

THE CMTA Report

NOVEMBER/DECEMBER
2013

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ www.cmtausa.org



OUR MISSION:

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

OUR VISION:

A world without CMT.

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Join the Family; Join the Fight

Did you know that the CMTA has never been closer to identifying a first treatment for CMT? Did you know that the CMTA is overseeing a world-renowned key opinion-leader network comprised of investigators and institutions in eight countries that are taking part in the fight against CMT? Did you know this is the only coordinated and integrated effort in the world designed to find pharmaceutical compounds which will slow, stop, or even reverse the progression of CMT?

Charcot-Marie-Tooth is the name for an inherited peripheral nerve disease for which 70 genes have been identified as a cause. Some types are well understood; CMT 1A, 1B, 2A, 2E and X, and others are just becoming better known—type 4, for example.

The researchers involved are working diligently every day to better understand all types of CMT, the manifestations of these disorders in people, and how they might stop the progression of the disease.

The CMTA has been the leader in funding these researchers. Since 2008, when STAR (Strategy to Accelerate Research) was born, the CMTA has committed over \$4 million to translational research dedi-



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cated to identifying pharmaceutical drugs which will treat CMT. Since 2008, major discoveries have been made and strategies to continue our successes are currently ongoing.

But, we are not finished yet. There are still discoveries to be found before we reach our goal of

delivering treatments for those with CMT, and ultimately, a cure for CMT. We know we can accomplish these goals. We know that we have the right framework in STAR, the right combination of researchers, and the state-of-the-art technology to reach these goals. We also understand the value of bringing collaborative partnerships focused on drug development on board. Major pharmaceutical companies are preparing to join the CMTA STAR effort to help us reach our milestones!

In short, we know we will deliver treatments for multiple types of CMT!

But we cannot do it alone.

The CMTA needs your help!

The family at the CMTA is all personally affected by CMT: four of the six members of the CMT staff have CMT; the other two love a person with CMT.

Every member of our Board of

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Helpful Products for
Daily Life from an
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Special Thanks for Exceeding the Warfield Family Challenge

So many friends, old and new, rose to help meet the Warfield Family Challenge during 2013! The Challenge was to match our donation of \$150,000 and, oh, did that ever happen.

As of November 1, the amount given to the CMTA by so many of you was \$195,645! Those 325 gifts brought the total to a wonderful \$345,645 for CMT research. There is still so much to do and so much more money to raise, but this was an exciting and successful campaign. Thank you, everyone!

The names of those who thoughtfully helped to meet the Warfield Family Challenge are listed below.

—Seth & Missy Warfield

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Adapting to Meet the Needs of Daily Life

BY TIMOTHY ESTILOW OTR/L, OCCUPATIONAL THERAPIST,
THE CHILDREN'S HOSPITAL OF PHILADELPHIA, Estilow@email.chop.edu

As an occupational therapist, my goal is to help individuals with CMT maximize their performance in Activities of Daily Living (ADLs). There are several ways to address improving independence in the completion of ADLs. Rehabilitation often focuses on specific performance components or areas (hand strength, balance, range of motion, dexterity, muscle endurance, etc.) that are limiting function, and attempts to remediate them are made through specific therapeutic interventions. However, these interventions may require a considerable amount of time before a functional improvement is noted, and in some cases improvement may not be possible.

Instead of solely following a standard remediative approach, I prefer to establish a program that is inclusive of remediation exercises, compensatory strategies, and the use of adapted equipment. Following a comprehensive evaluation, consisting of The CMT Pediatric Scale (CMTPEdS) or CMT Neuropathy Scale (CMTNS), an ADL screen, and a patient/caregiver interview, goals are established with the primary focus being to maximize function immediately with the use of compensatory methods and adapted equipment as needed. In addition,

The inability to use the thumb for grasp, manipulation, and stability creates many challenges.

specific therapeutic activities are identified to address the performance level deficits. The ultimate goal is to remediate specific skills/areas to allow for full independence without modifying tasks or using adaptive equipment; however, this isn't always possible.

Decreased thumb mobility, hand weakness, poor intrinsic function, ulnar clawing, and impaired sensibility are all

common clinical manifestations of CMT that can impact hand function and the ability to complete ADLs. The inability to use the thumb for grasp, manipulation, and stability creates many

challenges, especially in the areas of managing clothing fasteners and opening containers.

Decreased hand strength can limit the ability to open bottles, maintain grasp on tools, and participate in leisure activities requiring hand strength (racket sports, golf, baseball, etc.).

Clawing of the digits can prevent opening of the fingers for grasp of large objects and make typing and other isolated finger movements requiring intrinsic function difficult. Finally, impaired sensibility can result in dropping of objects, injury to the hand, and poor ability to manipulate small objects such as buttons, snaps, zippers, etc.

The use of compensatory strategies and adapted equip-

ment aims to utilize the motor/sensory skills that are intact along with a strategy /device that compensates for impairments to improve performance in specific tasks. The following are some examples of low-tech, affordable, adapted equipment or compensatory strategies that can assist with completion of ADLs for individuals with CMT. Be sure to consult with your local therapist to determine which items would be most helpful to meet your individual needs.

DRESSING

Button Hook. Provides a built-up handle to allow for a gross grasp on the device while eliminating the need for fine grasp and manipulation of the button.



Adapted Laces. Provides elasticity to the laces to allow the foot to get into a securely "tied" shoe, while eliminating the need for hand dexterity to tie shoes.



(Slip-on shoes such as Crocs, Uggs, and Danskos also eliminate the need to tie, but

(continued on page 5)

Rabia Chaudhry is a PhD candidate at The ANZAC Research Institute, The University of Sydney. She received a CMTA travel award to attend last summer's International Consortium in Belgium where she presented this research.

Examining CMTX3 Families with Next Generation Sequencing Technologies: An Update

The focus of my study has been on X-linked inherited forms of CMT, as it accounts for 20 percent of all cases. In X-linked inheritance, the mutation cannot be passed from father to son because the mutant gene is located on the X chromosome. The father can only pass the mutation to his daughters.

There are six different subtypes of CMT known to be located on the X chromosome and each is caused by a different gene mutation. To date, four mutations are known to cause X-linked CMT: GJB1 (CMTX1), AIFM1 (CMTX4/Cowchock syndrome), PRPS1 (CMTX5) and PDK3 (CMTX6). The Northcott Neurobiology Laboratory at Concord Hospital in Australia is one of the leading research groups working to identify the cause of different inherited neuropathies, including CMT. Our research group has the largest collection of patients diagnosed with X-linked CMT type 3 (CMTX3). To date, the pathogenic cause for CMTX3 remains unknown. The recent advances in sequencing technologies now provide us with powerful tools

for gene discovery. Using these technologies we are investigating the genetic cause for families with CMTX3 disease.

Originally, CMTX3 was reported in 1991 in two small American families. Using genetic linkage studies, the probable location for the mutation was located on the X chromosome, spanning a region of 31.2 megabases (Mb). A decade later two additional families of English, Australian and New Zealand ancestry were discovered who mapped to the same chromosomal region as the original American families. Fine mapping with these families narrowed the location of the CMTX3 mutation to a 5.7 Mb region.

Recently, using new sequencing technologies, we have examined the coding regions of one of the original American families with CMTX3. The data was filtered using specific criteria to identify a novel gene mutation in the family. The analysis did not find a gene mutation in the CMTX3 region but identified a previously reported mutation (N88S) in the gene Berardinelli-Seip congenital lipodystrophy 2 (BSCL2). Mutations in this gene

cause several neurological disorders.

A similar method was used for the large multigenerational English/Australian/New Zealand family, in which a more comprehensive sequencing tool was used, known as targeted capture. Targeted capture sequencing is designed to capture a specific region of interest and provides information on the coding and non-coding regions of the genome. By performing a target capture of the 5.7 Mb region, a novel non-coding mutation was identified. Bioinformatic analysis of this novel non-coding mutation suggests it may be important for gene regulation. Further experiments are required to understand the underlying mechanism causing the length-dependent neuron death.

This study demonstrates the power of new sequencing technologies as tools to identify gene mutations for small families in the absence of statistically significant linkage data. With the aid of these technologies, we have been able to identify a possible candidate variant for the statistically significant linked CMTX3 families. —*Rabia Chaudhry*

JOIN THE FIGHT

(continued from page 1)

Directors is deeply invested in finding treatments because of his or her personal connection to CMT. Our thousands of support and action group members,

online community members, and social media fans and followers are all committed to our cause to improve their quality of life and make needed resources available.

We are giving to the CMTA—won't you join us?

Please join our family members who are committed to fighting for those with CMT. Donate today and your gift, large or small, will help all of us achieve our mission of fighting to develop treatments and, ultimately, a cure for CMT. ★

ADAPTIVE DEVICES

(continued from page 3)

consultation with a physical therapist should be considered to determine if the shoes provide appropriate stability or can accommodate any bracing protocol you are following.)

Zipper pulls/Key Ring.

Provides a larger surface area to grasp or place finger through while eliminating need for precision pinch.



Button Extenders.

Allows you to keep jeans and dress pants buttoned while providing an elastic component to allow the pants to be easily pulled up/down over the hips.



(Buttons may also be sewn on the pants, and Velcro can be adhered to the insides to keep them fastened.)

BATHING/ GROOMING

Built-up Handgrips.

Can be used on toothbrushes, combs, razors, etc., to allow for ease of grasp when limited finger movement is present. Textured grips or the use of sticky tape can also be used to provide additional sensory input for those with decreased sensibility to prevent grasp slippage and drops.



Ergonomic Nail Clippers.

Provides larger surface area and non-slip pads for easier grip for those with sensory/motor impairments.



Loofah and Pump Soap Dispenser.

Provides ease of grasp and eliminates the dropping of soap for ease of bathing.



MEALTIME

Rocker Knife. Provides a built-up grip allowing for use of forearm muscles instead of a weaker lateral pinch with the fingers.



Jar Opener. Provides assistance opening objects of varying diameters by allowing use of stronger proximal muscles and prevents slippage.



Tremor Canceling Spoon.

Spoon adjusts to compensate for tremor when eating and reduces spillage for those with unsteady movement.



Handled Mugs/ Textured Grip.

By using a handled mug, you can grasp the mug itself and use the handle to provide additional support or to prevent slippage/dropping of the mug. In addition, the textured grip gives increased sensory input for improved grasp. Finally, the small opening allows for ease of drinking without spilling in the case of tremor.



HOME/OFFICE/ WORK

Adapted Scissors.

Can provide assistance in opening or closing scissors; allows for use of all fingers to cut for those with weakness or use of palm to depress mounted scissors for those without finger movement.



Ergonomic Pens.

Aid in reducing the effort to maintain grasp on writing implements and allow for a more stable and secure grip.



Active Hands

Grip Aid. Provides external support for grasp on tools, sports equipment, weights, etc., and requires minimal hand function to put on. ★



Finding Freedom: My Adventures with Woodrow

BY GINA MARIE MONDEL

I was first diagnosed with CMT when I was about 12 years old. It was the late 1980s and not much was known about this neuromuscular condition. With my diagnosis came multiple, dreaded trips to the DuPont Hospital for Children, which I remember as being quite uncomfortable. I developed abhorrence to the doctors' recommendations to refrain from most physical activities. I was stubborn, and this shield became my coping mechanism as I wasn't ready to admit I was challenged with a physical disability. This tough exterior also helped me to tolerate my classmates and teachers, who didn't understand the disease or necessarily believe in it.

As an escape from the many questions and glares about my altered gait, I found comfort in animals. My upbringing was blessed with dogs, cats, and horses that lived on the property. They didn't care how I walked or if my hands trembled when I petted them. These animals brought me great joy and comfort, but the horses were able to provide me much more: freedom. These big, beautiful creatures could offer me heartfelt hugs and a soft shoulder to shed tears of frustration, but most importantly, when I was on sitting on their backs, I was not hindered by physical limita-

tions. I was able to explore, to run faster than any human, to travel for miles without any pain or feebleness in my legs. When I was with my horses, I wasn't disabled, and the happiness they provided helped me forget all my discomfort and the daunting doctors' appointments.

This early love for horses led to my involvement in equestrian jumping competitions. Though it was obvious that CMT impaired my riding ability, I didn't care. I did the best I could, and my love for the horses and the sport was enough for me. My passion motivated me to work

My stubbornness became my coping mechanism.

endlessly to improve, and my stubbornness prevented me from giving up. Upon graduation from college, I started to show at the larger and more prestigious competitions, recognized as among the most competitive in the country. My "ticket" to riding at these shows was a very special horse: Woodrow, my greatest love. There was just something about that horse that worked for me. I enjoyed success on him from our very first show together, and it was if my riding ability was no longer thwarted by CMT. As years passed, Woodrow proved to be my greatest partner, earning a myriad of championships and blue ribbons. Though, after several years of showing him, I was facing the

reality that age was starting to limit his physical capabilities. Unfortunately, as Woodrow's days in the show ring were becoming numbered, the physical limitations of CMT were beginning to hinder me more.

The weakness in my calf muscles from CMT had always affected my riding. It was something that I had just learned to accept. Having shown Woodrow for almost nine years, he witnessed the decline of my health and the onset of atrophy in my leg muscles, allowing him to "understand" the nature of my disability. There were so

many times when he put in an extra effort to ensure that I stayed on his back when he sensed

I was imbalanced in the saddle or corrected mistakes by not listening to my command, to ensure our safety in jumping to the other side of the jump.

When I was in my mid 20s, I had a bad fall from Woodrow when competing. Though I gritted my teeth and brushed off my fall, it was enough to scare my trainers, who always worried about my wellbeing as a rider with a neuromuscular condition. My only concern was about Woodrow, who had sustained a minor injury in the accident. As he was an older horse, and I wanted to enjoy him long past his years in the show ring, I opted to retire him from showing, as I had other horses to compete. Though my trainers supported this decision, they

were concerned about my physical ability to compete with CMT and not have the reliable and dependent Woodrow to guide me. After a grave conversation, which ended with tears in all our eyes, my trainers explained that while Woodrow and I made a great pair, the weakness in my legs was becoming more apparent, and they were worried about my safety when competing. They said that they would never be able to buy another horse, or teach another horse, that understood what Woodrow did. Without him, they would not allow me to show.

I was devastated. I understood their concerns and knew that this decision was in my best interest, but I was not willing to surrender my passion so easily. The perseverance I had developed from all the doctors dictating what I could and should not do physically, all the gym teachers who felt that CMT was an excuse to get out of class activities, and all the long stares when I walked down the hallway motivated me to find a way to get back in the show ring.

Though CMT posed physical limitations, there were parts of my body that were still healthy and I was determined to strengthen them to compensate for my atrophied calf muscles and weak hands. With the threat of not being able to follow my passion, I could no longer ignore my physical condition. Drying my tears of frustration, I sought help from a physical therapist.

I remember the early days of my physical therapy routine including five minutes on the recumbent stationary bike and

using soup cans as weights. From such humble beginnings, I persevered six days a week in the gym, pushing past insecurities and focusing on possibilities, always trying to improve. More than ten years later, I am proud to say I routinely bike 12-15 miles, and I have developed my core and arm muscles beyond my initial expectations.

My physical therapy gym routine has become a lifestyle for me. While my original motivation was to get back in the show ring, my workouts have rewarded me with relief from fatigue and weakness due to CMT. I am able to walk better and further because other muscles can compensate and power my legs. Also, I am more physically fit. The core strength I have gained is an integral component to my daily life activities, as well as the key factor to riding my horses.

I am forever grateful that my journey, though frustrating and difficult at times, led me to

realize that physical fitness and core strength were vital elements in living with CMT. Despite all the appointments with doctors, surgery, and leg braces, it was a bad fall off of my favorite horse that motivated me to discover a way to cope with a disability to which I was not ready to surrender. If I convey any one message to those affected with CMT, it would be to not let the physical limitations define or inhibit a lifestyle. I realize it is difficult to cope with the complications and hindrances of the disease, but being victim to CMT won't build any core muscles or increase quality of life.

As my journey of living with CMT continues, I often reflect on this story I have shared and remember just how far I have come and how much better I now fare. And for anyone who is wondering, I still enjoy riding Woodrow. He is 24 and remains my inspiration, as well as my best friend. ★

Gina still enjoys the partnership she has with her horses.





WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,

My son is 17 and is applying to colleges for admission next fall. He has CMT, has just begun wearing braces, and has announced to us recently that he is gay. We are not thrilled by this news, although my husband and I are not completely surprised. We love him very much and we are just worried that having two challenges like this will be too much for him to handle.

Frankly, we are okay with his sexual preference but concerned that he will have a difficult time meeting someone with whom to have a lasting relationship. Do you have any advice?

David Tannenbaum answers:

First there is good news. He has great parents who love him and want him to experience a full life that includes an intimate relationship with someone he loves and who loves him. He seems to know who he is and has had the courage to come out to you which is also great and shows a



David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life," says David. Write to David at info@cmtausa.org.

lot of strength. Fortunately, in these times we live in, there is much more acceptance of the LGBT community than ever before and that will help. Many colleges have gay and lesbian organizations to support their students. His courage and acceptance of himself just as he is will be vital, because there is, sadly, disability discrimination within the gay community that focusses more on physical attributes than on emotional or personality traits.

Overall, being gay and having physical challenges poses specific issues for students on college campuses. Their needs are often overlooked because typically campus support services focus on only one specific cultural identity, as opposed to addressing students' multiple cultural identities in an integrated manner. There are departments that address one or the other, not both. A gay student with a disability might be left with a disjointed college experience. Many gay students with physical challenges report that dealing with their physical disability is more important because it is more visible.

I do believe, however, that a strong gay support system is imperative, and most colleges

have gay centers that could provide this for him. A good therapist who is knowledgeable about the specific issues that gay students with disabilities face can be invaluable particularly at this time. When one participant in a study of gay students with disabilities was asked what advice he would provide to future gay students with a disability, he responded that they should, "Be themselves. Don't try to cover up any part of you, because you are unique; you are special in your own way. We are humans, no more, no less. That's a quote that I live by from the Dali Lama." If your son can be that person who sees an obstacle as a challenge and seeks a way to overcome obstacles, he will be that much more appealing to the right guy. Gay men and lesbians who are physically challenged have the same needs for physical intimacy as anyone else, but too often they are viewed as asexual. It's time to come out of both closets and be viewed as whole and integrated human beings with loving hearts and passionate energy. ★

(The writer of this column is happy to announce his marriage in New Jersey to his long-time loving partner of 35 years on November 1, 2013!)

FLORIDA CMT PATIENT FAMILY CONFERENCE: A HUGE SUCCESS

On November 9, 2013 the CMTA hosted a patient/family conference at the Holiday Inn in Lake Buena Vista, Florida. Over 185 attendees enjoyed presentations by notable CMT specialists Dr. Michael Shy, Dr. Richard Finkel, Dr. Stephan Zuchner and orthotist Sean McKale. Representing the CMTA, CEO Patrick Livney and Director of Community Relations Jeana Sweeney also presented information about the STAR research program. Children in attendance enjoyed a special visit to the Walt Disney World theme parks.

A full write-up of this event will appear in the January/February issue of this newsletter.

Why an AFO?

(Even for those more mildly involved)

BY SEAN MCKALE CO, LO

Ankle-Foot-Orthoses (AFOs) are the most commonly prescribed medical aid. The reason an AFO is prescribed for someone with CMT is because of discordances or weak musculature above the ankle. This could be affecting both muscles that lift up your ankle as well as those that help to push your ankle downward.

Due to the chronic nature and the slow onset of symptoms related to CMT, it can often be seen as a sort of failure or a turning point in the degree to which the disease is affecting an individual's life. It is true, in many cases, that an individual could benefit from the use of an AFO long before a physician would write the prescription for one.

There are a variety of AFOs, some much more flexible than others, so determining the proper prescription for the individual who needs the device can be an art in itself. There are many decisions that factor into the prescription of an AFO design: an individual's physical presentation and limitations, material selection, trim lines, whether a joint will be used, and what the AFO will be used for. With more mild symptoms, as the day goes on, someone with CMT is likely to begin taking shorter steps, flexing the hip joint slightly more to avoid catching the toe, and landing

with a reversal of toe-heel progress and then back again. Eventually this is recognized as a high-steppage gait. These slight changes in gait can be extremely energy inefficient, but, because it happens in such a slow insidious manner, it can become a routine of life resulting in slightly less activity. The dog gets walked a little bit less, not as much time at the grocery store is being spent,

Slight changes in gait can be extremely energy inefficient.

or an invitation to join friends at a park is passed up.

The real goal of any AFO should be to *enable* and not *disable*! It should be used as a tool that allows you to

become more active, or, at the very least, to keep up your activity level. Additionally, there should be a reasonable expectation that it will assist in preventing joint deformity and in preventing injury that you are otherwise susceptible to because of increased muscle imbalances. In a perfect world you would be allowed the choice of these tools so that you could choose the right one for the situation.

Perhaps it is also better to discuss an AFO as a "dosage." Today's dosage is "taken," or used, when you are going on a hike with a friend, or only during your working hours. In my experience, CMT patients getting started with AFOs when they are more mildly involved, allows them to use the AFOs for situations that they seem fit for, rather than feeling they must

rely on them all the time. Reliance on AFOs might not always be good because a patient with CMT might have such a highly perceived benefit from wearing the AFOs that they feel they don't want to go without them, but that doesn't mean they can't.

Something you should think about, if you have pain, or fatigue, as a symptom related to your gait is that an AFO is a practical way of addressing those symptoms. If you aren't relating your problems caused by CMT to your gait, it might be something worth paying attention to and discussing with your physician. ★

THANK YOU...

We just had to share with you the news that we had the most amazing experience today. We had Jeana Sweeney come to our son Ethan's school and do a presentation about CMT for a group of 21 children aged 6-10. She was amazing and did an exceptional job teaching the children about



CMT. It was fun and informative! This is a program we would highly recommend to other parents for their schools. Our son Ethan was so proud of himself today, and it was amazing to see him shine as he did while he stood by Jeana as she talked about CMT.

We are so grateful to the CMTA for having a program like this and just wanted to share this amazing resource with you if you were not aware of it.

—Elizabeth & David Misener

Orthotic Bracing: My Story

DAVID MISENER, BSC, CPO, MBA

As members of the Advisory Board, we are asked to write articles once a year to share our expertise and stories. Since this is my first article, I thought I would introduce myself and my personal experience with CMT.

I am part of a family with CMT1B (grandfather, mother, aunt, uncle, 2 cousins, me and my son). Our form of CMT is early onset, and when I wasn't walking by 20 months my mother knew I had it. At the age

of 14, I had reconstructive surgery on my right foot (triple arthrodesis and phalangeal fusions) due to chronic sprains and instability. At age 15, I had spinal fusion (Harrington rods) due to scoliosis, which we now know is related to CMT. At age 23, I had a tendon transfer from my right third finger to right thumb to restore thumb opposition. The success of that surgery led me to have the surgery to my dominant left hand at age 24. To date, all of these surgeries

have been successful and have enhanced my daily life.

CMT helped me stumble into my career (pun intended). For the past 20 years, I have been practicing as an orthotist and prosthetist. My goal as an orthotist is to design, fabricate, and fit orthotic devices to enhance people's lives. I find it especially rewarding finding a solution in bracing that combines the orthotist and the patient in me. In building devices such as a foot orthosis

SAG FACILITATORS SPOTLIGHT:

Bridget Sarver, Nashville

I had not heard about CMT until I met my husband, but when I found out our son had it, it really pushed me to learn more and reach out to others about the condition. I learned about the Nashville group, and I jumped in to help the facilitator to raise awareness and funds for CMT and the CMTA. The group had a very sad turn of events when we lost the group facilitator, and I did not want to lose all he had tried to achieve here in TN, so I became the group facilitator.

Since we live in Nashville, our biggest fight has been getting people here to realize that CMT does not only stand for Country Music Television! We have made great strides by getting the proclamation for Awareness Month from the state of Tennessee, and we have actually gotten the word out to area high schools by having tables set up at various statewide events. We hope to continue to reach more people in the area by taking baby steps through blogs, tweeting, and social media. I truly hope in 2014 that we will be able to make a bigger impact in our area to continue our goal of raising awareness. December will be a big month as that will be the time to set up fundraisers for the coming year.

Just recently Gwen Redick stepped up to become the co-facilitator of the group! She has been extremely helpful to me and to the group. ★



Bridget Sarver and Gwen Redick co-facilitate the Nashville, TN Support and Action Group.

(FO), an ankle-foot orthosis (AFO), and a knee-ankle-foot orthosis (KAFO), etc., it is important to consider the biomechanics and physiological needs of my patients. If the device ends up in the closet from non-use, then the device has not helped anybody. (I, myself, have a few of these.)

I would like to see

orthotic management happen earlier for most CMT patients. Typically, as muscles weaken neutral foot/ankle alignment is lost. If you have, or are developing, a high arch, and long before you have muscle weakness producing a drop foot, a foot orthosis can help you maintain your alignment, balance, and stability. As muscle weakness continues, additional bracing may be required and is often much easier and requires less bracing if the foot/ankle structure is more neutral.

The common goal of the orthotic device for CMT is to:

- Maintain or correct joint alignment
- Prevent deformities and reduce orthopedic discomfort or pain
- Improve balance and stability
- Support weakened/lost muscles
- Increase mobility/endurance

Although I feel early intervention is helpful, I also feel it is very important to not “over-brace.” The body should be allowed to work and exercise the

muscles as long as it is occurring in the correct alignment. This is a difficult question which must be figured out between you and your orthotist, and open communication will improve this outcome.

Remember, the device should control or direct the deforming forces while keeping as much mobility as you can safely tolerate, while

correcting and supporting your body.

I believe the role of the orthotist is to educate the patient on design criteria in regard to the positives and negatives of each possible device. As someone with CMT, communicating your goals and needs/wants should also be part of the design criteria. Ultimately, you and your orthotist need to come to an agreement on the device selected. As a patient with CMT, you need to be aware that your practitioner may not have a lot of knowledge specific to CMT. Although your orthotist may be very knowledgeable about biomechanics, you might need to share information on how a device impacts you and feels on you.

I started wearing foot orthoses as a teenager to help stabilize and neutralize my feet. From a biomechanical standpoint, my feet were becoming typical CMT feet. The CMT foot typically is a cavus (high-arched) foot. This foot requires support along the lateral (outside) border to prevent the foot

from inverting (turning inward like an ankle sprain). Your muscles and balance will be at their best with neutral alignment. If your muscles weaken with CMT progression, then adding additional support such as an AFO to your foot/ankle complex will be much easier and require less bracing.

The photo at left shows the difference between an incorrectly posted FO (black) on the right foot and properly aligned FO (blue) on the left foot. Take note of the ankle position. Can you see the tilt? This creates instability. This simple FO can align your foot and improve stability and balance significantly.

The progression of CMT can lead some of us to require additional bracing beyond (or in addition to) a foot orthosis. Another device that provides more support than the FO is a supra-maleolar orthosis (SMO). This device is designed to offer additional side-to-side support; it can be used on its own or in combination with an AFO. AFOs can be made out of a multitude of materials such as plastic, metal, dense foams, silicone, or carbon, and all offer differing results.

If you have specific bracing questions, the CMTA has set up a specific forum to answer bracing questions. Go to: www.cmtausa.org and then to the Community; there you will find discussion groups. The one titled “Orthoses and CMT Discussion Group” is where you can post your questions or read other questions that have been posted and might give you information. ★



THE CMTA "CIRCLE OF FRIENDS"

Start the new year by creating your own fundraising Circle of Friends! Have your family and friends donate money to the CMTA on behalf of a birthday, anniversary, or special occasion. Need help getting started? You can email Jeana Sweeney at: jeana@cmtausa.org. Working together, we can create a world without CMT!

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THE THIRD ANNUAL WALK FOR CMT FERGUS FUNDRAISER was held on Sunday, September 29th, and it was a huge success! We had over 151 participants, both local to Fergus and from afar, with our furthest participants coming from New York! Everyone enjoyed the warm, sunny walk, and the children enjoyed face painting, the Archy coloring station, bubbles and more! What a great, inspirational day. The fundraising efforts went beyond all expectations, raising an unofficial amount of \$16,700, with donations still coming in! Everyone did a great job! We look forward to seeing everyone again next year!



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(continued on page 14)



Over 150 participants helped the Fergus Walk
for CMT raise over \$16,000 for research.

Dine and Dance for a Cure

While contemplating what I could do for a fundraiser for the CMTA, my friend said, "I know. Have a dinner and dance." My eyes got big with excitement, and I knew that was a great idea. Everyone likes to eat, and most people like to listen to music and dance. The planning of the event started then and there. The rooms were rented for the fundraiser; the menu was decided on; the band was lined up; the flyers were made; the invitations were printed, and tickets were sold. Everyone was so helpful and willing to donate time, money and items for a silent auction.

On Saturday, September 21, 2013, the Savannah, TN CMT

Support and Action Group hosted their first annual Charcot-Marie-Tooth fundraiser, "Dine and Dance for a Cure," with a silent auction. Approximately 100 people attended, and dinner was served buffet style



Angie Smith, Jamie Cagle and Reagan McGee organized the Savannah, TN, dinner and dance for CMT.

with smoked chicken, mashed potatoes, green beans, slaw, rolls, sheet cake and sweet tea.

A very close friend of mine (Jamie Cagle) began the fundraiser with a poem written by someone with CMT. I took

the floor, giving a big warm welcome to everyone present, and I explained to them in simple terms about the currently incurable Charcot-Marie-Tooth disease. The band Step N Tyme

took the stage and did a great job rocking the house and getting people in the mood to do some line dancing. The silent auction was a fun experience for all. It was a good way to raise money for the CMTA.

Everyone told me (especially the ladies) that they had a great time dressing up in their Sunday best, going to a dinner and dancing while learning about CMT and supporting a good cause. It made my heart burst with joy to see all those people there for us, the people living with CMT. I am proud to say that we raised \$3,500 on that special evening. The evening was dedicated to everyone there that was affected by Charcot-Marie-Tooth disease.

I want to thank everyone, from the bottom of my heart, who helped us put this big event together. Next year, we plan on it being even bigger and better.

Reagan McGee, TN Support and Action Group Facilitator

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(continued from page 13)

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Jewelry for Awareness

Introducing The Starstruck Jewelry Line

When Riverbank Handworks first realized that no one was offering a line of handcrafted awareness pieces for the CMTA community, we were hopeful for a positive response to our CMTstarstruck line. Wow, what a welcome! “I wear mine every day!” one client recently shared with us. Another, from Italy, went out of her way to order several pieces. Family members have even ordered multiples as gifts for their relatives. Because of your response to our CMTstarstruck line, we are offering five new limited-edition pieces for the Fall/Winter 2013-14.

These handmade pieces are selected and designed with the CMTA community members and their family and friends in mind. In fact, one of our crafters, Emily, has CMT2 and another crafter is a member of the CMTA. We’ve included bracelets strung on latex-free stretchy material with larger beads. We’ve responded to your requests for “storytelling” pieces and continue to offer classics. Our “one of a kind” creations will be available along with these limited-edition pieces.

The TriByz (priced at \$30) is a storytelling piece. You can see it in the first picture to the right. This design tells our CMT story. When Emily was diagnosed with CMT2, we were surprised to learn that one random gene protein alteration could make her vulnerable to such a wide variety of symp-



CMTstarstruck TriByz Bracelet: \$30

toms. It was the “shock” of that gene and how random it was that inspired the TriByz design. It shows that this gene didn’t conquer her life; it just altered the pattern to include something unexpected. It shows that a shock can also be a beautiful thing.

So when you are asked about your piece, please share your own CMT story! Please visit CMTstarstruck TriByz bracelet to see more pictures and to order this piece. We have only 45 available for the entire Fall/Winter, so get yours quickly!

The two Happy Beaded Stretchy Bracelets (priced at \$15) are smiles on a string. One is pictured to the right. We were encouraged by your requests to include some pieces strung on latex-free stretch material to make bracelets that would make you smile. “B,” our youngest designer and Emily’s best friend, wanted to take on that challenge. He is one of the happiest people you could meet and has been a great Riverbank Handworks designer/crafter on several



CMTstarstruck Happy Beaded Stretchy Bracelet: \$15

of our lines. This bracelet has larger statement beads, and can be slipped on and off easily. It has a whimsical quality, as it can be worn with a changing pattern by shifting the bracelet around to feature alternate beads. Please visit CMTstarstruck Happy Beaded Stretchy Bracelet #2 to see more pictures and to order this piece.

When you are considering birthday gifts, Christmas gifts or other holiday purchases, keep the CMTstarstruck line in mind as each purchase includes a donation to the CMTA. From May 1 through September 1, 2013, Riverbank Handworks donations to the CMTA have totaled nearly \$900!

If you or someone you know has CMT or you are interested in wearing your support for the CMTA and CMT research, or even if you just want a pretty piece that makes you smile, please visit Riverbank Handworks to check out all the pieces in our CMTstarstruck line. Remember, your purchase results in a donation to the CMTA. ★

Worrying About the Worst; Hoping for the Best

don't know if you all feel this same way, but I get in a place where I'm "comfortable" about my CMT. My dad calls it complacent, but I think comfortable sounds nicer. In fact, what that means to me is that I have dealt with what I can and can't do, and I really don't want to think about anything getting worse. For me, my CMT had seemed to level off, and I hadn't had any dramatic losses in recent months; that is, until very recently.

I have a lot more writing to do now that I'm in middle school, and I've noticed that my front feet (which function as my hands) get stiff and sometimes

curl up after I spend a lot of time holding my pencil and writing or doing math. I have avoided telling my parents about it because I don't really want to learn what is wrong. I'm actually a little afraid of losing more of my function.

Of course, whenever I try to hide something from one or both of my parents, I can always count on my older sister to tell on me. I think she's trying to be helpful, but maybe she's just trying to be a pain. I'm not sure. In any case, she told our mom that I was having trouble writing and that I was stalling and trying to keep them from knowing.

My mother did her normal overreacting and thought we should leap in the car and go to the doctor immediately. Even as a kid, I recognize that having foot (hand) cramps and stiffness in my front toes is not an "emergency" sort of event. So, I settled on having her call the doctor, who referred us to an occupational therapist named Hopalong Rabitz. (He said he had parents who grew up watching old black and white westerns on TV, and one of them was about Hopalong Cassidy.) He is, as he said, the beneficiary of their "gift" of a different name.

We made an appointment, and I suffered for three days thinking I was about to lose the ability to write, the way I had lost the ability to run and compete in most sports.

When we got to the therapy offices, I was slightly less worried because they just didn't seem as "hospital-ish" as my doctor's office is. Hopalong was really cool, and he reassured me right away that the cramping and

stiffness was not a big problem, just one

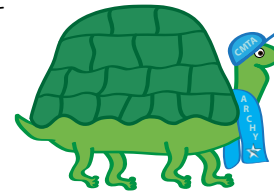
that should not be put off and hidden from my parents. (Yeah, I pretty well knew that!)

He put my front feet in some

warm solution and had me

just relax and enjoy the feeling. While I was doing that, he recommended that I use some squeezing and stretching exercises to keep my toes (fingers) supple. He also wrote out a permission slip for me to use the school's voice-command computer when there is a lot of writing to do for a project. That way, he said, I will be able to do the shorter tasks more easily because the long tasks won't require that I write by hand. When I'm at home, he told me to use the balls and bands to keep my feet flexible so they won't cramp up so much.

And, if all of that weren't comforting enough, he told my mother that I needed to watch Hopalong Cassidy on Nickelodeon at least once a week! (That final instruction might have been in jest, at least a little, but I'm holding my mother to it. After all, you should never ignore what a doctor or therapist tells you to do.) ★



Our mascot "Archy" writes about his experiences as a turtle with CMT.

THE CHRISTINE A. HOOK MEMORIAL CONCERT

On Sunday, October 6, 2013, a memorial concert was held at St. Michael the Archangel Church in Troy, New York to remember Christine Hook. Christine had CMT; the symptoms first showed when she was 13 years of age, but she remained undiagnosed until age 25.

Performers at the concert were the acclaimed a cappella men's singing group, One Man Short. The coordinator of the group is Christine's older brother, Paul. In addition to the monies raised from the sale of admission tickets, four of Christine's original paintings were placed on display and raffled off. When Christine could no longer work, she turned to her art (she had an undergraduate degree in fine arts) and her writing. Christine touched many people in her life, which was cut short at the age of 41 from heart failure.

In 2012, Christine received the national I'm a Star award from the CMTA. She was very proud of this award and also proud of her work with the local CMT support group. She coordinated an art gallery in Albany (at a local medical office) and the proceeds from the sale of any art piece went to the CMTA. In December, that gallery will be named the Christine A. Hook Gallery in her honor.



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CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

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The World's Fastest GMC Motorhome

BY BRETT PALMER

My symptoms of CMT actually began back in 2002. I began developing a consistent achiness in my legs and feet as well as general weakness. I noticed that my feet were losing muscle and that the bones in my feet would hurt after long walks or any type of repetitive activity.

The doctors sent me to physical therapy and for MRI's of my back; they thought it could be a sciatic nerve issue. Each year my symptoms got slightly worse, and the pain in my legs increased. My arms and hands then began hurting in the same fashion. Gradually, my legs and feet became weaker, and I lost most of the muscle mass in my feet and lower legs.

In 2010, after insisting that this was not normal, my doctors ran a series of tests, including an EMG and NCV test. The results immediately indicated the nerve damage in my legs; they confirmed that I had CMT. One of the key deciding factors was my high-arched feet and hammer toes combined with the results of my tests and the progressive nature of my symptoms. At the time, I didn't

realize how much my life was about to change.

As my CMT has progressed, the disease has physically slowed me down. I don't walk long distances anymore. I'm not very active at all, but I can still drive a car.

Many people have asked me how my project began and why. It really began in June 2010 when I was first diagnosed with CMT. I knew nothing about it ... absolutely nothing. The disease had a strange

name and sounded like a dental condition but wasn't, and it took some time for me to accept that this disease was serious.

I wasn't about to let this disease stop me, so one evening while I was having a "pity party" for myself, I came across a 1977 Kingsley GMC motorhome for sale up in Fort Collins, Colorado. Immediately I had flashbacks of the movie *Stripes*, starring Bill Murray, where they used a GMC Motorhome as the iconic EM-50. I loved camping and exploring, so my first thought was that I could use the motorhome to make it easier when I go camping with my family. After searching the Internet and doing a lot of investigative work on the history of the GMC Motorhome, I came across an article about the GMC Motorhome holding the World Land Speed Record of 104 mph at the Bonneville Salt Flats. You

have to understand that I'm a motor-head, as are all my friends. So it didn't take long before we had a plan to build the World's Fastest Motorhome (one that I could still camp in after the race).

I decided it was time to let the world know about CMT. Instead of letting CMT slow me down anymore, my team and I intend to build awareness for CMT by going fast. And thus, the GMC LSR Motorhome, aka the "MoHo" Project, was born.

Long story short, we took a completely stock GMC Motorhome and gave it to world-renowned car builder Dennis McCarty, of Vehicle Effects, to give it a complete makeover. Dennis is the exclusive car builder for the *Fast & Furious* movie franchise with Universal Studios.

Dennis and an associate of his, Luke Richards, of Lucra Cars, removed everything flammable, including the floors, wheel wells, cabinets, old wiring and appliances and replaced everything with aluminum and fiberglass. We then installed a full-length chromoly roll cage from front to back. The entire suspension system was replaced with new and more modern parts like quad air bags, Air Ride suspension, 6-wheel disc brakes, stabilizer bars and Fox shocks, A-Arms, new steering components, and more. Applied GMC was a huge help in supplying all

My CMT has slowed me down, but my motorhome allows me to go fast and inform people about what CMT is.

The "guys" pose beside their superfast motorhome at the Bonneville Salt Flats. If you want to see more pictures and video of the GMC LSR "MoHo" project, go to www.gmclsr.com.



of our parts to rebuild the entire suspension system. We installed military grade wiring, an HD camera backup system, a fuseless Smartwire System, a Racepak IQ3 dash with data logger, a fire suppression system and a full blown SCTA-certified race cockpit with full containment Kirkey seat. We redesigned the aerodynamics on the front and rear. We gave it a new “MoHo” grill and added seamless windows. We streamlined and smoothed the outside body before painting it black and adding sponsor logos. Finally, it was fitted with a new 600HP Chevy big-block 502 Ram Jet fuel-injected motor and an upgraded TH425 transmission.

At Speed Week on the Bonneville Salt Flats, the MoHo stole the show. We had more people stopping by to confirm that we were actually racing this vehicle and that it wasn't just there as a support vehicle. With 12,000 people and many international news organizations attending the event, it was a great opportunity to let people know about CMT. On August 12, 2013, we successfully drove the GMC LSR “MoHo” 120.8 mph. We were only 7.8 mph short of the overall Guinness World Record for “World's Fastest Motorhome,” but we were very pleased with the results. Although we didn't get the overall fastest motorhome record, it's a cool feeling to know you have the fastest GMC Motorhome on the planet.

In 2014, we will be installing a supercharger, and perhaps we'll make another final drive gear ratio change. Then we will head back to Bonneville to finish what we started. ★

CMT Does Not Have Us

BY ANGIE SEAMES

My name is Angie Seames. My 18-year-old son, Jesse Bertram, and I are being treated for our CMT. Jesse has had both hamstrings and both Achilles tendons lengthened twice since 2007. This summer, both Jesse and I had surgery that included left foot calcaneal osteotomy, left foot Steindler stripping, left posterior tibial tendon transfer, and left foot dorsiflexory wedge osteotomy of the first metatarsal. They basically had to rebuild our feet.

Jesse and I decided to do something special in September because it was CMT Awareness Month. We organized and planned a walkathon to help raise funds for the CMTA. We named the walkathon “We Got This” coming from the statement we like to say, “Keep calm ‘cus’ we got this.” We had more than 70 people walk locally including friends, church family, members of the local CMTA support group and even three of our physical therapists! We had family and friends also walk in other states, including California, Tennessee, Kentucky, North Carolina, Arkansas, Minnesota, and New York.

The outpouring of love and support from our community has been overwhelming! We raised \$1,800 for the CMTA! We also raised awareness of this condition! Our future has had to change because of CMT. Jesse had always planned to teach music. He can play 30 instruments, but as CMT has begun to affect his hands, he has decided to take another road. Jesse wants to become a youth minister and work with children with disabilities. We both have CMT, but CMT does not have us! We appreciate the efforts of the CMTA and are happy to be able to present the CMTA with this donation of the proceeds from the walkathon.



Seventy family members and friends joined Jesse and Angie Seames to demonstrate that CMT does not have them.



SUPPORT AND ACTION GROUP NEWS

• AZ—Phoenix Area

The September 28th meeting had a great turnout with a number of new members. They celebrated CMT Awareness Month with a lot of food and goodies. They talked a bit and watched two videos from the 2012 November SAGF Conference in Chicago. They discussed several dates for future meetings.

• CO—Denver Area

The group met on October 19th. Beth DeLoria served as guest speaker. Beth suffers from drop foot due to back trauma, but this has not slowed her down. She had a goal to do 48 half marathons in a two-year period. She has now run all 48 of them.

• DC—Washington, DC

Thanks to everyone who was able to make the October 20th meeting. There were over 20 in attendance. Thanks to Jayme Brendle, from Allard USA, for coming and talking about Allard braces that are used by people with CMT. Also, thanks to

Allard USA for being an official corporate partner of the CMTA.

• FL—Tampa Bay

There were 38 people in attendance, including four new members, at the September 21st meeting. A variety of topics were discussed, including I-Give, monthly CMTA webinars, State Proclamations, the Rare Disease Consortium Research Network, various Awareness Month activities, the upcoming CMTA Patient Family Conference in November, and research news. The group lost two members, Linda Benhase and Bob Wolf. In their memory, the group passed a hat and raised over \$70, which was donated to the STAR fundraising effort.

• MI—Kalamazoo

There were 21 people in attendance at the September 19th meeting. They had a few special guests. Dr. Sindhu Ramchandren visited. She talked about her new CMT clinic in Ann Arbor, MI, and about her

research protocols regarding children with CMT, pain, and quality of life. The members of the group had many questions for her. Also, they had a very special young lady visit. Ten-year-old Allison, winner of the 2013 CMTA Shooting Star contest, and her family came. She and her family had a chance to share their “CMT story.” Allison was presented with a plaque from the CMTA and flowers. During the meeting, they held a mini fundraiser and raised \$77 for CMTA research.

• NC—Durham Area

Thank you to all who attended the September 15th meeting. Even though they were few in number, the group enjoyed meeting and learning from one another. The orthotics specialist was wonderful. Robert’s presentation was very enlightening.

• NY—Upstate NY

The group met on September 14th. Deacon Neil Hook led the meeting by discussing the Memorial Concert for Christine that was held on October 6th. Rich discussed the opportunity to meet and greet Jeana Sweeney, Director of Community Services for the CMTA, at Buca Di Beppo on October 5th. Thanks to the group for attending the Valley Cats game on August 9th. Those in attendance saw a great game, with fireworks, and they were able to raise awareness and money for the CMTA. Also discussed was the importance of the Starry Night celebration on December 5th. Festivities for

(continued on page 22)

The Westchester NY Support and Action Group held their holiday luncheon in Hartsdale, NY in November.



CMT Support and Action Groups in Your Community

AL—Birmingham

No group currently meeting

Will accept calls
Dice Lineberry
205-870-4755

AL—North Florence

North Florence, AL CMT Support and Action Group
Tina Smith
256-757-9250

AZ—Phoenix Area

Arizona CMT Support and Action Group
Pamela Palmer
ppalmeraz@gmail.com
Jim Blum
480-272-3846

CA—Los Angeles

Los Angeles, CA CMT Support and Action Group
Steve Fox
805-647-8225

CA—Stockton

Stockton, CA CMT Support and Action Group
Nina Anselmo
209-460-1716

CA—South Bay Area

San Francisco Peninsula/South Bay CMT Support and Action Group
Elizabeth Ouellette
1-800-606-2682 x107
Rick Alber
650-924-1616

CA—San Diego Area

San Diego, CA CMT Support and Action Group
Jordan Thomas
619-549-0872

CA—Santa Rosa

Santa Rosa, CA CMT Support and Action Group
Carol O'Bryan
707-823-0165

CA—Visalia Area

Visalia, CA CMT Support and Action Group
Melanie Pennebaker
559-972-3020

CO—Denver Area

Denver Area CMT Support and Action Group
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CT—Hartford East

Hartford, CT East CMT Support and Action Group
Roy Behlke
239-682-6785

CT—North Haven

North Haven, CT CMT Support and Action Group
Lynne Krupa
203-288-6673

DC—Washington, DC

Washington, DC CMT Support and Action Group
Steven Weiss
Kimberly Hughes
301-962-8885

FL—Naples

Naples FL CMT Support and Action Group
Roy Behlke
239-455-5571

FL—Tampa Bay Area

Tampa Bay, FL CMT Support and Action Group
Vicki Pollyea
813-251-5512

FL—West Palm Beach

South FL CMT Support and Action Group
Phil Lewis
561-630-3931
Eileen Martinez
561-777-8471

GA—Atlanta Area

Atlanta, GA CMT Support and Action Group
Susan Ruediger
678-595-2817

IA—Great Lakes

Iowa Great Lakes and SW MN Regional Virtual CMT Support & Action Group
Daniel Bachmann
507-399-0592

IA—Iowa Area

Iowa City, IA CMT Support and Action Group
Jeffrey Megown
319-981-0171

IL—Chicago Area

Chicago Area CMT Support and Action Group
Dale Lopez
708-499-6274

IL—Norridge Area

Chicagoland (North) Support and Action Group
Charles Barrett
224-628-5642

IN—Fort Wayne Area

Fort Wayne, IN CMT Support and Action Group
Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488

IN—Lafayette

Lafayette, IN CMT Support and Action Group
Connie Chance
574-595-0674
Lawane Lord
765-474-4000

KS—Wichita Area

Kansas Area CMT Support and Action Group
Karen Smith
316-841-8852

KY—Burlington Area

Burlington, KY CMT Support and Action Group
Pam Utz
859-817-9338

LA—Baton Rouge

Louisiana CMT Support and Action Group
Kathleen Douglas
985-215-3926

MA—Boston

Boston, MA CMT Support and Action Group
Mimi Works
617-913-4600

MD—Easton

Easton, MD CMT Support and Action Group
Missy Warfield
Seth Warfield
410-820-0576

ME—Portland Area

Portland, ME CMT Support and Action Group
Mary Louie
207-450-5679

MI—Chesaning Area

Chesaning, MI CMT Support and Action Group
Carolyn Koski
989-845-5731

MI—Kalamazoo Area

Southwest Michigan CMT Support and Action Group
Jori Reijonen
269-341-4415

MN—Benson Area

No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MO—Anderson Area

No group currently meeting
Will accept calls
Libby Bond
417-845-1883

MS—Mississippi/Louisiana

Clinton, MS CMT Support and Action Group
Flora Jones
601-825-2258
Cindy Chesteen
601-668-5439

NC—Durham Area

North Carolina CMT Support and Action Group
Margaret Lee
919-359-6003

NJ—Central New Jersey Area

Central New Jersey CMT Support and Action Group
Mark Willis
732-252-8299
Jacqueline Donahue
732-780-0857

NJ—Morris County

Morris County, NJ CMT Support and Action Group
Alanna Huber
973-933-2635

NM—Albuquerque

CMT New Mexico Support and Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area

Las Vegas, NV CMT Support and Action Group
Jerry Cross
775-751-9634
Virginia Mamone
702-343-3572

NY—Horseheads

Horseheads, NY CMT Support and Action Group
Angela Piersimoni
607-562-8823

NY—Long Island

Long Island, NY CMT Support and Action Group
Shari Loewenthal
631-254-8960

NY—Manhattan Area

New York, NY CMT Support and Action Group
Amanda Imbriano
516-680-2981
Barbara Abruzzo
212-473-4157

NY—Upstate New York Area

The Upstate NY CMT Support and Action Group
Melinda Lang
518-783-7313

NY—Westchester

Westchester, NY CMT Support and Action Group
Beverly Wurzel
201-224-5795

OH—Cleveland Area

Cleveland, OH CMT Support and Action Group
Heather Hawk Frank
440-479-5094

OH—Greenville Area

Greenville, OH CMT Support and Action Group
Dot Cain
937-548-3963

PA—Bucks County

Bucks County, PA CMT Support and Action Group
Linda Davis
Mitch Davis
215-943-0760

PA—Ephrata, PA

Ephrata, PA CMT Support and Action Group
Rachel Weaver
717-344-6063

PA—Johnstown Area

Johnstown, PA CMT Support and Action Group
J.D. Griffith
814-539-2341
Jeana Sweeney
814-269-1319

PA—Northwestern

Erie, PA CMT Support and Action Group
Joyce Steinkamp
814-833-8495

RI—East Providence

Rhode Island CMT Support and Action Group
Meredeth Souza
401-433-5500

SD—Hartford Area

Hartford, SD CMT Support and Action Group
Serena Clarkson
605-215-8853
Tom Clarkson
605-370-7595

TN—Nashville Area

Nashville, TN CMT Support and Action Group
Bridget Sarver
615-390-0699
Gwen Redick
256-655-0391

TN—Savannah Area

Savannah, TN CMT Support and Action Group
Reagan McGee
731-925-6204
Melinda White
731-925-5408

TX—Dallas Area

Dallas, TX CMT Support and Action Group
Michelle Hayes
972-539-0905
Merissa Lovfald
214-394-8907

TX—El Paso, TX

El Paso, TX CMT Support and Action Group
Veronica Gallegos
915-852-2273

UT—Orem Area

Orem, UT CMT Support and Action Group
Melissa Arakaki
801-494-3658

VA—Harrisonburg

Harrisonburg, VA CMT Support and Action Group
Anne Long
540-568-8328

VA—Shenandoah

Northern Shenandoah Valley CMT Support and Action Group
Teresa Frederick
540-336-4496

VA—Williamsburg

Williamsburg, VA CMT Support and Action Group
Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Seattle Area

Seattle, WA CMT Support and Action Group
Ruth Oskolkoff
ruth.oskolkoff@gmail.com

WI—Brodhead Area

Southern Wisconsin CMT Support and Action Group
Molly Hawkins
608-921-0032

WI—Milwaukee Area

Southeastern Wisconsin CMT Support and Action Group
Polly Maziasz
262-439-9009

WV—Vienna Area

Parkersburg /Vienna WV Support and Action Group
Rebecca Knapp
304-834-1735

GROUPS IN CANADA AND MEXICO

CAN—British Columbia

Victoria, BC CMT Support and Action Group
Melanie Bolster
250-888-7713

CAN—Ontario

Eastern Ontario CMT Support and Action Group
Robin Schock
613-389-1181
Southern Ontario CMT Action and Support Group
Kelly Hall
519-843-6119

Mexico

(This group will be in Spanish.)
México CMTA Grupo de Apoyo y Acción
Gina Salazar
Gina_oviedo@hotmail.com

Most Support and Action Groups can be accessed at www.cmtausa.org. They can be found in the CMTA Online Community under Support and Action Groups.

SUPPORT GROUP NEWS

(continued from page 20)

Starry Night will include wine tasting, lite fare, a 50/50 raffle, and a silent auction. Rich also talked about supporting the CMTA by shopping at Zazzle and making frequent use of the information on the CMTA website. He also let the group know about the teleconference,

featuring Dr. Shy, on September 5th which is available for viewing. Group discussion included facing the challenges of CMT on a daily basis. Handouts included Gary Shepherd's CMT Challenges and Solutions. The importance of proper bracing, exercise, positive attitude, special devices and having the ability to network was also noted.

• NY—Westchester

There were 14 people in attendance for the September 7th meeting. Everyone was excited to spread the word about CMT Awareness Month through the posters, wristbands, magnets, etc. A lot of information was shared by all the members.

On November 2, 2013, the Westchester, NY Support and

Crazy Jewelry Lady with CMT

My name is Rikki Callantine. I am an Independent Jewelry Lady for Premier Designs, Inc., and I have been diagnosed with CMT for over 25 years. I inherited it from my mom, and we have four children that are at risk of having it. Growing up with this disability has been frustrating and embarrassing—just “walking funny” alone is enough to make a person cry, but as I continue to age, the day to day difficulties with little tasks—picking up small items, holding a hair-spray can, buttoning my children's shirts,

going up stairs and bending over—and the progression of pain are an ongoing struggle that I would not wish for anyone. Regardless of my physical difficulties through life, having CMT has also strengthened my character and fine tuned my passion to enrich lives. It has not stopped me from marrying and starting a family or

becoming involved in my church and community. I have climbed my way up the career ladder and now find myself with a growing home-based business that allows me to work at my own speed, but more importantly, sprinkle



Rikki Callantine and Denver Support and Action Group Facilitator Dick Kutz worked to raise money through a sale of Rikki's jewelry.

happiness through fun and jewelry and give as I'm called to do; therefore, I would not change my circumstances. However, with my passion and my business, I'm hoping to raise money and awareness so that perhaps circumstances can be changed for my children and other children with CMT!

Our first annual “Crazy

Jewelry Lady with CMT” fundraiser went well! We raised over \$500 through a silent auction and jewelry sales. I am excited to continue to try fundraising events within our community and grow the “CJL with CMT”

fundraiser year to year so that it will produce thousands of dollars in future years! My main hope is to empower women, and I can do this through CMT awareness events. Most of us women suffer from some ailment, and being able to motivate and empower others through, and past, our disabilities is

my ultimate dream. I hope through this and future events I will have provided hope to at least one woman. The fundraising money earned and donated to the CMTA through this event is just the icing on the cake, and I am honored to make a small difference in the research for a cure. —Rikki Callantine, CJL

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If you are a member or are joining 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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CMTA T-Shirts (White with blue logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
Be a STAR Wristbands			1-5, \$1.50 each 6-10, \$1.25 each 11 or more, \$1 each	
Be a STAR Necklaces (Includes battery)			1-5, \$3 each 6-10, \$2.50 each 11 or more, \$2 each	
NEW! Unframed Sunflower Poster			\$5	
NEW! Sunflower Bookmarks			1-5, \$1.50 each 6-10, \$1.25 each 11 or more, \$1 each	
CMTA Brochure & Neurotoxic Drug Card			FREE	
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Mail to: CMTA, P.O. Box 105, Glenolden, PA 19036; or fax to 610-499-9267

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

Action Group had their Holiday Luncheon at Pas Tina's Restaurant in Hartsdale, NY. We had 46 people in attendance. Whole Foods donated a gift card. Starbucks and Super Cuts donated items for the raffle, and Pas Tina's donated a gift certificate to their restaurant. Other raffle items were donated by our members. We raised \$1,560 for STAR. It was a very successful event, and everyone had a wonderful time.

• **PA—Bucks County Area**

The Bucks County Support and Action Group held their first annual buffet dinner and basket raffle at the Golden Eagle Diner in Bristol, PA, on Saturday, September 21st. Everyone had a great time socializing and enjoying a great buffet dinner. The winners of the basket raffle were exceptionally happy as were the winners of the door prizes. By the end of the evening, everyone had made at least one new friend who understood their life with CMT and were already looking forward to next year's dinner.

• **WI—Milwaukee**

There were 12 in attendance at the September 7th meeting. Dr. John Svaren, University of Wisconsin STAR researcher, updated the group on the latest CMT research. The group shared stories and gathered information on how to spread the word about CMT to their various communities. Thanks to all who came.

• **CAN—Ontario**

The group welcomed three newcomers and had a great Skype chat with Elizabeth Ouellette from the CMTA! Thanks Elizabeth! ★

CMT PATIENT MEDICATION ALERT:

**Definite high risk
(including asymptomatic CMT):**
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
Taxols (paclitaxel, docetaxel)
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)
a-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.