from, we carefully selected the one to close out the spot. After a few rounds of viewing, pace, scenes, voice and music, we had our PSA.

Quite a production, but the success of any spot doesn't rely solely on the idea. It takes many individuals committed to telling their stories. It also takes the passion and commitment to do the very best in what you believe in. That part was easy. Just being around people with CMT and seeing their courage, positive attitude, kindness and energy makes you want to do it all again. And, we will! ★

PATIENT/FAMILY CONFERENCE COMING TO CHARLOTTE, NORTH CAROLINA

The CMTA will hold a half-day Patient/Family conference in Charlotte, North Carolina, on Saturday, September 19, 2015. The conference will take place from 9 a.m. to 1 p.m. at the beautiful Harris Conference Center at 3216 Cpsc Harris Campus Drive, Charlotte, NC 28208.

Patrick Livney, CEO of the CMTA, will kick off the program with some exciting research news, followed by presentations from some of the most prominent minds in the fields of CMT research and treatments, including Steven S. Scherer, MD, PhD, professor of neurology at the University of Pennsylvania.

This event provides a tremendous opportunity not only to hear but to interact personally with these experts. Registration is just \$30 per person (non-refundable) and includes a light breakfast beginning at 8:00 a.m.

Don't delay. Register now for this informative and interactive conference. You can do so online at www.cmtausa.org/nc-pf or you can mail a check made payable to the CMTA with "Charlotte, NC PFC" in the memo line. The deadline for registration is September 5.

Discounted rooms are available at the Sheraton Charlotte Airport Hotel, 3315 Scott Futrell Drive, Charlotte, North Carolina 28208, located just 1.5 miles from the Charlotte Douglas International Airport, with a 24-hour complimentary airport shuttle. To reserve a room at the discounted rate of \$142, call 1-800-325-3535 and mention "CMTA." Reserve by August 16 to ensure the discount.

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.

Monthly Giving a Commitment, Not Just a Convenience

People who make monthly donations to the CMTA don't do it just because it's convenient. They don't do it because it saves them a stamp or because it helps the CMTA budget its resources and expenses more effectively, though those are all good reasons. People who make recurring donations to the CMTA do it because they are committed to its mission of eradicating CMT. They do it because they know that they are investing in their own futures

and those of their own children and grandchildren.

Marilynn Dodge has been making monthly gifts to the CMTA since 2008. She retired from her career as a legal secretary 19 years ago and moved from Southern California to Washington State. Even though she's on a fixed income, Marilynn budgets for a donation to the CMTA each month. She says she finds it easier to take a little bit out when she has it rather than save up. Giving a gift

of \$20 a month is much easier than writing a check of \$240 at year's end.

The world would be a better place if there were more people like Marilynn. "I believe we've all been taking from the world since the day we were born," Marilynn says, "and if everybody keeps taking and no one gives anything back, we're going to empty it."

Marilynn, who has CMT, but isn't sure of the type, knows that her monthly giving puts her

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squarely on the CMTA's research team. "I know I'll never be a doctor but I can help find a cure for CMT," she says, adding: "I wish I had a million dollars I could give to you guys."

Karen Kukwa from Ohio is another monthly giver. She says she invests in the CMTA monthly because while a treatment may come too late for her—she underwent a below-the-knee amputation due to a failed right-foot fusion in June—she thinks it may come in time to help her 23-year-old daughter, who also has CMT1A.

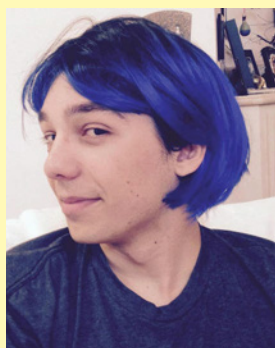
Like Marilyn and so many other CMTers, Karen's attitude toward life is an inspiration. She isn't going to let the amputation stop her from helping the CMTA. She told her physical therapist before the surgery that she has to be ready to go with her new prosthetic by September when she plans to join the Northeast Ohio Branch in its Walk4CMT.

When Christine Helmke's 37-year-old daughter was first diagnosed with CMT1A 20 years ago, there was virtually no information about CMT, she says, and even less hope. Today, by contrast, Christine's 6-year-old granddaughter Ava already goes to physical therapy regularly and wears braces, treatments that will help her maintain her mobility. The family's monthly donation is "just part of our expenses," Christine says, adding that she's "very hopeful for the future."

To make a monthly investment in hope for your future, contact CMTA Finance Director Kim Magee at kim@cmtausa.org or 1-800-606-2682, ext. 105. ★

CMTA SUMMER INTERNS RAISE FUNDS, AWARENESS FOR YOUNG PEOPLE WITH CMT

The CMTA's two summer interns have hit the ground running. Both were tasked with increasing youth participation in the CMTA, and both are doing just that.



Yohan Bouchard, a rising senior at Pitzer College, is working on an initiative called Go Blue for CMT. He promises to dye his hair blue if he gets \$5,000 in pledges for STAR research and he is daring others to do the same. In just a couple of weeks, Yohan raised \$1,082 toward his goal. He says the prospect of going back to college with blue hair is a bit daunting, but he isn't letting that stop him. To ensure that Yohan goes blue, visit www.firstgiving.com/CMTA/GoBlue4CMT.

Yohan is also working on a College Survival Guide for young adults with CMT, aimed at helping them with the difficult transition from being dependent on their parents to living semi-independently on a campus. The guide will outline all the basics needed as students begin that transition, from how to get around the campus, how to work with their schools and finding out what resources are available.

Rebecca Silverman, a rising junior at the University of Wisconsin-Madison, is also working to raise youth involvement in the CMTA. She created and is managing the Instagram account for the CMTA, @cmtausa, where she's posting pictures of young people with CMT, CMT events nationwide, and information about CMT and the CMTA.



Rebecca will also be sharing these posts on the CMTA Youth Facebook page and assisting in managing that page in order to facilitate conversation in the group.

Rebecca is also planning fundraising events targeted at college students in Milwaukee and Madison.

Rebecca says that witnessing firsthand the focus, determination and passion of the CMTA staff has left her more optimistic than ever that the CMTA will reach its vision of a world without CMT.

Stranger in a Strange Land: A Trip to the Iowa CMT Clinic

BY SHARON BELLO*

Gatherings with my family members are often filled with raucous laughs and jokes. The evening before our visit to Dr. Michael Shy's CMT clinic in Iowa City, Iowa, was no exception. Musings about our family band being named "The Hammertoes." Dramatizations of how suave and sexy the guys are when sitting on exam tables without shoes, socks, or braces while their feet dangle. Parodies of the "joys" of nerve conduction testing. Mock "tantrums" of "finally having enough" and throwing diagnostic equipment off of the table, then storming out of the clinic.

My brother, mother, aunt and cousin had been to Dr. Shy's clinic before and weren't nervous. Their moods were light as we arrived, and they hugged Dr. Shy and genetic counselor Shawna Feely like old friends. Me? I was a nervous wreck. While I've worked for the CMTA since January 2015, I'd never before visited a clinic or seen loved ones poked and prodded in the name of medicine. As it turns out, I had nothing to be nervous about. The day, the experience, the time spent with my family and the amazingly cohesive team in Iowa was intense, but it was also touching,



Dr. Michael Shy testing the upper arm strength resistance of the author's brother

educational, meaningful, motivational and even fun.

The day flowed like a round-robin. One person's vitals and meds were checked while another was in with the physical therapists, a third was with the occupational therapist, and the last was doing nerve conduction.

I was intrigued by the symptoms my family members reported. I live across the country from most of them, and our conversations revolve around subjects like work, kids and hobbies. We rarely speak about CMT and how it affects their daily lives. In this setting, though, I heard about my cousin's back pain and my brother's very cold hands (this from the guy who's seemingly never cold, and keeps his thermostat below 65 in the winter, even

during the day). He also reported increasing difficulty with typing. Stairs are the biggest challenge for my aunt, who also wondered about mobility with the hinged versus non-hinged brace. My mother's problem area is balance. I found it fascinating—four different people all with the same type of CMT (X) and very different gripes, concerns, symptoms and issues.

I accompanied my brother to his

physical therapy evaluation, where his therapists questioned him about his physical activity, strength training, balance and tripping. They suggested (as they did for everyone) modified yoga, tai chi and weight training. As he always does, my brother used humor to diffuse an awkward situation, telling them: "Must be a thrilling part of your day and job to be able to examine my feet" as they both knelt on the floor and poked and prodded his feet with their thumbs. I also witnessed my mom taking a nerve conduction test, watching her get "zapped" repeatedly in the wrist and elbow region, twitching as the technician increased the intensity but showing no signs of discomfort in her facial expressions. Throughout

*Sharon Bello is the CMTA's conference planner and self-proclaimed lead singer of "The Hammertoes."

the morning, I felt melancholy at times, the reality of their situations weighing heavily on me. I felt awkward too, as if I was a voyeur, intruding just by being there even though I'd been welcomed to "experience it all" with each one of them.

After lunch, Dr. Shy gathered everyone together and ran through a battery of tests with continuity and fluidity. He started with a thorough question-and-answer period about everyone's symptoms and health issues since he'd seen them last. Hands-on diagnostics followed, including motor function and sensation testing. With his eyes closed, my cousin couldn't tell if his toes were going up or down. My brother couldn't feel the pin prick until it reached his ankle. My aunt wasn't sure about the intensity of the tuning fork. No one could touch thumb to pinkie and my brother had little reaction to the knee reflex test. Their struggles with seemingly simple tasks that I take for granted provided me with a glimpse of living with CMT.

Fine motor testing involved grabbing 20 small plastic pegs from a slippery plastic dish and putting them into holes in the dish's other side and then returning them. This is about the time I started to lose it. Jokes and light-hearted moods aside, it's simply heart-breaking watching people you love struggle to pick-up a peg the diameter of a pencil and half the length of a golf tee. It took most of them a long time. Pegs fell to the floor and rolled around the table. Finally, knuckle joints and the sides of thumbs were used to pick them up one by one and

put them into the holes. There was a palpable sense of relief in the room as each person completed the test.

Everyone did very well on the hand grip strength test and the pincer test, in which the forefinger and thumb press a sensor to detect and measure strength and pressure. Only my mom, though, was able to place her thumb in the correct position on the sensor without using

her other hand to help put it in place. Try to picture it: Not being able to move your thumb in the way you want, not being able to just turn your hand over into a desired position.

And then—the dreaded gait observation. Maybe it was the time of the day. I might have been overly tired or perhaps I'd been holding everything in. But watching my brother stand

(continued on page 11)

CMT PROJECT WINS A FIRST IN FIFTH-GRADE SCIENCE FAIR

The CMT community just may have a new scientist on its already crack research team. Maddie Leard, 11 years old, won first place in the health category at the Northland Christian School Science Fair in April.

Maddie understands the importance of awareness, even at her tender young age, and says that she hopes her project will demonstrate to people with CMT just how important it is to stretch—if only for a little bit each day.

Maddie structured the experiment around her hypothesis that daily stretching improves flexibility in patients with CMT1A. Maddie, who has Type 1A, goes to physical therapy every two weeks, and tries to stretch daily. She also wears splints at night that stretch her feet and legs.

There were two participants in the study—Maddie and CMTA Development Director Susan Ruediger, who also has Type 1A. Over a 12-day period, each did three pre-determined leg and foot stretches. They did the three stretches three times a day for two days, then measured their ankle/foot flexibility with a goniometer, a device similar to a protractor that measures a person's degree of flexibility. Each kept track of her own ankle flexibility.

After two days of stretching, they rested for two days and again measured the ankle flexibility with the goniometer. This was repeated three times for a total of 12 days. Both Susan and Maddie had improvements in their flexibility with stretching. Going just two days without stretching resulted in tighter muscles and less flexibility.

Congrats to Maddie on the win—and thanks for the valuable lesson!



Balance with Benefits

DR. JOSEPH GREGORY STILWELL, DPM, FACFAS

Imagine being a four-legged animal, using Nordic walking poles to prowling city streets with the strength and balance of a big cat on a savannah. Now imagine using Nordic walking poles to participate in yoga and Pilates. Imagine walking outside, breathing deeply, chest wide and spine lifted tall.

Exercise walking? Some of us just want to increase our confidence on stairs, step gracefully over a curb or get help with a weak ankle or painful back. Nordic walking poles have a patented three-piece strap that allows the user to open the palm of the hand and push downward into the poles, lifting the rib cage and giving the lungs plenty of room for expansion. A whole hour can be spent using the poles for bending, stretching or squatting—all exercises that help with balance.

Those of us with Charcot-Marie-Tooth disease are used to walking a little differently. We may “lurch” when fatigued, the result of our upper bodies favoring one side or another as we walk. With a set of walking poles, though, we become rhythmic, smooth and mostly pain-free. While few of us can achieve the physical therapists’ ideal of symmetry between the

two halves of the body, with walking poles we can function as if our length, strength and flexibility were equal throughout our bodies.

Walking poles offer people with CMT not just a way to get and stay fit, but also a training aid for walking and balance. Medical studies on “pole walking” uniformly show better breathing, less stress on joints, and other significant advantages over running, including more calories burned in less time. In a related note, evidence has been mounting that using a tempo like a simple musical rhythm helps with neurological re-training. Walking with poles at a basic metronome-like pace results in smoother nerve conduction. For urban or hard surface walking, a rubber tip can be placed on the end of each pole. This allows one to truly push into the pole, lift the spine and propel the legs forward. These high-traction rubber tips help keep one from sliding when performing a leg up stretch or pushing the body into a lifted twist using the arms and shoulders.

The beauty of using two



CMTA Advisory Board member Dr. Greg Stilwell demonstrating his Nordic walking stance

Nordic-style poles when walking is that as your legs get tired and foot drop or ankle rolling gets worse, the poles can be “push-pulled” to use the stronger muscles of the shoulders and trunk to take stress off the tired legs and feet. Plus, you can always stop and do some stretches, deep knee bends or twists with the poles to bring a spring to your step.

My wife and son and I recently pole-walked through the Loop area of Chicago. It was a joy to be able to gaze upward at the tall buildings with confidence that our poles would keep us upright, stable and able to lean back to peruse the beautiful architecture. The same technique works in wooded areas or parks where we can admire the tree tops, listen to nature’s sounds and even muse at the clouds—much like being a kid again.

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

Interested in implementing Dr. Greg’s recommendations and getting Nordic fit? Balance Walking will donate \$30 to the CMTA for each set of poles sold. The CMTA and your body will both thank you! Visit www.balancewalking.com and enter the coupon code “CMTA” to get started! A free motivational book is included in your order.

In shopping for poles, the choice is among one-, two- and three-piece poles. The cheaper poles (under \$50) are probably not worth the price, unless one just wants a quick trial of the technique. Opt for the true Nordic poles with the fancy Velcro wrist strap. I find that my one-piece carbon fiber poles bend more easily when I really need them to stabilize or lift me. Adjustable multi-piece poles are easier to transport, but check for a reputable brand with good-quality locks on the adjusting mechanisms. I have not personally seen anyone injured with a collapsing pole, but one should always be on high alert for such a travesty.

To learn to use poles, Foot Solutions Inc. has a Nordic walking program called Balanced Walking, which offers incentives for those wanting to teach pole walking and earn money selling walking poles and accessories. (Many of the videos online show relatively healthy people walking at a rather fast pace with poles, but these techniques may be too advanced in the beginning for anyone with CMT and associated musculoskeletal conditions.)

There are dozens of wonderful teachers of Nordic walking across the United States, but nowhere near enough to meet the demand of the CMT population, much less those looking strictly for fitness or weight loss. It usually takes three hour-long sessions to become a “pro,” walking with ease and grace and utilizing the poles to stand tall and swing the legs smoothly. ★

VISIT TO IOWA CLINIC

(continued from page 9)

there, pant legs rolled up, waiting for the “OK, go” signal from Dr. Shy, I was a goner. Why, you ask? The legs. They’re just legs, but suddenly I was crying. Perhaps it was their thinness, or their lack of muscle tone. Maybe it was how delicate they seemed. It might have been my over-protective little-sister instinct coming to the forefront. But, suddenly, I was crying. My brother caught sight of my moist eyes and later apologized to me saying “I’m sorry that was hard for you.” Wait, what? You’re apologizing to me?

Desperate to change the mood, my cousin and I ran to the nerve conduction room and asked the technician to give me a “zap.” She complied, though I’m sure she thought we were insane. With the most stoic expression I could muster, I sat through her “normal strength” pulses. While it didn’t hurt, I wouldn’t wish repeated doses of this on anyone.

The orthotist was the light at the end of the tunnel. He tweaked my cousin’s brace, recommended that my mom try one with the post on the other side and suggested one without a hinge for my aunt.

Finally, Shawna and Dr. Shy gave summaries and neuropathy scores. The scores run from 1-36, with the higher numbers representing more severe symptoms. My family’s scores varied, but none was more than one or two points higher than the previous exam almost four years ago. The good news was that no one’s symptoms are expected to

get much worse. The other news was that aging can exacerbate things.

Tired, yet grateful and ready to tackle the world, we hugged the entire staff goodbye. That evening was filled with what you’d expect from a close family. We ate, we talked, we laughed and we reminisced about the day and about life with CMT. But something felt different to me. The already strong bond I had with these people was even stronger. The love I felt for them was deeper, which I wouldn’t have thought possible. The passion I have for contributing to the efforts being made to find treatments and an eventual cure was even more intense.

As someone who doesn’t have CMT, but whose family members do, I can’t tell you the value of this experience. What for me was a once-in-a-lifetime experience is something they’ll have to go through time and again. It left me more determined than ever to fight for them, advocate for them, and try to raise funds for them. And for you. I’m doing it for you, too. Thanks for reading. ★



The author’s cousin sporting CMTA Blue toenails during his tuning fork test

NEW CMT1A CHALLENGE GRANT:

The End of CMT Begins with You!

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.

When this family's young son was diagnosed with CMT1A in 2010, they quickly joined the CMTA to connect to the community and get information about CMT. They also invested what they could to help find treatments for CMT.

A few years later, they asked a generous friend to consider a donation to the CMTA. After due diligence and a conversation with CMTA CEO Patrick Livney, the friend challenged the CMT community to match his \$500,000 gift. These generous, dedicated and passionate supporters know that CMT will be treated and ultimately cured

through funding the CMTA's STAR research efforts.

The chart on page 13 details those efforts and the extraordinary progress made in just 48 months. In 2012, the CMTA's 1A project team had developed a cell assay and had one compound candidate. The team had also hypothesized the incorporation of an adult human stem cell pathway into STAR. Fast forward to 2015 and the CMTA has screened 2.4 million compounds with an improved state-of-the-art cell assay, has four compound candidates being tested in models, has implemented an adult stem cell pathway for assay development, has banked adult skin and blood cells, has developed adult human stem cell lines, and has two robust lab models validated, licensed and in use for drug testing.

In the immediate future, funds are urgently needed to

prepare for clinical trials for CMT1A. Specifically, researchers need to develop tools to measure improvements in pathology and/or symptoms of CMT in future human trials of lead candidates and to demonstrate the success of any potential treatment. Researchers also need to develop biomarkers to measure the down-regulation of PMP22 in context to ensure selectivity of the potential compound.

If you are interested in CMT1A specifically, or if you hope to see treatments for all types of CMT, now is the time to give. Double your donation by giving to the CMTA today. If your company matches your gift, you will triple your impact to STAR!

HOW CAN YOU GIVE?

- Donate online at www.cmtausa.org/1A.
- Call Kim at 610-499-9264.
- Send a check to the CMTA, PO Box 105, Glenolden, PA 19036.
- Ask your friends and family to get involved, as this family did.
- Plan an All-Star event to raise funds for the match (see box at left).

If you have questions about this match or the STAR initiative, please contact Susan Ruediger at 678-595-2817 or sruediger@cmtausa.org.

Let's meet the challenge and turn this generous donation into \$1 million to benefit the CMTA's CMT1A research effort! ★

IT'S COMING! THE CMTA ALL-STAR WILL BE HERE BEFORE YOU KNOW IT

The CMTA All-Star is a coordinated set of events during September 2015, when people will walk, cycle and swim "4CMT!" These events, which will be held nationwide, will bring us together to raise awareness of CMT and funds for CMT research. During the month-long CMTA All-Star Event, you and others in your community can come together to raise critical funds for the CMTA's drug discovery program, STAR. Every dollar raised will go directly to CMT research.

To find a CMTA All-Star event near you, go to www.firstgiving.com/CMTA.

If you don't see one in your community, contact Jeana Sweeney at jeana@cmtausa.org to plan event in your area.

Are you ready to make a difference?

Then save the date and get ready to Walk4CMT, Cycle4CMT or Swim4CMT this September!



STAR RESEARCH

Advances in Drug Discovery

2012

2015

**TYPE
1A**


- Developed cell assay
- 1 compound candidate
- Hypothesized an adult human stem cell pathway
- Adequate lab models



- Screened 2.4M compounds with improved cell assay
- 4 compound candidates
- Implemented adult stem cells pathway
- Banked adult skin and blood cells
- Developed adult human stem cell lines
- 2 robust lab models validated, licensed and in use for drug testing

**TYPE
1B**


- No discussion or assets



- Protocol developed
- Hired post-doc at NIH/NCATS devoted to 1B
- Cell lines and assays under development
- Adult human stem cell lines under development
- Lab model under development

**TYPE
1X**


- Planned to test stem cells in lab models



- Tested stem cells in lab models
- Results under review
- Adult human stem cell lines under development
- Plexikon engaged in testing compound in vivo

**TYPE
2A**

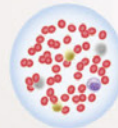

- Struggled to develop lab models
- Hypothesized role of MFN1 and MFN2 cause of disease



- Validating genotypic lab models developed for 2 mutations
- Validated role of MFN1 and MFN2
- Cell assay under development
- Adult human stem cell lines under development

**TYPE
2E**


- No lab model
- Protocol proposed



- Validating genotypic lab model
- Aggregation proven in actual cells of in vivo model.

**TYPE
4**


- No discussion



- Under discussion with translational project to be approved
- Team identified

Pharmaceutical Partnerships

Sanofi/Genzyme, Pfizer, NIH/NCATS, Plexikon, Addex, Affectis, Psychogenics, Isis Pharmaceuticals, New York Stem Cell Foundation

Oxford Biathlon Plus Raises \$90K for CMTA

BY STEVE O'DONNELL

Despite earlier forecasts of rain, Saturday, May 30 turned out to be a picture-perfect day in tiny Oxford, Maryland. Under a cloudless blue sky, 84 participants ran, walked, swam, and rolled for CMT in the 2015 Oxford Biathlon Plus, raising \$80,000 in the process.

The festivities kicked off at 9:30 a.m. A Coast Guard vessel closed the river and boats and kayaks kept watch as a team of 12 CMTA swimmers were ferried across the sparkling waters of the Tred Avon River, then swam back. Led by co-organizer Steve O'Donnell, this year's swimmers included Portland, Maine, CMTA Branch Leader Mary Louie, Sean O'Donnell, Jaime O'Donnell, Stuart Gray, Carter Gray, Alex Koff, Beth O'Connell, Robert Carter, Thomas Haslach and Bruce Matthai.

After a quick change of clothing, an awards ceremony, and optional ice cream consumption, swimmers peddled or drove through downtown Oxford to arrive at the Mast-



CMTA swimmers emerge from the Tred Avon River.

head, a waterside eatery. Here, scores of volunteers, including co-organizer Missy Warfield, the CMTA's own Jeana Sweeney, her husband Chris Sweeney, Silent Auction Czarina Marilyn Mann, and many others registered participants and distributed T-shirts like a well-oiled machine.

With a police escort waiting, 25 bikers, including co-organizer Clark Semmes, headed out onto Oxford Road at 11 a.m., just as an army of 42 walkers marched off for their own events.

The entertainment arrived around noon in the form of a handsome and talented ensemble called the Free and Easy Band.

Burgers, crab cakes, and southwest chicken salads began flowing shortly thereafter. The bike pack had a great time pedaling the back roads of Talbot

Next year's
Oxford Biathlon
Plus will be held
on Saturday,
May 21, 2016.

County, and through the major urban centers of Royal Oak (population 808) and Bellevue (population 612), culminating in a ferry ride back to Oxford. Special props to Sag Wagon Mistress Jeannine Mjoseh, photographer Steve Hilmy and 11-year-old cyclist Mason Weiss for his amazing, "never-say-die" attitude on the ride.

Back at the Masthead, the party kicked into full gear around 1 p.m., with many folks enjoying the opportunity to speak directly with CMTA CEO Patrick Livney and bid on a wide array of silent auction items that included yoga instructions, a crab feast, and Baltimore Ravens tickets. ★

The CMTA 25 head out on Oxford Road.



STEVE HILMY

CMT-PROOFING THE BATHROOM

BY GARY SHEPHERD, NEW MEXICO CMTA BRANCH LEADER

Most of us CMTers don't have the best balance, especially when we are barefoot. This means that the bathroom can be a troublesome or even dangerous place unless we have "CMT-proofed" it for convenience and safety.

THE TOILET: Although you probably can't tell from the photo, the pictured toilet is a "high rise." You would be surprised just how much that extra three or four inches of height can help. It is also an "eco-flush" or "jet flush" and uses much less water than older style toilets. This unit was about \$350 installed, but many municipalities will give you a credit on your water bill when you install an eco-friendly unit. If



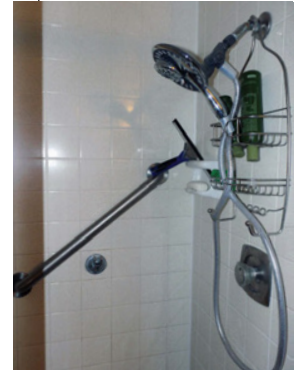
replacement of an old-style toilet is not feasible, you can get elevated toilet seats at a medical supply store to raise the seating position. The side handles are a recent addition, one I put in after a knee surgery. Even though they are no longer needed for that reason, I still find the side handles to be convenient and have kept them. They are also available from medical equipment stores.

THE SHOWER OR TUB: It's really important that you CMT-proof this area. I was fortunate that my bathroom already had what is called a "Roman shower," which is really just a shower stall but is the same size as a standard bathtub. A shower seat is really a help so you don't have to risk

standing/slipping. But in any case be certain to have at least one grab bar installed (or even more if you need them). This particular showerhead is nice because it is a handheld with a spray ring that can work together or separately.

TOWEL RACKS: Consider replacing regular towel racks with grab bars where they would prove helpful. They still work as towel racks but will provide you with another place to grab hold as necessary. I replaced all towel racks with grab bars.

You may have to spend some money to CMT-proof your bathroom but I guarantee that it's worth it. If you have additional tips to offer, please share them with me at gary@shepdesignassoc.com. ★



Showerhead and towel rack in author's bathroom

THE CMTA ANNOUNCES THE 5TH ANNUAL "I'M A STAR!" / "I'M A SHOOTING STAR!" CONTEST

Everyone with CMT is a special individual. Each faces daily challenges that people without CMT can't begin to imagine. Do you know an extraordinary person living with CMT? Please share that person's story with us and he or she may be selected as the recipient of the Fifth Annual "I'm a Star!" Award (ages 18 and up) or the "I'm a Shooting Star!" Award (ages 10-17).

In 500 words or less, please tell us about your extraordinary individual. How old was that person when he or she was first diagnosed? What type of CMT does the person have? How does living with CMT affect his or her ability to have a full and rewarding life? What does that person do to rise above disability and prove his or her abilities on a daily basis? What does that person excel in?

Any additional information you can provide about the person such as family life, community involvement, mentoring, sports, hobbies, and interests will all be considered in the selection of our winners.

You can submit your entry by emailing your submission to: info@cmtausa.org or by mailing your entry to: CMTA Extraordinary Person, c/o CMTA, PO Box 105, Glenolden, PA 19036.

**All entries must be submitted or postmarked by midnight, August 23, 2015.
Winners will be announced during Charcot-Marie-Tooth Awareness Month, September 2015.**

This contest is sponsored by the CMTA.

Regrettably, CMTA employees and Branch Leaders and their immediate family members are not eligible for participation in this contest.

Yoga Instructor Proud to Bare Feet, Teach Others to Do the Same

BY CLARK SEMMES

Growing up in Michigan, Chelsea Singer did not realize her feet were misshapen. She thought she was just growing faster than everyone else. She wasn't diagnosed until the age of 11, when her mother underwent foot surgery for her own CMT. Chelsea's struggles with CMT were compounded by watching her mother succumb to a pain pill addiction, and she left Michigan at the age of 15 for a new life in Colorado.

While still in her teens, Chelsea opted for surgery to ensure she would not end up in pain like her mother. Chelsea planned to have surgery on her left foot first, then her right. The surgery included straightening her toes, correcting her bunions,

having a screw inserted into her ankle and cutting her heel cords. Despite the fact that cutting the heel cord was the only really successful aspect of the first surgery, after three months of recovery she felt physically and mentally strong enough to have the same procedures done on her right foot.

While the surgery on her left foot was not a complete success, the surgery on her right foot was a downright disaster. Chelsea recalls screaming in pain as the doctor unwrapped her bandages at her post-surgery appointment. Everything from her right knee down was black. Four emergency surgeries followed, and Chelsea twice almost had her right foot amputated.

Finally a long hospital stay and the application of leeches on her toes (a new leech every 45 minutes for an entire week) brought circulation back to Chelsea's toes and she managed to keep both her feet, but the experience left her mentally scarred and physically weakened. At the time of her discharge, she was unable to stand on her left leg for more than a few seconds at a time.

Bedbound for almost three months, Chelsea grew depressed and nearly suicidal. When she finally regained her strength, she resolved to leave the cold behind forever and moved to St. Petersburg, Florida. While she was able to leave the weather behind, she could not do the same with her own physical and emotional



Certified yoga instructor Chelsea Singer

trauma. Hospitals and even medical commercials filled her with anxiety. Eventually she was diagnosed with post-traumatic stress disorder (PTSD) and began getting counseling.

Chelsea reluctantly tried her first-ever yoga class at the age of 26. While she initially thought there was no way she could handle it, Chelsea quickly discovered she loved yoga. Within the year, she was in a teacher training program and is now a nationally certified instructor.

Chelsea's yoga practice focuses on the meditative aspects of yoga, including visualizing energy, breathing and healing energy. She teaches many classes, including a free one sponsored by the Muscular Dystrophy Association, and finds it a blessing to do something she loves that is also good for her. Today Chelsea meets lots of people with CMT and has even made DVDs for people who cannot attend her class in St. Petersburg.

One of the things that Chelsea feels best about is teaching others not to be ashamed of their disability. She remembers when she was unwilling to let anyone see her bare feet, and now she's barefoot most of the day. Chelsea looks forward to reaching an even larger audience with her message of yoga's healing powers. She has formed an informal support group with her friends Tia and Elisa that they call the CMT Sisterhood. They meet once a month and the group has now grown to seven.

Namaste, Chelsea and the CMT Sisterhood! ★

DISABILITY BASICS

BY DEANNA POWER, COMMUNITY OUTREACH SUPERVISOR,
DISABILITY BENEFITS CENTER

If CMT, its symptoms, and/or pain associated with the condition keep you from working, you may be eligible to receive financial assistance from the Social Security Administration (SSA).

The SSA oversees two of the largest public assistance programs: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

SSDI is a program for working adults who recently suffer from disabilities. It is funded through Social Security payroll taxes, and as a result, is only available to those who have paid those taxes for a number of years.

The SSA gauges eligibility by requiring each applicant to accumulate a certain number of work credits, which are based on earnings each year the applicant worked. In order to qualify, applicants will need to supply a significant employment history to meet the minimum threshold, which varies depending on the age of the applicant. For most people, the rule of thumb is that they must have worked for any five of the past 10 years.

The other program funded by the Social Security Administration is SSI. SSI is a needs-based program that aids elderly and disabled individuals with low incomes. In order to qualify, applicants must supply financial information instead of work history. SSI applicants cannot have more than \$2,000 in assets, excluding their home and car.

In addition to meeting the general requirements for either SSI or SSDI, anyone seeking disability benefits through the SSA must also be considered disabled according to the blue book, which is the SSA's guidebook of all the conditions it considers potentially disabling.

Applicants must match their specific case to the criteria in the corresponding listing for their condition in the blue book in order to receive benefits. CMT falls under the listing for Peripheral Neuropathies, which is found in Section 11.14 of the blue book. This listing requires disorganization of motor function in two extremities or either sensory or motor aphasia that causes ineffective communication. This means that someone applying for CMT must not be able to properly use two limbs such as an arm and a leg, OR the applicant must be unable to communicate by speaking, writing, or otherwise.

The application process for Social Security Disability benefits can be done online or in person with staff from the SSA at a local SSA office. You will need to supply substantial medical information that supports your claim that you are unable to work due to your condition. If you don't receive an approval the first time, there is an appeals process available online for applicants who still wish to receive disability benefits. To start the application process, an applicant with CMT can simply visit the SSA's website to apply for SSDI. SSI applications must be completed at an SSA office.



THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS:

IN MEMORY OF:

MARGARET ARENA

Ms. Rachel Aronis
Mr. Jeff Aronis
Ms. Margaret Bird
Bourne Middle School
Ms. Linda Breen
Cedar Point Association
Ms. Jane Conlon
Cushing Sunshine Fund
Dr. and Mrs. Daniel Mishkin
Mrs. Deanne Noiseux
Mr. and Mrs. John Sciretta
Mrs. Susan Slishman
Mrs. Marjorie Spalding-Williams
Mr. James Williams Jr.

BARBARA BATALO

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Mrs. Kay Aletto
Ms. Michelle Bellavance
Mr. and Mrs. William Casey
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Ms. Mary Anne Gosselin
Mr. and Mrs. Timothy Lannan
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Mr. and Mrs. Robert Sheehan
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Mr. and Mrs. Bruce Jones
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DELANEY VAN RIPER

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AMY WONDERLAND

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THOMAS WOODFORD

Mrs. Mary Woodford

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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Send acknowledgment to:

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CMTA Branch Leader Spotlight: Flora Jones

It's not surprising that Flora Jones didn't get diagnosed with Charcot-Marie-Tooth disease during her childhood in the tiny town of Brandon, Mississippi, in the 1950s. Her doctors originally told her she had polio and scheduled regular operations on her feet so that her recovery coincided with summer vacation. Flora, now 78, still recalls how miserable it was to be stuck in a hospital or at home during the Mississippi summer when neither location offered air conditioning.

After attending nursing school, Flora worked as both a private and hospital nurse until the CMT in her hands left her unable to open sugar packets or milk containers for her patients. Flora was officially diagnosed with CMT in 1982 and joined a local support group started by a family who thought they were the only ones in the country who had Charcot-Marie-Tooth disease.

In 1988, Flora journeyed to far-off Toronto for an international CMT conference. She describes the experience of sitting in a room with 200 other people who all had CMT as one of the highlights of her life. It was that experience that fueled her determination to educate the medical profession about CMT. Flora became the leader of the Clinton, MS CMTA support group, a position she held either by herself, or in tandem with a friend, for many decades. At one point, as many as 20 or 30 people attended branch meetings, with folks coming from as far as 75 miles away.

Flora describes a visit to her group by Jeana Sweeney, CMTA Director of Community Services, as another high point of her life.

Today, Flora focuses much of her time on spreading the word about CMT to members of the medical community. She carries CMTA literature in the basket of her scooter and distributes it to every doctor and nurse she encounters. Flora explains that it is more important to give CMTA literature to nurses than to doctors, because nurses see patients when they walk into rooms and are more likely to notice an unusual gait. Doctors frequently see patients only after they are seated.

Just recently, Dr. Scott Denton, a postdoctoral research associate at the University of Sidney in Australia, sought Flora out on a visit to the United States. Dr. Denton, who both has CMT and specializes in CMT, wanted to talk to a fellow CMTer from America's heartland. He couldn't have found a better spokesperson than Flora. The two sat together for many hours, engaging in a wide-ranging discussion of their CMT experiences. They still talk and share insights frequently.

Flora is encountering many CMT-related difficulties, including trouble with her breathing, but she remains adamantly upbeat and determined. Flora believes that that the secret to life is putting on a happy face in the morning, regardless of how



Branch Leader Flora Jones with CMTA Community Services Director Jeana Sweeney

you feel. According to Flora, in the process of convincing others that you are happy, you often convince yourself as well. ★

TIME TO CONTACT YOUR GOVERNOR FOR AN AWARENESS MONTH PROCLAMATION

It's only July, but the CMTA is busy preparing for CMT Awareness Month because September is right around the corner.

In years past, the CMTA has asked CMTA Branch Leaders to contact their governors to request that they declare September as Charcot-Marie-Tooth Awareness Month. Well this year, we are asking EVERYONE to do the same! The more state proclamations we get, the more awareness we create.

To get more information about making a request, please visit www.cmtausa.org/proclamation. You'll be able to download a sample proclamation request, and there are easy-to-follow instructions on how to complete and print it.

If you have any questions please contact Jeana Sweeney at jeana@cmtausa.org. If and when you receive a proclamation, be sure to scan and send Jeana a copy so she can share it with the CMTA community!





CMTA BRANCH NEWS

• Central Alabama

Eighteen people and a baby turned out for the branch's first meeting. The importance of staying active was discussed, along with a suggestion to join the Lakeshore Foundation. The next speaker will be a GeneDX representative. The group will be holding a Walk4CMT during September Awareness Month, possibly at Veteran's Park. People who are able will walk the trail while people who aren't will wear their shirts and sit at the pavilion.

• San Francisco, CA

At the May 23 meeting, group members discussed the new branch in the North Bay area, as well as efforts to collect specialists' names for the CMTA directory. They also discussed the necessity of follow-up visits at CMT Centers of Excellence so that doctors and researchers can track disease progress.

• Denver, CO

A dozen people, including one new person, came out for the branch's latest meeting. They had a chance to view and sign the traveling quilt and sent it on its way to the next location. Thanks to the efforts of some branch members, the CMTA-produced public service announcements may be airing daily on Denver PBS stations.

• Southern Connecticut

The branch welcomed CMTA Advisory Board members David and Elizabeth Misener, leaders of the Upstate New York CMTA Branch to its meeting on May 2. Thirteen people, including three



Assistance dog Motive with trainee Iggy at South Florida meeting

new members, heard David and Elizabeth present *CMT (Continue Moving Today): Our Stories with CMT*. They shared stories and ideas on how to continue to move, especially on days it might feel impossible and how their family lives with the daily challenges of CMT. David also provided valuable information about bracing and orthotics.

• South Florida

Andrew Collins and his assistance dog "Motive" demonstrated Motive's support skills at the April meeting of the South Florida CMTA Branch. Motive, a Genesis assistance dog, is fitted with an ultra-light aluminum brace and is trained to place his body in position to provide Andrew with stability when he walks and stands from a sitting position. Motive, Andrew and his mother Julie were joined by three representa-

tives of Genesis and assistance-dog-in-training Iggy, a beautiful 4-month-old Golden Retriever. The Genesis dogs go through a rigorous training program that graduates only two to four dogs yearly (<http://genesisassistance-dogs.org>). They are highly trained to provide specific services to their partners, who are screened for medical need, and granted all rights under the Americans with Disabilities Act and Florida statutes. While Andrew and Motive have only been together a relatively short period of time, they've already developed an incredible bond.

• **Ashland Tri-State, KY, OH, and WV**
Jackie Ball of The Brace Shoppe in Huntington, West Virginia, and Michelle Watson of Premier Physical Therapy were the guest speakers at the Ashland Tri-State CMTA Branch meeting on

(continued on page 22)

CMTA Branches

AL—Birmingham Area

Central Alabama CMTA Branch
Bethany Tongate
205-533-8558

AL—North Florence

North Alabama CMTA Branch
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Todd Oyen
256-810-6582

AZ—Phoenix Area

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Jim Blum
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CA—Los Angeles Area

Los Angeles, CA CMTA Branch
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CA—Los Angeles Area

Los Angeles, CA (South)
CMTA Branch
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Tara George
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CA—North Bay Area

North Bay Area, CA CMTA Branch
Sharon Bello
650-465-3953

CA—Orange County

Orange County, CA CMTA Branch
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310 987-3289
Casey Greenberg
951-317-9911

CA—Sacramento

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

San Diego, CA CMTA Branch
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CA—South Bay Area

San Francisco Bay Area
CMTA Branch
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Tau O'Sullivan
408-796-7141

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Denver, CO CMTA Branch
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Dick Kutz
303-988-5581

CT—Hartford

Hartford, CT East CMTA Branch
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CT—North Haven

Southern Connecticut
CMTA Branch
Lynne Krupa
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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
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FL—Tampa Bay Area

Tampa Bay, FL CMTA Branch
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Edward Linde
813-712-4101

FL—West Palm Beach

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

GA—Atlanta Area

Atlanta, GA CMTA Branch
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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

IL—Chicago Area

Chicago, IL (South) CMTA Branch
Dale Lopez
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IL—Norridge Area

Chicago/Land (North) CMTA Branch
Charles Barrett
224-628-5642

IL—Springfield Area

Central Illinois CMTA Branch
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IN—Fort Wayne Area

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Priscilla Creaven
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IN—Indianapolis Area

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Patricia Wood
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KS—Wichita Area

Kansas Area CMTA Branch
Karen Smith
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KY—Ashland, KY

Ashland Tri-State CMTA Branch
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LA—Louisiana

Louisiana CMTA Branch
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Jill Ricci
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MD—Easton

Easton, MD CMTA Branch
Missy Warfield
Seth Warfield
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MI—Kalamazoo Area

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MN—Central Minnesota

Central Minnesota CMTA Branch
Jo Smith
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MN—Minneapolis Area

Greater Minneapolis CMTA Branch
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Asheville NC - Greenville, SC
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NC—Durham Area

Research Triangle Area, NC
CMTA Branch
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NJ—Central New Jersey

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Jacqueline Donahue
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Morris County, NJ CMTA Branch
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NM—Albuquerque Area

New Mexico CMTA Branch
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NV—Las Vegas Area

Las Vegas, NV CMTA Branch
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Jerry Cross
775-751-9634

NY—Buffalo Area

Buffalo, NY CMTA Branch
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NY—Manhattan Area

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NY—Upstate New York

The Upstate NY CMTA Branch
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David Misener
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Cleveland, OH CMTA Branch
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Mandy Kimpton
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OH—Dayton Area

Dayton, OH CMTA Branch
Laura Wootan
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OR—Grants Pass

Grants Pass, OR CMTA Branch
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541-846-8525

OR—Portland Area

Portland, OR CMTA Branch
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Joyce Beals
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PA—Bucks County Area

Bucks County, PA CMTA Branch
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Mitch Davis
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PA—Chester County

Chester County, PA CMTA Branch
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PA—Ephrata, PA

Ephrata, PA CMTA Branch
Rachel Weaver
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PA—Harrisburg

Harrisburg, PA CMTA Branch
Erin Gaul
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PA—Johnstown Area

Johnstown, PA CMTA Branch
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Jeana Sweeney
814-269-1319

PA—Northwestern Area

Erie, PA CMTA Branch
Joyce Steinkamp
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RI—East Providence

Rhode Island CMTA Branch
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Raymond Souza
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SC—Greenville Area

Asheville-Greenville CMTA Branch
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Kitty Hodinka (Greenville)
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SD—Hartford Area

Hartford, SD CMTA Branch
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Tom Clarkson
605-370-7595

TN—Hendersonville Area

Central Tennessee/Southern
Kentucky CMTA Branch
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TN—Nashville Area

Nashville, TN CMTA Branch
Bridget Sarver
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Gwen Redick
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TN—Savannah Area

Savannah, TN CMTA Branch
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Melinda White
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TX—Dallas Area

Dallas, TX CMTA Branch
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TX—El Paso Area

El Paso, TX CMTA Branch
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TX—Houston Area

Houston, TX CMTA Branch
Kristin Leard
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TX—Vidor Area

Vidor, TX CMTA Branch
Angie Beaumont
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UT—Orem Area

Wasatch Front, UT CMTA Branch
Melissa Arakaki
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VA—Chesapeake Area

Chesapeake, VA CMTA Branch
Donna Koch
757-650-2417

VA—Fredericksburg

Fredericksburg, VA CMTA Branch
Leigh Van Doren
540-370-1968

VA—Harrisonburg Area

Anne Long
540-568-8328

VA—Shenandoah Area

Northern Shenandoah Valley
CMTA Branch
Teresa Frederick
540-336-4496

WA—Seattle Area

Seattle, WA CMTA Branch
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WI—Milwaukee Area

Southeastern Wisconsin CMTA Branch
Susan Moore
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BRANCHES IN CANADA AND MEXICO

CAN—British Columbia

Victoria, BC CMTA Branch
Melanie Bolster
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Neville Tate
250-656-2547

CAN—Ontario

Eastern Ontario CMTA Branch
Robin Schock
613-389-1181

Northern Ontario CMTA Branch

Brenda Spencer
705-788-0408

Southern Ontario CMTA Branch

Kelly Hall
519-843-6119

Mexico

(This branch will be in Spanish.)
México CMTA Rama
Gina Salazar
Gina_oviedo@
hotmail.com

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

CMTA BRANCH NEWS

(continued from page 20)

May 16. Michelle demonstrated exercises for strengthening muscles and Jackie demonstrated some newly available braces. The two guest speakers have agreed to help with the Walk4CMT in September and the goal is to get other area specialists to join the walk as well. The next meeting will be held from 11 a.m. to 2 p.m. on Saturday, July 25, at the Ashland Public Library.

• Louisiana

After everyone introduced themselves and shared their CMT stories, the group reviewed the resources available from the CMTA, including the quarterly STAR report and the Louisiana CMTA Branch page. The Louisiana Branch is on Facebook, but the group decided to create a closed group on Facebook as well. The group discussed locations for a Walk4CMT in September, including Lakeview Regional Hospital, which has a walking track and has hosted non-profits in the past.

• Baltimore, MD

The branch had a great meeting on June 7, featuring genetic counselor Shawna Feely, who traveled all the way from Iowa to speak. Shawna gave an amazing presentation on the genetics of CMT and generally dazzled everyone with her vast knowledge of CMT and other genetic diseases. Shawna works directly with leading CMT neurologist Mike Shy at the University of Iowa CMT clinic, and they always welcome new patients.

• Boston, MA

The group heard two guest speakers at its June 3 meeting. Dr. Vera Fridman spoke about the CMT Center of Excellence at Massachusetts General Hospital and the upcoming Patient Conference at the Seaport Hotel August 29. Suzanne Malinowski spoke about a shoe orthosis she created for her own foot drop issues. More information is available at www.nefootdropcenter.com. Emily Goodwin, 11, presented a few of the handmade wood products she sells to raise money for the CMTA.

Please visit her Circle of Friends page to join her group and view all her products. Members were reminded about the Third Annual Vittorio's Circle of Friends Fundraiser to be held July 18 from 5 p.m. to 8 p.m. at the Cape Ann Marina in Gloucester (Route 133) with BBQ, a DJ, door prizes and auction items including Red Sox tickets and restaurant and shopping gift cards. The price is \$25 per ticket and checks should be made out to the CMTA. RSVP to Jill Ricci, 100 Middleton Road, Boxford, MA 01921. In other fundraising news, the branch's Walk4CMT will be held on September 19, location TBD.

• Southwest Michigan

Ten people turned out for the branch meeting in May, four of them first-timers. Two counseling interns who wanted to learn about CMT also attended the meeting on the topic of genetics and genetic testing. Two speakers from GeneDx described inheritance patterns for the various types of CMT and discussed genetic testing. The next meeting of the Southwest Michigan Branch is set for July 15, 2015.

• Greater Minneapolis

The 20 people at the branch's inaugural meeting on April 15 talked about the CMTA and the different membership benefits, how to join the group on the CMTA site and the information and resources available at www.cmtasua.org. The group, which plans on meeting every other month, discussed fundraising ideas and good shoes for CMTers, including Finn Shoes and New Balance. Shuler Shoes (www.shulershoes.com) was

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Members of the Westchester NY CMTA Branch at their potluck brunch

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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.

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| <p>Subscription Membership Benefits:</p> <ul style="list-style-type: none"> • Online access to valuable information about living with CMT • Access to the CMTA's Online Community, including access to CMTA Branches and Discussion, Circle of Friends and CMTAthletes groups • An information kit and a 10% discount at the CMTA store • Bimonthly delivery of <i>The CMTA Report</i>, (electronic and/or hard copy) • The <i>CMT Facts</i> series (electronic copy) | <p>STAR Membership Benefits:</p> <ul style="list-style-type: none"> • All of the benefits of Subscription Membership <p>PLUS</p> <ul style="list-style-type: none"> • One free pair of Aetrex Shoes in the style of their choice (new STAR members only) • 50% off all Aetrex shoes (new and renewing STAR members) • An expanded and updated copy of the CMT Survivor's Guide • A 20% discount at the CMTA Store • One <i>You're a STAR</i> auto decal |
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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	
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Be a STAR Wristbands		\$1.50 each*		
Be a STAR Necklaces (Includes battery)		\$5 each*		
Washable CMTA Tattoo (Pack of 5)		\$1 per pack		
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CMTA Brochure & Neurotoxic Drug Card		FREE		
Donation to the CMTA (100% Tax-deductible)				
Shipping & Handling (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)				
*Quantity discounts for these items available online				ORDER TOTAL

- 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.

mentioned as a source. Dr. David Walk from the CMT Center of Excellence at Fairview Maple Grove Medical Center talked about the clinic and what to expect at an appointment there.

• **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 personal struggles and small triumphs with the disease and several people displayed various kinds of braces. 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.

• **Westchester, NY**

The Westchester branch held a potluck brunch on May 2, 2015. The group is planning a fundraiser for STAR on November 7, 2015, and will meet again in September after a summer break.

• **El Paso, TX**

Meeting on May 9, the group discussed fundraising ideas and settled on two: A dine and donate at Fuddruckers and a food truck fundraiser with face painting and bounce houses. The group is also looking for a site for an All-Star Walk in September. The next meeting will be held on July 18.

• **Southeastern Wisconsin**

The branch welcomed several new people at its latest meeting. They talked about Independent Living Supplies, assistive devices, and the health benefits of essential oils.

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):

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

Moderate to significant risk:

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

Uncertain or minor risk:

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

Negligible or doubtful risk:

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

THE CMTA Report

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WHAT IS CMT?

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