THE CMTA Report

MAY/JUNE
2015

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

FOLLOW-UP VISITS NEEDED AT INC SITES

An Open Letter from Dr. Michael Shy, Scientific Advisory Board Chair

Dear CMT Community:

Thanks to the CMTA's STAR initiative, candidate therapies for many of the most common forms of CMT will soon be ready for testing in clinical trials. The success of these trials will largely depend on how much we know about the "natural history" of CMT—how different types of CMT progress over time and whether novel medications are slowing the course of the disease.

Here's where you can help. Although the Inherited Neuropathies Consortium (INC)—a group of academic medical centers, patient support organizations, and clinical research resources—has evaluated thousands of patients with CMT, many individuals have only been evaluated a single time. WE NEED follow-up evaluations one, two, and three years after the initial visit to determine change over time. If you have been evaluated at one of the 17 international INC sites (which roughly correspond to the CMTA's Centers of Excellence), we ask you to please schedule follow-up visits. WE NEED YOU!

INC'S KEY AIMS

- Enrolling patients with CMT into natural history studies
- Identifying new genetic causes and genetic modifiers of CMT
- Developing standards of care for people with CMT
- Discovering new laboratory markers of disease
- Creating banks of various types of specimens from people with CMT
- Conducting clinical trials to look for new treatments for CMT
- Training new young investigators in the field of CMT
- Establishing a Patient Contact Registry to connect patients with researchers
- Working with support organizations like the CMTA to spread the word about CMT

You can find information about the locations of all the INC centers by visiting www.rarediseasenetwork.org/INC/centers/index.htm. By visiting one of the INC centers, you can not only receive clinical care, but you can also participate in research projects being conducted through INC *(see related article p. 2)*. Every time someone participates in a project, researchers get one step closer to improving the quality of life for people with CMT and realizing the CMTA's vision of "A World without CMT."

Participating in research through INC can also be done by joining the online Patient Contact Registry at http://rarediseasesnetwork.epi.usf.edu/INC. This registry has been created to inform patients and families of clinical research studies for which they may be eligible. By joining the registry, you may be emailed when new studies are active, and some may only require that you complete an online form to participate.

Developing effective treatments for CMT will only work if there is a partnership between patients and investigators. Please give us our best chance to test treatments we are developing.

Thanks to you all,

Michael Shy and all
the INC investigators

INSIDE:

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.

EMAIL CMTA AT:
info@cmtausa.org

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The Road Less Traveled

BY SHAWNA FEELY

"Is this Heaven? No… it's Iowa." This classic line from the movie *Field of Dreams* refers to the state where I now reside. I have lived in a random assortment of places during my life. But my most recent move was the most unexpected, by me and certainly by my friends, who to this day continue to ask me, "Where do you live again? Ohio? Idaho? Oh, yeah, Iowa!"

So why the big move to the Midwest and the middle of Heartland USA for a girl from the coast? To help build a Charcot-Marie-Tooth (CMT) Clinic with a focus on multidisciplinary clinical care and translational medicine that will ultimately advance research in the area of hereditary peripheral neuropathies.

"If you build it, they will come."

This was what I hoped as I moved to Iowa in January 2012 during the middle of a cold winter, the first of many. Our then-small team, which included Drs. Michael and Rosemary Shy and me, began work to build the CMT Clinic at the University of Iowa Hospitals and Clinics (UIHC) in Iowa City. There were connections to make, specialists to find, and approvals to get through the UIHC in order to open our doors and start seeing patients. It took the better part of four months, but we finally welcomed the first visitors to our clinic in April that year.

And people did come—from all over, including California, Australia, Illinois, and of course Iowa. They flew into our small airport in Cedar Rapids to visit us and get involved in the clinic and the research. Amazing people, some new friends and some old friends, would drive or fly and come visit us at our new home. We began to build, seeing more and more people each week, and we also began to branch out, utilizing more subspecialties in the clinic than we ever had before.

The multidisciplinary care experience means a long day at clinic for most people. Patients might see physical therapists, occupational therapists, orthotists, neurologists, electrophysiologists and genetic counselors in one day. They might also see orthopedic surgeons, audiologists and pulmonologists. It can be overwhelming to meet with so many different providers, and people often leave the clinic as tired as they would be after a long day of work. The specialists we work with are committed to serving the patients, learning and providing information and improving the quality of life for people with CMT. The approach can be amazingly informative to the patient, and a great resource to help guide local providers on how to help manage or treat this lifelong disease.

At INC clinics, information flows from "bench to bedside, bedside to bench."

"The Voice is back. Oh, Lord, you're supposed to build a football field now?"

So we've grown, in number and diversity, creating a stronger clinic and also helping to expand the knowledge about different types of CMT, their genetic causes, and how they progress through a person's life. Working in partnership with the people who came to see us, our clinic, along with the other clinics connected through the Inherited Neuropathies Consortium (INC), continued to focus on the translational medicine model, which brings knowledge from research directly to patient care and vice versa. This model allows advancements in medical research to directly benefit patient care. It allows patients to directly inform researchers about what is important and how to measure or treat CMT: bench to bedside, bedside to bench. It is through this process that more and more forms of CMT are being identified genetically, more is known about the progression of the most common forms of CMT like CMT1A, CMT1B, CMT1X, and CMT2A, and more possibilities lie ahead for clinical trials and potential treatments for CMT (*see related article on p. 4 for an update on INC's progress in the last five years*).

"When did these ballplayers get here?"

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It is an exciting time for research advancements, but also an exciting time for the UIHC CMT clinic as we continue to build, train new providers and add wonderful people to our ranks. Over the past few years, we have been joined by people like Tiffany Grider, MS, CGC, my fellow genetic counselor and friend. She loves working with the families who visit us, and she is an amazing advocate and educator for people who have or are at risk for CMT, always working with kindness, grace and intellect.


Tiffany Grider, MS, CGC


Laurie Gutmann, MD


Nivedita Jerath, MD

We have also been joined by two neurologists who are experts in neuromuscular disease and are helping with both clinical care and research for people with CMT. Laurie Gutmann, MD, started with the UIHC last year after moving from West Virginia University (WVU). She has years of clinical trial experience with organizations like the National Institute of Neurological Disorders and Stroke (NINDS) and NeuroNEXT, a network established by the National Institutes of Health (NIH) to conduct neuroscience clinical trials. Around here, Dr. Gutmann is known for her sharp wit and excitement, along with her drive to help patients manage their disease.

Another neuromuscular disease expert, Nivedita Jerath, MD, started with us last year during her UIHC Neuromuscular Fellowship. During that time, she was awarded a clinical research grant through the Muscular Dystrophy Association (MDA) to evaluate whether or not CMT can affect driving performance on the road. Through her research, assistive devices may be identified to help people drive safely. She was appointed as an assistant professor in the UIHC Neurology Department this year and continues to work with our team by providing clinical care and management to people seen in the CMT clinic.

“It’s okay, honey. I … I was just talking to the cornfield.”

Despite all the twists and turns in my life, I am happy that my path led me to this place, with these people, surrounded by cornfields. We have a wonderful team that wants to learn, and grow, do good work, advocate for patients, and ultimately treat CMT. We have amazing, courageous people who come to visit us, who teach us more and more about CMT, what it is like to live with it, and what their hopes are for a future without CMT. And, we have a global network created and set in place by mentors in the field like Dr. Michael Shy, Dr. Mary Reilly from the UK, and Dr. Steven Scherer from the University of Pennsylvania. This network is powered by people and families affected by CMT, focused and inspired by advocacy groups like the CMTA, and ready to move ahead and continue to learn as much as we can about all forms of CMT until a cure is identified. I am excited about what lies ahead, all that we will learn, and all the people we will meet along the way.

So, if you have a chance, and can swing by Iowa City someday, come and visit the CMT Clinic that took three years and many lifetimes of knowledge to create. We can have a catch on the real Field of Dreams and we’ll “See if you can hit my curve.” ★

GET READY FOR THE BIGGEST EVENT IN THE CMTA’S 32-YEAR HISTORY!

Are you ready to be a **CMTA All-Star**? The CMTA All-Star Event 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.

Are you ready to make a difference? Then save the date and get ready to Walk4CMT, Cycle4CMT or Swim4CMT this September!

CMTA ALL-STARS
CYCLE | SWIM | WALK

Update on the Inherited Neuropathies Consortium (INC)

BY SHAWNA FEELY, MS, CGC, AND CARLY SISKIND, MS, LCGC

The Inherited Neuropathies Consortium (INC) is an integrated group of academic medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in different forms of CMT and improving the care of patients. Funded by the National Institutes of Health (NIH), the CMTA and the Muscular Dystrophy Association, INC is part of the Rare Diseases Clinical Research Network, which comprises 22 distinctive consortia and a Data Management and Coordinating Center that are working in concert to improve availability of rare disease information, treatment, clinical studies, and general awareness for both patients and the medical community.

In the past five years, INC has grown from eight clinic sites to 17, 16 of which provide clinical care. INC is also reaching more people with CMT than ever before. A total of 6,936 participants (as of April 28, 2015, with more accruing every day!) have been recruited into a variety of projects that help researchers learn how different types of CMT begin, how they progress over a lifetime, and the biological and genetic basis for the disease. As the state of knowledge about CMT has advanced, INC has committed itself to an increasing number of key aims to move research forward.

Natural history studies are one of those key aims. Natural history studies identify early symptoms in CMT subsets and how they progress over time. When researchers know how a disease progresses without a treatment intervention, they are able to better evaluate whether a treatment is actually working—if it is slowing or stopping the rate of progression.

Valid outcome measures are also important in telling if a treatment is working. Outcome measures are reproducible items that can be performed at multiple visits and compared over time to show statistical differences. INC continues to improve the outcome measures it has already developed and to create new measures that will be used in future CMT clinical trials. The new measures will be used to assess children and infants with CMT, along with incorporating the patients' perspectives of disability to create patient-reported outcome (PRO) instruments. Standard

CMTA PARTNERS WITH INVITAE

The CMTA is excited to announce a new partnership with the genetic testing company Invitae. Invitae's mission is to bring comprehensive genetic information into mainstream medical practice, improving the quality of healthcare for billions of people. They accomplish this by aggregating most of the world's genetic tests into a single service with higher quality, faster turnaround time, and lower price than many single-gene tests today. The company currently provides a single diagnostic service comprising over 34 genes for a variety of genetic disorders associated with CMT. Any test is $1,500 with a three week turnaround time. Insurance may cover the cost. Tests can be ordered through a neurologist or primary care physician. Visit www.invitae.com/en/cmt-testing for specific information

The CMTA firmly believes in the importance of genetic testing for CMT. Not only does it help people with CMT understand more about symptoms, inheritance patterns and progression, but people who are diagnosed may be eligible for human clinical trials when they are announced. To learn more about CMT and genetic testing, please visit www.cmtausa.org.

measurements such as the CMT Neuropathy Score (CMTNSv2), the CMT Pediatric Score (CMTPeds), and the CMT infant score (CMTInfS) are being used, along with PROs like the CMT Disability Severity Index (DSI) and CMT Quality of Life (QOL) instruments to better define disease severity and its impact on the overall quality of life of a patient. All of these have been created by INC, and have been or are being validated, analyzed for better sensitivity, and utilized at INC clinical sites. Use of these measures will ensure cohesive data, which will help further refine these measures and allow people with CMT to understand how their disease is progressing, no matter at which INC site they are seen.

While developing the necessary infrastructure for future clinical trials, INC has also been training new young investigators…

Although the natural history studies are one of the aims to better understand some of the more common forms of CMT, such as CMT1A, CMT1B, CMT1X, and CMT2A, INC has also focused on identifying new or rare forms of CMT. By utilizing next generation sequencing (NGS) technology, INC has identified more than 15 new genetic causes of CMT, and the number of genes we know can cause different forms of CMT has increased to at least 83. Working with collaborators, INC has also created a pathway by which genetic information for patients with unknown forms of CMT can be shared with an international network to allow researchers to compare information about each other's patients in a protected way to maintain confidentiality. This allows patients with rare or new forms of CMT from all over the world to be identified.

Along with finding new causes for CMT, INC has worked to identify genetic modifiers for the most common cause of CMT, CMT1A. Although everyone with this form of CMT has the same genetic cause, a duplication of the *PMP22* gene, symptoms can vary significantly, even in the same family. Because of this variability, INC has conducted a Genome-Wide Association Study (GWAS) to help identify other genetic changes that may influence the severity of disease for people with CMT1A. Understanding how other genes interact with *PMP22* and how that interaction affects disease severity may lead to possible clinical treatments down the line for this common cause of CMT.

INC has also been working to create a biobank of samples from people with different forms of CMT. The hope is to use these samples to identify biomarkers that could help detect disease progression in CMT, which would eventually be used through the course of a clinical trial. Samples are donated from the patient population seen in clinic and recruited from Patient Advocacy Groups (PAGs) like the CMTA. Samples, such as cell lines derived from patient skin or blood, can be differentiated (a process where one cell type changes into another) to become a nerve cell. The CMTA is collaborating with INC centers to develop stem cells from skin biopsies to be used in drug development assays. In this way, the CMTA and INC have partnered to develop new models that can be used to test out treatment agents and their efficacy on various forms of CMT.

The culmination of these projects allows INC to be at the forefront for clinical trials as they emerge, such as those that are coming down the pipeline for CMT1A and CMT1B. Through the use of outcome measures, biomarkers, and connections with patients and families through the CMTA and the INC Patient Contact Registry, INC will have the ability to conduct clinical trials, the means to measure change over time, and the access to the patient population that is essential for the success of any clinical trial. This is the goal of translational medicine—going from "bench to bedside" by bringing what is learned in labs to help actual people with the condition. While developing the necessary infrastructure for future clinical trials, INC has also been training new young investigators both in clinical research and clinical care for people with CMT. This includes fostering interest in new projects, recruitment to establish new CMT clinics around the world, and support of the clinical subspecialties necessary to provide multidisciplinary care to patients. ★

Physical Therapy and Exercise: Getting the Right Dose

BY AMY WARFIELD, PT, DPT, NCS

Research tells us that exercise can be an amazing "medication." But exercise, like medication, is only effective if it is right for a patient's condition and dosed at the appropriate level.

Because CMT affects each person differently, exercise has to be tailored to the specific impairments identified and dosed effectively. As a mobility expert, a physical therapist can provide guidance in finding the optimal program to get a person to the next level.

I was asked to join the Advisory Board because I am a physical therapist, and, most importantly, because my husband and two of our children have CMT. During our experiences with CMT, we have encountered many people, including physicians and patients, who are unclear as to the role physical therapy plays for those affected by CMT. If we are going to help them, we all need to be on the same page.

As a physical therapist, I work with children and adults in a one-on-one setting. A new patient visit starts with a comprehensive evaluation. I discuss the patient's medical history and assess the current level of function and the neuromusculoskeletal system. This assessment also includes assessing the client's balance, sensory system, strength, range of motion and functional skills. I ask about any history of falls or medication changes, and I inquire into the client's daily living activities, recreation activities and housing situation. I am not asking these questions because I am nosy, but because I am trying to learn the client's goals and develop an individualized plan of care specific to the situation.

In an ideal world, I would know what type of CMT a patient has—and its natural progression. I would then try to determine which muscles are weak due to a lack of a nerve connection between the nerve and the muscle and which muscles are weak because they aren't used regularly. Muscles that are weak because they aren't used enough can be strengthened. Muscles that are weak because the nerve signal doesn't reach them cannot be strengthened and therefore should not be over-taxed with strengthening attempts. Like all physical therapists, I put thought and consideration into the client's specific goals, past experiences and physical capabilities when designing a program to address specific impairments.

In the physical therapy clinic where I work, I have helped people with CMT maximize the efficiency of their gait pattern in order to decrease their fatigue at the end of the day. Clients have thanked me for teaching them stretching and exercise routines that have allowed them to return to their previous activity level or to confidently negotiate a hallway at school. Pain management strategies can be taught to improve a client's quality of life. With improved balance, a client can better handle public transportation systems or the playground. One of my greatest pleasures has been helping children achieve the gross motor milestones they need to participate in their recreational activities and school life.

OXFORD BIATHLON ADDS 5K AND HALF-MILE WALK OPTIONS

One of the CMTA's biggest fundraising events is getting EVEN BIGGER! The CMTA Oxford Biathlon, which will take place on May 30, is now the Oxford Biathlon *Plus*.

Started last year by Steve O'Donnell and Clark Semmes, the Oxford Biathlon still offers a one-mile open water swim and a 20-mile bike ride. But this year, in an effort to reach out to athletes at every level of fitness, the Oxford Biathlon has expanded to offer both a 5K and a half-mile walk. Everyone registering will receive an event T-shirt and a free lunch at The Masthead, a beautiful waterside restaurant with fabulous food and a great view of the Tred Avon River.

Those unable to participate as athletes are also welcome to come out, enjoy the beautiful setting and attend the event party at The Masthead. Event co-organizer Missy Warfield has added a silent auction with items that include box seat tickets to a Baltimore Ravens game and a quilt created just for this event!

To register as an athlete or to attend the event party for the 2015 Oxford Biathlon *Plus*, visit: www.cmtausa.org/oxbi or contact Clark Semmes (clarksemmes@gmail.com or 410-350-4812). You may also donate in support of the athletes at www.cmtausa.org/supportoxbi.

In a case of practicing what I preach, I have taken my own kids to PT to get an objective assessment and guidance on how to best encourage their gross motor development, strength and balance. Each time the therapist had some amazingly creative ideas (and the advantage of not being Mom) to achieve our goals. Most recently, we sought out the help of a physical therapist as our son was about to start kindergarten. He still couldn't ascend stairs with a step-over-step pattern, and I worried this would single him out as it wasn't a playground skill but rather an everyday skill. I also worried about how he would ever get up the huge school bus steps. The therapy worked. He gained the strength he needed to negotiate stairs of all sizes and his confidence grew as well. In our home, daily stretching is part of our routine, night splints are worn and range of motion and strength exercises are done daily. We realize the work has to be done in order to achieve our goals, but it isn't always easy.

In our home, we are challenged by CMT even with a physical therapist and a pediatrician living under the same roof. We are all doing the best we can. When I reach out to another physical therapist, or when you do, you should know the physical therapist that you seek out has trained for years to provide individualized care and guidance for your particular situation. In the absence of specific evidence for a patient's situation, our education guides us in interpreting the research that exists and in making the best clinical decisions we can. ★

CMTA ENTERS COLLABORATION WITH AFFECTIS TO ADVANCE THERAPIES FOR CMT1A

The CMTA announced April 20 that it has entered into a collaboration with Affectis Pharmaceuticals AG to evaluate the efficacy of advanced Affectis compounds in neurological and behavioral models of CMT1A.

Affectis is a therapy development company and, since 2013, a fully owned subsidiary of the Lead Discovery Center GmbH (LDC), a spin-off of Max Planck Innovation GmbH. The goal of the collaboration is to evaluate the pharmacology of small molecule antagonists of the P2X7 ligand-gated ion channel that are being jointly developed by Affectis and the LDC. P2X7 is an ATP-gated ion channel which is essential for cellular calcium homeostasis, and for the maturation and release of pro-inflammatory cytokines, including interleukin-1beta (IL-1).

The collaboration's aim is to demonstrate the potential of P2X7 antagonists that have high potency for the human form of P2X7 and are orally bioavailable in treating CMT1A. Use of such antagonists may impede the development of motor and sensory control defects associated with progression of the disease.

Pre-clinical studies previously demonstrated a likely role for P2X7 over-activity in the pathogenesis of CMT1A. An altered calcium homeostasis was observed in Schwann cells from rats that exhibit a CMT1A pathology due to the expression of extra copies of the *PMP22* gene; this is hypothesized to lead to the disruption of myelination associated with the disease. The investigators further showed that the changes in intracellular calcium coincided with overexpression of the P2X7 ligand-gated ion channel, and that its inhibition leads to myelin repair.

CMTA CEO Patrick Livney said the "Affectis collaboration represents an exciting new opportunity for the CMTA to both de-risk and accelerate development of a novel drug class for the treatment of CMT1A, the most prevalent of the genetic neuropathies."

Affectis CEO Michael Hamacher said of the collaboration: "Our P2X7 lead compounds have excellent pharmacological properties and repeatedly showed efficacy in various animal models. With initiation of the CMT1A studies we see the unique chance to evaluate both the role of P2X7 as well as the potency of the Affectis' compounds in the Charcot-Marie-Tooth 1A disorder, a demyelinating neuropathy with unmet medical need. We are very much looking forward to the collaboration with the excellent team of experts from the CMTA to jointly progress the P2X7 leads into an effective therapy for Charcot-Marie-Tooth 1A."

Continue Moving Today (CMT):

Using Mindfulness and Gratitude Against CMT

BY ELIZABETH K. MISENER, PHD, LMSW

Sitting in the waiting room at Albany Medical Center, I thought I would be strong. I had papers to grade, books to read and lots to keep my mind busy. But the longer my husband was in surgery to reconstruct his foot, the harder it was for me to hold it all together. After two hours, I was mentally exhausted and my mind was playing tricks on me. I kept imagining the doctor coming to tell me that something had gone very wrong. I spent the last hour crying, in a waiting room full of people, feeling very alone and scared.

Six months later, my husband and I were in another hospital waiting room waiting for my 9-year-old son to come out of his surgery on both feet. This time I was more prepared, and when my thoughts tried to hijack me, I had tools to fight back. I had spent time preparing. I read books, explored the research and listened to the experts about how to avoid getting sucked down a black hole. The tools worked, both in that waiting room and during my son's recovery. I am not saying it was easy and sometimes we were on the edge of that black hole. But when my son reflects back on his four-month ordeal, what he remembers is how much he loved just sitting and reading together as a family. He has positive memories of this time, which is a blessing as he will need more surgery.

My husband and son both have CMT1B. Their surgeries were all successful, but I was better prepared for my son's surgery. The coping tools I used—and continue to use in facing the challenges and the joys of life with CMT—are mindfulness and gratitude. Both of these tools are based on the research in positive psychology and my own experimentation with my family. Dr. Martin E.P. Seligman, director of the Positive Psychology Center at the University of Pennsylvania, defines positive psychology as "the scientific study of the strengths that enable individuals and communities to thrive." The field is founded on the belief that people want to lead meaningful and fulfilling lives, to cultivate what is best within themselves, and to enhance their experiences of love, work and play (www.positivepsychology.org).

MINDFULNESS means purposefully paying attention in a particular way (Jon Kabat-Zinn). Take a moment and stop reading. Be aware of what you are thinking. Has your mind wandered, are you texting while reading or is someone trying to talk to you? If so, take a deep breath and re-focus or stop reading and do what you need to do and come back later. Mindfulness is our awareness of what is going on in the here and now. It is normal for our minds to wander. The problem occurs when it wanders to the past and we rethink it over and over. This can lead to depression. Conversely, when our minds wander to the future and we're continually thinking "What if?" or "What will I do?" anxiety may follow. Being mindful of the present—living in the here and now—buffers us from depression and anxiety. Research shows that we can cultivate mindfulness. Just like reading, one can learn to be mindful over time. Just as a child doesn't start reading with a novel, an adult can't immediately be mindful 100 percent of the time. Start small. For example, the next time you are in the shower or tub, be aware of what you're thinking about. Is it something in the past or future or right here and now? Here and now could be something like the water temperature or the shampoo you use. Many years ago, I would get out of the shower and not even remember if I had

IDEAS FOR CULTIVATING MINDFULNESS AND GRATITUDE

- ★ *Notice one new thing about the person you see next and share it with them.*
- ★ *Pay attention to the water while in the shower.*
- ★ *Next time you have a drink, focus on the sensation—its temperature, taste and color.*
- ★ *Next time you talk to someone, just listen. Do not text or do another activity.*
- ★ *Write down five things you are grateful for each day—for example water to drink, the sun, good coffee, Netflix (with no commercials).*
- ★ *When you wake up, be grateful for your first look outside.*
- ★ *What are the good things about having CMT? List as many as you can.*
- ★ *Who are you grateful for and why? Share this with them.*
- ★ *A smile four times a day will cultivate mindfulness and gratitude in you and benefit those around you.*

washed my hair because I was too worried about things I had to do that day. Now I enjoy almost every moment of a shower or a cup of coffee. I have cultivated mindfulness and it buffers me against my anxious thoughts, such as whether my son's CMT will get so bad that he can't walk. I find it exhausting to worry about the future unless I can do something about it.

During my son's surgery I worked very hard to be present in each moment and not think about what was to come next. I did not want to lose control of my thoughts. I decided that if anything went wrong I would deal with it when the time came. Post-surgery, we all focused on each moment and not the long four months without walking. Mindfulness allowed us to be present. Today, we are still cultivating mindfulness. When my sons get off the bus, I put my phone aside and I pay attention to them—purposefully. I still have to put my phone out of reach to avoid temptation, but I am working on it. As a family, we just did a 24-hour car ride and being in the moment made it pleasurable and a special time for us to bond and talk and learn about each other. I challenge you to cultivate your mindfulness. Over the next few days, pause each time you take a drink and bring your

(continued on page 11)

WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,

I am a 29-year-old woman with CMT. Fortunately, it is relatively mild and I am able to work and support myself. I wear orthotics for stability and I have a small but wonderful group of friends who are incredibly supportive. I never really thought I would meet a guy who could love me and find me attractive, but recently someone I have known through church for a while has been pursuing me. We have gone out on three dates and I can't believe he really likes me. This is making me so anxious that I find myself coming up with reasons to end it. He is a great guy who seems very sensitive and says that my awkward gait and funny feet don't bother him at all. Why am I pushing him away?

David replies:

There are many reasons we push away the possibility of intimacy. Many of us have convinced ourselves that because of our CMT we can't have a full life that includes a loving relationship. We find it hard to believe that someone could actually love what we often try to hide. We reject the possibility of intimacy to avoid the pain of rejection. Just this past week, a young woman I am working with who is slightly overweight said, "I really like this guy and we have been out on five dates. When is he going to see that I'm fat?"

Trust is a major stumbling block, especially if one has not been exposed to healthy models of relationships as children. Being hurt makes it very hard to allow ourselves to be emotionally exposed again. I am sure I have said this before, but in loving and accepting our true and unique selves, we can slowly open up to the possibility of real intimacy with someone who can see who we really are. We don't have to be perfect to love or be loved. A new relationship can provoke anxiety, but not taking the risk of allowing someone to get close to you is cheating yourself out of something you deserve. Give yourself the time and opportunity for it to feel safer. I saw a clip of a very funny comedian who is an Arabic woman with cerebral palsy. She starts off her act by saying: "I have 99 problems and my palsy is just one of them." I found that funny and touching at the same time because it reminds us how we identify and focus on one thing about out ourselves that we dislike. We are so much more than our CMT, and the right person will have the sensitivity and maturity to see that. Our ability to rise above our challenges makes us incredibly attractive in so many ways. Even the pain we have endured on our journey can help us develop a sensitivity and compassion that demonstrates just how much we have to give. Receiving love is often more difficult than giving it, but removing the obstacles we have created to avoid being emotionally vulnerable is worth it. Allow yourself opportunities to be loved simply because you are human and beautiful. As the poet Rumi said: "Your task is not to seek for love but merely to seek and find the barriers within yourself you have built against it." ★

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.

My Secret Disease

BY K.A. VANDERHOEF

I'm 30 years old, and I've just finally confirmed that I suffer from CMT. I was 5 the first time I thought: "There is something wrong with me." My sisters were running around outside. I stood inside, throwing pieces of our pink and green play cutlery into a hula hoop on the floor. I was trying hard to keep my feet planted firmly on the ground and my body straight, as the doctor had instructed my mom to instruct me. This doctor told her my problem was that I had tight tendons. This exercise and the itchy casts they gave me to put on at night were supposed to loosen my tendons and fix my problem.

I had no way of knowing that this was the beginning of a lifelong struggle. Even worse than having a disability, though, was my inability to understand it or explain it to others. Because of that, I buried it beneath a guise of normalcy. And it became my secret disease.

Some people have visible disabilities. Some have invisible disabilities like diabetes or depression. People like me fall in between and have a disguised disability. We must decide whether to disclose our disability every time it becomes apparent, or work to keep it hidden. The choice becomes simple when the *disguised* disability is also undiagnosed: How can you disclose a disability when you yourself don't know what it is?

The elementary school tradition called Field Day first challenged my young perspective on the world and forced me into making these decisions. Field Day was supposed to be a day of fun outdoor competition where kids get to run around, bond with teammates and win awards for their athletic abilities. The whole school came out to watch the kickoff event, a relay race. I was the third to run the relay for my four-person group. As the kid in front of me came around the last bend, we were the second out of five teams. Everyone around me was cheering, but I was so scared I thought my heart was going to beat right out of my chest. I held out my trembling hand and waited for the baton, and as I felt it hit my palm I started to run. Within a matter of seconds, all the other kids had passed me. I ran as hard as I possibly could, but it felt like there were heavy weights on my legs. I fell so far into last place that the final relay runner for the first place team actually passed me before I could complete my lap.

We came in last place. My teammates didn't understand how I could be so slow and run so weirdly. Neither did I. I had no explanation to give them, and I was simply left wondering, "Why am I different?"

It was one of the worst days of my young life, and I hoped and prayed I would never have to do anything like that again. But I did. I had to participate in Field Day every year of elementary school. I had nightmares about it—long rows of hurdles that I knew my legs weren't capable of jumping, being forced to try and falling on my face. Worse yet, my classmates became quickly aware of my inadequacy, and they never tried to hide their disappointment if I was picked for their team.

When I graduated to middle school I thought "Thank God I will never have to endure Field Day again." But something even worse replaced it: Annual Fitness Tests—sprints, long distance running, standing jump, running jump, and my most dreaded event, the shuttle run agility test. The worst part about these tests was that you had to do them in front of your entire grade. I couldn't have picked out a worse hell for myself.

Once I got to high school, I tried telling my gym teachers I couldn't participate in the fitness tests. But without a doctor's note, they wouldn't excuse me. I didn't have a doctor's note because I didn't have a diagnosis. I didn't have a diagnosis because I didn't have a doctor. And I

Stumbling Souls

By K.A. Vanderhoef

The secret is in the struggle:
Yours and mine and ours.
Spinning, it's wild, out of control,
Sucking up the pieces of our twin souls.

But no matter how we stumble,
It's ours and mine and yours.
So regardless of what is down the road,
Just remember we're never alone.

Kim Vanderhoef

didn't have a doctor because I was trying so hard to ignore my physical limitations and pretend I was normal.

But deep down I knew how much my physical limitations were affecting my everyday life. I started avoiding situations where my disability would become obvious. I started skipping gym class. I avoided walking to class with my friends, taking the long way around so I could go up the ramp instead of the stairs. I became anxious when I went any place unfamiliar for fear there would be some physical obstacle I would have to conquer. Stairs became my worst enemy.

What really frightened me was the anticipation of going off to college. I had learned how to avoid the obstacles in my teenage life. But now I'd be going off to a place where I was completely unfamiliar with the landscape, the people and the way of life. While other kids on college visits considered majors and party atmospheres, I was on the lookout for any and all obstacles I'd face and formulating ways to avoid them.

It was around this time I began to notice that I was getting worse. I wasn't okay, and I needed to figure out what was wrong with me. My parents took me to a university hospital in New York City where I heard the words "Charcot-Marie-Tooth disease" for the first time. I thought, "What's wrong with these people? It's my *legs* not my *teeth*!"

The doctor was intrigued and invited in a slew of interns while he did a physical examination on me. It was the first, but certainly not the last, time that a doctor said that my problem was "scientifically intriguing." That's because most of the doctors I saw over the next 10 years lacked a clear understanding of Charcot-Marie-Tooth disease or how it affected me. The most I ever got out of them was, "Oh, yeah. I remember. We spent a day on that in med school."

While that first doctor told me he suspected I had CMT—which he also told me had no treatment or cure—he couldn't definitively diagnose me unless my family and I all went through genetic testing. But I learned enough to know that my leg, feet and hand muscles were deteriorating, and that nothing could change that. So in hopelessness and avoidance, I put my initial diagnosis aside until after college. But, as it often does, life got away from me, and before I knew it more than 10 years had gone by without an official diagnosis.

Although I entered college with an unofficial diagnosis, I

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CULTIVATING MINDFULNESS

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mind to the present, really taste the drink. Eventually it will become a way of being and help you buffer your negative thoughts. For more great exercises to cultivate mindfulness, visit www.mbsrtraining.com.

GRATITUDE has been proven to increase life satisfaction and reduce anxiety and depression. It is also good for our bodies: It lowers blood pressure, strengths the immune system, and lessens the impact of aches and pains (Dr. Robert Emmons, http://greatergood.berkeley.edu/topic/gratitude/definition). This is a tool I use a lot. Dr. Elisha Goldstein, author of "Uncovering Happiness," recently posted words that sum it all up for me: "Gratitude turns what we have into enough" (http://elishagoldstein.com/mindfulness). I love this. CMT is not a choice: The choice is how we think about it. I was grateful in the waiting room that my son had CMT and not another condition. I was grateful for a skilled surgeon and supportive nursing staff. We can cultivate gratitude too. I try to end the day with my sons by asking them what they were grateful for that day. The simple question shifts their thoughts away from what they do not have and makes what we have enough—beds that they are safe in, a house with heat, books to read, and the list goes on. It may seem strange, but I am grateful for CMT because it has exposed us to a community of people who are exceptionally kind, supportive and full of love! ★

MY SECRET DISEASE

(continued from page 11)

continued to hide my disease, now with the added struggle of knowing what it meant for my future. As luck would have it, my room was on the top floor of my freshman dorm and I had to walk up three long flights of stairs numerous times a day. I continued to avoid walking up stairs with people and making excuses to linger behind after the others left (making me chronically late for classes), but it was impossible to find an excuse every single time. Toward the end of my freshman year, my roommates finally confronted me about why I had such problems going up the stairs and why I never participated in intramural sports. To my surprise, I told them the truth. And it felt *amazing*. I couldn't stop it from pouring out of me, and my whole body trembled with a mixture of fear, anticipation, and most of all, relief—the kind of relief that only comes from sharing a deeply held, agonizing secret.

From that point on, I didn't try to hide my struggle when I was with my friends. Whenever we went upstairs or a hill, without a word they would instinctively reach out a hand to support me. They didn't make fun of me, pity me, or question me. They gave me the title of "soccer mom" when I started coming to watch all their games from the sidelines to cheer them on, rather than pressuring me to participate. And I realized, after almost two decades of hiding, that the truth had set me free. Things got a little easier after that, and slowly the circle of people I trusted with my secret began to expand.

Let the truth set you free.

In the eight years since college, I've continued to struggle with social anxiety in new situations or with new people. I'm still self-conscious about my disability and still find it awkward to disclose to acquaintances or strangers. But knowing the truth about why I am the way I am, and being open to share that with others, has made it significantly easier to actually face my disease head on.

This year, through the CMTA website, I finally found a neurologist who is an expert in CMT, who took the time to understand my individual battle with it, and gave me an official diagnosis. She explained how all the other physical problems I'd been dealing with stemmed from my CMT, and helped me come up with a game plan for addressing it all. And she told me that, while 10 years ago there weren't any real treatments, there is a significant amount of genetic research being done today that may lead to treatment and maybe even a cure within my lifetime. Best of all, she gave me not only a diagnosis, but a prognosis. And it wasn't all bad.

While I will have to undergo permanent pain management and therapy, she told me that given the trajectory of my disease, she is convinced that I will maintain functional use of my legs and hands for the rest of my life, without the need for a wheel chair. It was the first time I'd ever cried tears of joy in a doctor's office the first time I'd ever allowed myself hope for the future. I only wish I had confronted this and found her sooner.

I know that many of you experience the same struggles, some more than I. But there is always hope for the future. While we can't control the fact that we have this disease, we can control how we respond to it. I don't want anyone, particularly the youth of today who are battling this disease in silence, to waste decades like I did, hiding from the disease, hiding from themselves and from society. Let the truth set you free. Take control of your disease. *Own* it, don't let it own you. And don't ever give up hope because you're not alone. Every time you face your stairs, we are all out there with you, reaching out our hands to support you and cheering you on. ★

DONATIONS WERE MADE TO THESE CMTA "CIRCLES"

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Mount Vernon Chapter No 97 OES

WALK WITH ME FOR CMT
Ms. Laura Fava
Mr. Chris Helferty
Ms. Rebecca Hundert

CHARCOT-MARIE-TOOTH
CIRCLE OF FRIENDS

Meet Becky Lee:
The Face of the CMT Exercise Video Series

BY DONNA DEWICK

Rebekah Lee is the perfect physical therapist to lead the CMTA's seven-part exercise video series. Not only is she friendly, with a charming Welsh accent, but most importantly, she has CMT. She knows the challenges that people with CMT face—and even has the occasional wobble on screen, just like they do.

Becky got involved in the CMTA's exercise video series via the CMTAthletes Facebook group. Group administrators reached out to Becky to ask if she would like to help create a video series suitable for people with CMT. Working alongside CMT research physiotherapist Dr. Gita Ramdharry and the CMTA, Becky not only demonstrates the exercises, she is producing the videos. Becky says she is "thrilled to be able to contribute in a positive way and to be able to share the benefits of physiotherapy for CMT on such a big platform and to reach so many people across the world."

The exercises are designed to be done by CMTers with a wide range of symptoms in the comfort of their own homes. Launched in February, the series focuses on functional improvement for people living with CMT. "Because there is little, if anything, that can be done about the nerves themselves, I want to help people to manage the musculoskeletal symptoms associated with CMT to help them keep active and enjoy a better quality of life," Becky explains.

As experts in movement and function, physical therapists, or physiotherapists as they are known in the United Kingdom, help people stay active and healthy by rehabilitating them after an injury and by playing a proactive role in injury prevention and health promotion.

Becky was diagnosed with CMT during her first year of physiotherapy studies at university in the U.K., where becoming a physiotherapist includes extensive training in anatomy and physiology, biomechanics, pathologies, injuries, exercise and manual therapy treatments, and the clinical reasoning process.

According to Becky, as the class started to work its way through the practical teaching sessions, including physical tests and gait analysis, it became obvious that something wasn't quite right with her. She had numb patches on her feet and a slap-footed gait, particularly on her left side, among other quirks. After a practical session on reflexes in which none of her classmates could elicit a response from her, a lecturer suggested that she look into it. She received her diagnosis of CMT Type 1A a couple of weeks before her first-year exams.

Becky, who works at Baseline Physiotherapy in Caerphilly, Wales, says the most challenging part of the videos "is doing something so open about a disease that still feels quite personal." Most of the time, she says, she feels as though she has come to terms with CMT and is in a peaceful place about it. But she still has her moments: "It is challenging to face this head on and to put myself out there—and to get my feet out on camera when I've trying so hard to hide them for years! Knowing that people are finding the videos helpful and are as a result taking steps to get stronger and be more active makes it all worthwhile," she says.


Physiotherapist Becky Lee

Outside of her work as a physiotherapist, Becky loves to go to the gym, spend time with her family, and walk her dog at the beach near her home. When not at the beach or at work, she is busy planning her wedding. You can read more about Becky's CMT story at: https://baseline-physio.wordpress.com/2015/01/31/me-myself-and-cmt.

The CMT Exercise Video Series is located at https://www.youtube.com/user/CMTAssociation. Email info@cmtausa.org with any feedback for Becky or ideas for future episodes. ★

Carol Andrews Bests Opponents In Words with Friends Tournament

After six long weeks of holding off her competitors, Carol Andrews was victorious in the CMTA's latest Words with Friends tournament. Forty contestants competed in the *CMTA Word Lovers WWF Tournament*, which kicked off on Valentine's Day. The tournament raised $1,000 for the CMTA, making it the most successful CMTA WWF fundraiser to date.

Carol has participated in all three WWF tournaments, placing second in each of the previous contests. The Silicon Valley resident is an easy-going, joyful and spry 70-year-old, retired from teaching elementary school. Carol is looking forward to downsizing her empty nest now that her two children have grown and begun families of their own. She says living in a smaller home with less to maintain will allow her more time and energy to devote to her two grandchildren and her sewing hobby.

Conserving energy for the important things also allows Carol to deal with the foot-drop and other effects of HNPP (Hereditary Neuropathy with liability to Pressure Palsies) that have become more prevalent in her life. She doesn't dwell on all that impaired-extremities-and-AFOs stuff, though, and talking with her is like having a warm conversation with an old friend.

Post-retirement, Carol found her passion in wearable art. A programmable embroidery machine allows her to create custom designs with a computer and then embroider them on clothing that she also sews herself. In addition to wearable art, Carol has used the technique on quilts and wall-hanging tapestries, but she most enjoys creating custom clothes for her granddaughter and matching designs for her granddaughter's baby dolls.

Carol says WWF keeps her mind active and she always has a game or two going. She has become WWF buddies with her ultimate challenger in the tournament, second-place winner Mary Ann Kirkland of Langley, Washington. Both women love people and miss seeing them now that they are retired. WWF gives them the opportunity to keep up with family and friends in a casual and entertaining way and meet others with similar verbal skills, like third-place winner CMTA CEO Pat Livney. Tournament prizes included Amazon gift cards, a CMTA STAR membership, CMTA "Shark" T-shirts, and CMTA car decals.

The CMTA sincerely thanks all WWF participants, not just for their registration fees, but also for promoting awareness of Charcot-Marie-Tooth disease and our efforts to eradicate it by encouraging friends and family to join in on the fun.

—Joyce Steinkamp

CMTA REMEMBRANCES

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

Honorary Gift:
In honor of (person you wish to honor)
____
Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____

Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding
☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)
____
Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____

Amount Enclosed: ______________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card # ______________________________
Exp. Date ______________________________
Signature ______________________________

Gift Given By:
Name: ______________________________
Address: ______________________________
____

October in Paris

BY DENISE SNOW

Last night I had a dream. I walked past a group of people at a banquet. When I say walked, I mean strode without my AFOs, without my trusty walking sticks, without CMT2E. My friends and family were in attendance at this banquet. I like to believe that it was a celebration of the end of CMT. WOW!

A year ago I had another dream. The dream was to spend a month in Paris with six other women. It was not a dream; it was an invitation from friends and family members who were celebrating significant birthdays in the City of Lights.

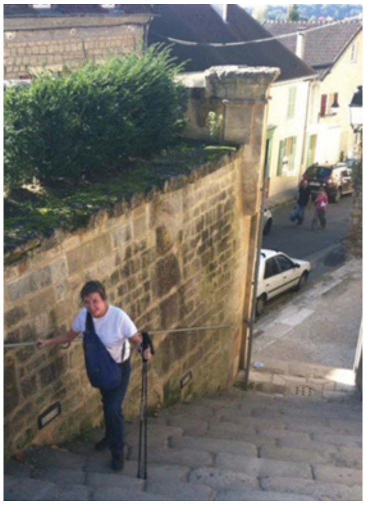
My first thoughts: How could I possibly do that? How could I possibly navigate the cobblestone streets? How could I possibly walk through the Louvre, Versailles and all the many sights of Paris? How could I possibly use the subway (Metro)? But I have always believed that you don't know what you can do until you try, and if you don't try you're missing out. My philosophy has always been to do as much as I can as long as I can. After wringing my hands for a few days, I listened to my husband's common sense: "Why would you not take this opportunity of a lifetime?"

So, with support from friends and family and physical therapy to strengthen my core muscles and to learn how to effectively use my super lightweight walking sticks, I spent the whole month of October 2014 in Paris! Yes, I did it all. Even with CMT2E, I navigated all of it.

We stayed in the Bastille area, around the corner from a subway stop, and across the street from a *boulangerie* (bakery), *charcuterie* (deli), and *magasin de fromage* (cheese store). From there we explored every corner of the city. We did something different every day for the entire 31 days, and believe me, 31 days was not enough. The only thing I couldn't do was climb the narrow steps to the tower at Notre Dame, and the only time I needed help was with my baggage, two very small blips in the overall scheme of things. We also took several day trips and one longer trip to Montpelier, where my friends laughed as I dipped my fingers in the Mediterranean. For the entire month, there was an adventure around every corner.

Now, when asked about the best part of Paris, my response is, "Everything!" When asked about my least favorite I often say that the subway steps were laborious. Maybe the most difficult part of all was the fear that I would not be able to meet the challenge. Silly me. Even with CMT, with the help of my friends and my family's backing, I did it all!

The moral of the story is that CMT is challenging, but a positive attitude along with perseverance can allow us to do just about anything! ★



Parisian for a month Denise Snow

SMALL DOSES, BIG IMPACT

Are you energized by the wealth of information you read about in *The CMTA Report*? Are you considering making an investment in the CMTA to allow us to continue the programming and research that is so meaningful to you? Please consider making a monthly gift to the CMTA. Your fellow community members give anywhere from $20 – $250 a month to the CMTA. Whatever giving level is right for you, it all makes an impact. Please visit www.cmtausa.org/donate to make your monthly gift today!

CMTA BRANCH NEWS

- **San Francisco Bay Area, CA**

The branch's first meeting of the year was a barbecue where members caught up, shared stories, and heard updates about STAR from branch member Elizabeth Ouellette, vice chair of the CMTA Board of Directors. The branch also discussed having semi-monthly meetings spread throughout the Bay Area, as well as some casual meetups in between regular meetings. The branch is also working hard to expand its resource directory of doctors and medical specialists who are well versed in CMT. Members were urged to utilize the CMT Center of Excellence at Stanford when possible because the CMT community data is being collected there. Last but not least, Tau O'Sullivan's daughter, Sesilia, ran a lemonade stand with her friends on the day of the barbecue and collected more than $500 for the CMTA.

- **Washington, DC**

Thirty people turned out at the March meeting to hear Trish Dranchak, a CMT researcher at NIH. Trish is a molecular biologist with a focus in molecular genetics, currently working in the Assay Development and Screening Technology group at the Chemical Genomics Center in the National Center for Advancing Translational Sciences (NCATS) at NIH. For more information about Trish's work on CMT1A, visit the following link on the CMTA website: http://bit.ly/1xokhU6.

- **Sarasota, FL**

Physical therapist Margherita Charania demonstrated exercises that people with CMT can do while lying down, sitting or standing at the March 24 meeting of the Sarasota, FL CMTA Branch. Charania, a physical therapist with Sarasota Memorial Health System, emphasized that exercise is very helpful to keep people with CMT moving and flexible. Members shared anecdotes of how they adapt to various situations, and many of the stories brought laughter and acknowledgement from the members.

- **Tampa Bay Area**

Two new members joined 24 members at the latest meeting to hear three guest speakers from Assured RX give a presentation on pain creams and supporting compounds for neuropathic pain. These compounded creams, which are produced entirely from components provided by state and federally licensed wholesalers, are designed to deal with a number of aliments including acute and chronic pain. The next meeting is on Saturday, May 16 at 10:30 a.m. The meeting will be at St. Anthony's Hospital in St. Petersburg, Florida, and MDA clinic neurologist and CMT friend Dr. Franklin will be speaking.

- **Indianapolis, IN**

Midwest Regional Branch Manager Michelle Hayes presented a slide show on CMT, the CMTA and STAR at the branch's most recent meeting. She updated the group on how to register with the RDCRN, how to get genetic testing, and the upcoming Patient/Family Conferences in Chicago (half day) and Nashville (full day). Seven new members attended the meeting and joined in the discussion about CMT, the branch's upcoming CMT All-Star Walk4CMT in September and future guest speakers. The next meeting will be June 6.

- **North Iowa**

At its inaugural meeting on February 21, the group discussed CMT, how to get members involved, fundraising and future guest speakers. The group also nominated a secretary, signed members up on the CMTA website, talked about starting a resource directory and how to promote awareness. Misty Johnson from Disability Rights Iowa spoke to the North Iowa group on April 18. Disability Rights of Iowa assists people between the ages of 14 and 65 get disability benefits while continuing to work, help people with disabilities get training for new careers, and build up their skill sets for their current jobs.

- **Ashland Tri-State**

Ten people attended the branch's inaugural meeting April 18 in Ashland, Kentucky—four CMTers and six family members. Members shared stories, ideas, and plans for the next meeting, which will be held from 11 a.m. to 2 p.m. on May 16 at the Ashland Public Library in Ashland, Kentucky. The group plans to have a number of guest speakers, including a representative from The Brace Shoppe in Huntington, West Virginia, a neurologist, a physical therapist and a counselor/

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CMTA Branches

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

CMTA BRANCH NEWS

(continued from page 16)

psychologist. The group is contacting the local television station and newspaper to see if they will do stories on CMT.

- **Easton, MD**

Licensed acupuncturist Katherine Binder explained the basics of this form of Chinese medicine to 16 members of the Easton, MD CMTA Branch at their March meeting. Binder, owner of Eastern Shore Acupuncture, shared details of her training in New York and Beijing and some of the implements she uses in her practice. She passed around delicate needles, a small glass bowl used for “cupping,” various sized tuning forks used to treat children or needle-phobic adults, and jade (a stone that tends to be cool) scrapers and rollers. Binder, who treats many patients with neuropathy, explained how acupuncture can help reduce its effects and help with balance and proprioception.

- **Southwest Michigan**

Meeting on March 19, six branch members welcomed guest speaker Major Sam LaBara, a master trainer in resilience who provides training for the Army National Guard. Members discussed some of the myths about resilience, ways to develop and strengthen resilience, and how to apply these techniques to coping with CMT. A representative of GeneDX, the genetics testing company, will be presenting at the group’s next meeting May 14.

- **Central NJ**

The Central NJ CMTA Branch met March 14 at CentraState Medical Center, in Freehold, New Jersey. Thirteen people braved a dreary rain to hear CMTA Social Media Director Bethany Meloche talk about living with CMT in a presentation called “Tumbling Forward.” Following Bethany’s presentation, Laurie Lasky from Allard led a discussion on bracing alternatives, including Allard’s stronger, custom-made BlueRocker, which has a much stronger post for those who tend to break their braces. Group members went on to discuss other helpful products, including Socks for Life and Dr. Comfort Shoes, which were described as light, comfortable with braces and orthotics, and “not old man orthopedic shoes.”

- **Portland, OR**

Meeting in Beaverton, Oregon on April 14, 13 group members

THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS:

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learned for the first time that they are now the Portland, OR CMTA Branch instead of a Support and Action Group. The new name more clearly identifies the group's function, but does NOT reduce the goal to support one another. Branch leader Warren Beals presented a summary of CEO Patrick Livney's report on the encouraging advancements in STAR research and shared Elizabeth Ouellette's Quarterly Review of reports from various department heads in CMTA and their activities. West Coast Regional Branch Manager Tara George, based in southern California, was the guest speaker. She shared the resources available to the branches, and put the CMTA's research activities in a global perspective. The next meeting is July 9.

- **Nashville, TN**

Sixteen people turned out for the first branch meeting of the year March 7 at the Pi Beta Phi Rehabilitation Institute. Branch Leader Bridget Sarver talked about the walk the branch is holding at Long Hunter State Park for the CMTA All-Star Event in September and about getting corporate sponsors for the event. Guest speaker Penny Powers, PT, MS, ATP, from the Seating & Mobility Clinic at Vanderbilt, told the group how she deals with her foot pain and how the physical therapy that she does helps. The next meeting in June will be a picnic, with the exact location, date and time to be determined.

- **Savannah, TN**

Four members attended the branch's March 28 meeting, including the North Alabama co-leader Todd Oyen. Members caught up with each other, discussed fundraising, and updated everyone on the CMTA. ★

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THE CMTA Report

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www.cmtausa.org

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)
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, 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-Fluouracil
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)
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Negligible or doubtful risk:

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

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.