FALL 2021

THE CMTA REPORT

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HOT FUN
IN THE SUMMERTIME

BACK
TO SCHOOL

CELEBRATING 20 YEARS OF FUN & FUNDS

PAGE 6

CONTENTS

FALL 2021

COMMUNITY

LIVING WITH CMT

FUNDRAISING

YOUTH

CMTA
Charcot-Marie-Tooth Association

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THE CMTA REPORT | FALL 2021

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CMTA
Charcot-Marie-Tooth Association

A MESSAGE FROM THE CEO

Dear Friends,

Coming on the cusp between summer and fall, this issue of *The CMTA Report* covers both the fun and games of summer and the back-to-school and parenting issues of fall.

For members of our CMTA community, summer fun often comes with a fundraising component and this summer was no different. From the Bucks County annual picnic to the daylong extravaganzas mounted by the Vermont Cycle (and Walk!) 4 CMT and the FunAthlon, CMTers were out walking, riding and swimming, all in the name of CMTA-STAR research.

Four board members stood out for their fundraising efforts this summer. In June, Steve O'Donnell held the Seventh Annual FunAthlon, raising more than $110,000 for CMTA-STAR. And in the waning days of August, Chris and Elizabeth Ouellette and Gilles Bouchard held the Eighth Annual Vermont Cycle (and Walk!) for CMT, raising more than $300,000 for CMTA-STAR research.

The Jenkins family of Thornton, Colorado, also deserves special mention: Wendy and her family held their own very special "Summer Games for CMT" at their home in Thornton, Colorado, in July, raising $300 for CMTA-STAR research. Wendy credits her kids with the idea for the games. Her 11-year-old son Carter wanted to do an Olympic-themed day camp for the kids in the neighborhood and her 15-year-old daughter Allison, who has CMT, had the idea to raise money for the CMTA. The entire family is a shining example of the way our entire community works to support our research efforts.

We also have stories about CMT feats of strength in this issue. You last read about Jamal Hill in our Winter 2020 issue, when he thought he'd be going to the Tokyo Paralympics that summer. Obviously, they were canceled, but we are so proud to tell you that Jamal took the bronze in the 50-meter freestyle on August 29. Our other award-winning athlete is George Simmonds-Gooding, who took second in the Neuromuscular Division of the CrossFit games this summer.

Finally, because the fall semester is on every parent's mind, we're bringing you stories on how to ensure your child has a good school year and tips on parenting a child with CMT.

We feel so lucky to have a community that works so hard to support each other and even during the dog days of summer works to support the CMTA.

With warm regards,

Best,

Amy Gray

CMTA Chief Executive Officer

VERMONTERS CYCLE (AND WALK!) 4 CMT

The Vermont Cycle (and Walk!) 4 CMT returned to the charming Old Lantern Inn in Shelburne, Vermont, on August 29, turning "compassion into action" with rides and walks through the lush countryside.

Event co-founder and CMTA Board Member Chris Ouellette had a vision for the event in 2014. Inspired by his nephew Yohan's CMT, he came up with the idea of connecting Vermonters' passion and energy for outdoor activity to a day of fundraising so individuals with CMT may one day enjoy those same simple pleasures.

"The only way to accomplish this vision is through fundraising in support of research to stop the progression and prevent CMT in the future," Chris said. Since its inception in 2014, the Vermont Cycle has raised $1.7 million, more than $300,000 in 2021 alone.

The speechmaking portion of the proceedings was exceptionally moving this year, with speakers keeping the memories of departed CMTers alive. Patrick Zahn, brother of cycling legend Anthony Zahn, talked about the importance of the CMT community in his brother's life. He also had some practical advice for the audience, "Follow your heroes, but be your own hero too," he said, adding, "And be sure to wear a helmet."

Paul Kang, second cousin of Juliana Snow, who passed from complications of CMT at the age of 5, talked about her love of life and the inspiration she provided not just her family, but the entire CMT community.

Speakers also looked to the future. Erin Black and Emmily Stufflet of the CMTA Youth Council (and social media interns for the CMTA) spoke movingly about the challenges of CMT and how important community is in overcoming them.

Erin, 20, of Cleveland said, “I have never met a group of people as passionate and driven as those involved in this event. They embody all that it means to turn love into action and lean on the generosity of others to create a cause greater than anyone could imagine. I am beyond grateful I got to experience the magic of this community come to life at this year’s event—we’re just getting started!”

SINCE ITS INCEPTION IN 2014, THE VERMONT CYCLE HAS RAISED $1.7 MILLION FOR CMT RESEARCH.

Emmily, 18, of Orlando said, “An event like Cycle 4 CMT is truly life-changing for those living with CMT. It is truly breathtaking to see a group of passionate and proactive individuals come together to work for one main goal—a world without CMT. Community is everything, and the people involved with Cycle 4 CMT understand the power that community holds.”

Event co-founder Elizabeth Ouellette emphasized that the event isn’t over: “What started as a local fundraiser to raise awareness and research dollars to cure CMT has morphed into a national movement with the national Virtual Cycle 4 CMT. Throughout September, cyclists from all over the country will be cycling virtually to end CMT.

Leading the charge, Chris is flying to California at the end of September to cycle Mount Tam alongside Yohan. This will be the first time the two have ever ridden together, making a long-awaited dream come true.

Chris, Elizabeth’s brother and Cycle 4 CMT co-founder, said seeing the Burlington community give back to something that they know very little about is really powerful. “The Cycle 4 CMT aims to make sure that individuals with CMT will one day be able to enjoy the ability to move and enjoy activities without limitations.”

Youth Council Members Emmily Stufflet (left) and Erin Black (right).

Daniela Soares and her daughter Olivia, one of the youngest cyclists!

Walkers Suzi Moore and Joe, Nicole and Anna Diebold

Vermont Cycle (and Walk!) 4 CMT Co-Founders Elizabeth and Chris Ouellette

2021 FUNATHLON FUELS CMT RESEARCH WITH FUN

The 2021 FunAthlon on June 13 kicked off with a prayer that the search for a cure for CMT proceed not by inches or steps, but by leaps and bounds. The celebration of Board Member Steve O'Donnell's 20 years of fundraising for the CMTA raised more than $110,000 (and counting), enough to fuel a very big bound.

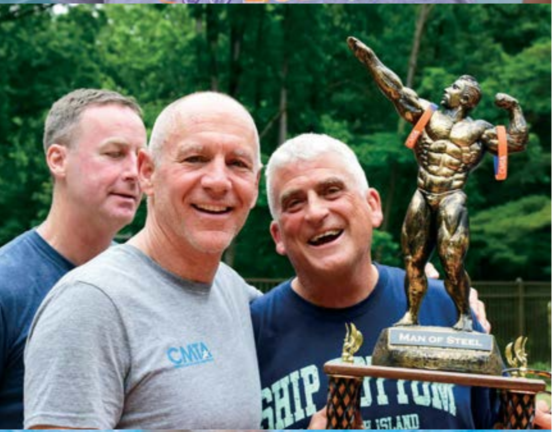
Swimmers gathered at the Meadowbrook Swim Club in Baltimore at 7 a.m. for the first leg of the FunAthlon. Spurred by Steve and Sherri O'Donnell's challenge match of $5 per lap, participants free-styled, breast-stroked and back-stroked with added intensity.

Bikers were up next, taking to the North Central Rail Trail in Baltimore County to meet a second challenge match of $5 per mile biked. A gaggle of walkers shared the bucolic trail.

Everyone then moved to Camp Puh-Tok in the Pines for a picnic and awards ceremony. "Everyone with this disease relies on their friends and family," O'Donnell said before presenting the Man of Steel award to long-time friend Tom O'Grady. Last year's recipient, 3-year-old Quinn Fernandes, joined her fellow Men of Steel at the podium.

This year's FunAthlon brings Steve's lifetime fundraising total to $1.9 million (and counting), a huge leap forward in the search for a cure for CMT.

From left to right: Tom Haslach, Bruce Matthai, Steve O'Donnell, Gavin Strait, Dan Chanby and David Todd



EVERYONE WINS AT SUMMER GAMES FOR CMT

The Olympics weren't the only games in town this summer. Wendy Jensen and her family held their own very special "Summer Games for CMT" at their home in Thornton, Colorado, on July 31. The CMTA was the big winner: The Jensens raised $300 for CMTA-STAR research.

Each of the 22 participants created their own country and a flag to represent it. "We had some pretty great countries," Wendy recounted, including everything from Lucy Loveland to Minecraft World to a "whole slew of Pokemon countries."

After kicking off the day with a photo shoot, athlete interviews and opening ceremonies, the athletes dived into the main events, which included table tennis, gymnastics, track and field and archery. The athletes not only gave their all, Wendy says, but showed great sportsmanship as well. Post-competition, they went on to enjoy some tasty treats and test their Olympic knowledge in a trivia contest.

Wendy credits her kids with the idea for the games. Her 11-year-old son Evan wanted to do an Olympic-themed day camp for the kids in the neighborhood, and her 15-year-old daughter Allison, who has CMT, had the idea to raise money for the CMTA.

Allison was diagnosed with CMT when she was 6. She is now almost 16. Wendy says Allison continues to learn and grow and navigate the condition with perseverance and grace. Wendy's 4-year-old son Jeremiah was recently tested and has CMT as well, though 14-year-old son Carter does not.

Wendy pronounced the Summer Games for CMT a great success, and said, "My heart is full of gratitude that we were able to raise funds for an organization close to our hearts." The CMTA is full of gratitude to the Jensens and their Olympic-level fundraising.

Summer Games for CMT!

Arrive & Opening Ceremonies
9:00-9:30
Photo Shoot
Athlete Interviews
Flags
Torch Run
Pictogram Charades

Events
9:30-10:30
Track & Field
Watergun Shooting
Basketball Shootout
Golf
Gymnastics
Table Tennis
Soccer
Tennis
Artistic Swimming
Volleyball

Oreo Medals
Snack Break
10:30-10:45
Tasty Torches

Olympic Village:
10:45-11:15
Stories: History of the Olympics
Crafts: Discus Decorating, Coloring
Games: Olympic Trivia, Playdoh Challenge
& Hang-Out Time!

Closing Ceremonies
11:15-11:30
Medals, Video & Picture Show!

CAMP FOOTPRINT CAMPERS FIND JOY, CONNECTION AND QUEEN CORONA'S KEYS

Sixteen Camp Footprint counselors and staff (seekers) gathered at a hotel in downtown Pittsburgh from August 2 to 6 to lead campers on the hunt for "Queen Corona," who stole the keys to the real Camp Footprint and locked them out. In an elaborate real-life/video game hybrid, some 118 campers spent the week looking for clues to the keys' whereabouts so they can return to sleepaway camp in Pennsylvania next summer.

This was the sixth year of Camp Footprint, the country's only camp solely for kids with CMT. Camp Footprint gives campers from 10 to 18 the chance to feel understood and to blend in. Last year, Camp Footprint took place on Zoom, thanks to the CMTA's Camp-in-a-Box, which held everything necessary for a typical camp experience—singing, crafts, drumming, a powder battle, pizza night, a dance and even a traditional campfire, complete with flickering lanterns and S'more Pop-Tarts. This year's Camp-in-a-Box included coffee mugs with feet and a Camp Footprint onesie for maximum coziness. Zoom sessions ran from 9 a.m. to 10 p.m., with a break between 5 and 7 p.m.

This year, mornings and middays were normal online camp for all participants, but each evening the special activity incorporated five clues that led the seekers from the front of the hotel around downtown and finally to the location of that day's key. To add to the fun, the CMTA created a virtual downtown online map and avatars for each of the 16 seekers so that campers could watch the avatars moving through virtual Pittsburgh in real time using the Find My iPhone app. So, for example, when Camp Director Jonah Berger introduced the first night's drum circle, a flash mob playing the theme from the Pink Panther on kazoos disrupted his speech before holding up a series of letters that campers had to unscramble to point the seekers in the direction of the next clue.

Days started with the Youth Council Morning Report, then moved on to chair dancing and stretching. The midday was filled with back-to-back activities—everything from sign-language to pet show-and-tell to Harry Potter trivia. After a dinner break, campers went back online every night to participate in more activities, including a campfire, a scavenger hunt, a magic show, movie night and the final night's big dance. Through a hybrid of in-person and online animation, Queen Corona interrupted the proceedings each night to give campers clues for finding the right-color key. The campers then used their maps and their wits to solve the clues and direct the seekers on the ground in Pittsburgh. They found one key each night and the Golden Key on the last night, which unlocked the camp and started the planning for an in-person reunion for Camp Footprint 2022.

Camp Director Jonah Berger said, "For the sixth year in a row, campers and staff showed that the magic of camp comes in community with others who just get it. In person and even online, we have the time of our lives because we are a family. A Tribe. And we always will be."

CAMPERS

Camper **Elsa Groenink,** 16, a rising senior from Michigan, felt the magic: She says Camp Footprint changed her life. "Before Camp Footprint I truly felt alone in my journey with CMT. I felt that I had no one to turn to, and I really did not understand what CMT was and how it affected me. When I went to Camp Footprint for the first time, I was super nervous because I did not know anyone there and I had no idea what to expect."

Those nerves went away fast, Elsa said, because "the minute I met all of the other people like me it felt like I had met my long-lost family. They were so welcoming and truly understood what I was going through. This is the only place that I feel comfortable to talk about what I am going through and know that others are going through the same thing. They won't judge me or think I am faking it. I can know that they will push me beyond my limits but also know the line with CMT."

Elsa said Camp Footprint is the best week of her year and she feels loved and understood throughout. She has made lifelong friendships with people she can call anytime she is struggling even if they are hundreds of miles away. “Camp Footprint is truly one of the best things that has happened to me, and I cannot wait to go back next year and hopefully become a counselor someday,” she added.

Fifth grader **Edie Rose** from Arkansas also felt the magic: “Camp was so fun, and it showed me that I am not alone. I have so many friends now that have felt the same way I have. I have always been different, but camp showed me that’s okay and that I rock at trashketball. I finally felt like I belonged and now whenever I need someone to talk to, I have people to text and that is awesome.”


Edie

PARENTS

Edie’s mom Tasha shared her daughter’s feelings, saying, “I cannot express the gratitude we have for the Camp Footprint and CMTA staff for putting on such a dynamic and entertaining week. It was almost easy to forget it was over Zoom and not in-person. One benefit of Zoom camp is that our family got to know the staff and campers at the camp and also feel like an extended part of the ‘Tribe.’ We cannot wait to meet everyone in person in 2022.” Tasha particularly praised the counselors and staff who worked tirelessly over the week to ensure everyone had a fantastic time and felt included.


Adam and Sean Palermo


Reda

Ibrahim Nwar Al-Mari, father of Camp Footprint’s only Egyptian camper, 11-year-old Reda, said “Camp Footprint puts an indescribable feeling inside us. It makes my son happy to see and live with people like him and feel what real heroes feel. They challenge a disease that literally has no cure at all.”

Laurie Palermo, mother of campers Adam, 14, and Sam, 13, said she can’t wait for her kids to age out at 18 so she can be a camp counselor.

“I knew Camp Footprint would be awesome for my boys, but in what ways and how, I had no idea,” Laurie said, adding, “From day one, I saw smiles on their faces that I had not seen since the pandemic began in March 2020. Finally, they were with a group of kids who could relate to them, as fellow teens, dealing with similar struggles. There were no explanations necessary, no fear of being discovered and no fear of being left out.”

Laurie has CMT and tries to be a positive role model for her sons but says that, “Being with peers was something they were missing. For the very first time Adam and Sean were sharing and talking to other kids about their thoughts and feelings about CMT. They were empowered to share and were taught skills that will help them to talk with others and not be afraid of being discovered.

Laurie said that one of her sons noticed an increase in symptoms over the past year and was struggling to remain positive. Camp Footprint helped, Laurie said, adding, “He learned that he is not alone, and he learned from campers and peers that you can face your challenges with a positive attitude. In fact, Camp provided him with the confidence to put AFOs on for the very first time—in public and in shorts!!”

continued on page 11

Ohana

By Camp Counselor Rob Weis

Ohana in Hawaiian means family
But for us it really means tribe,
When we all get together
We feel a wonderful vibe.

A circle is formed all around us
Encompassing us all in its love,
How special it is to be part of
And feel truly blessed from above.

We all have our daily struggles
Our challenges both great and small
But we bravely push through the jungle
And together overcome all.

We used to feel less than some others
As we stumble, trip and yes fall!
But CMT can’t possibly beat us
When our “treatment” encircles us all.

It’s truly a wonderful feeling
To know our Ohana is there
It’s a connection we can really rely on
A bond that we’ll always share.

We’ve spent time in our cabins together
Sharing all that we are
Learning to lean on each other
Knowing together we can really go far.

In our jungle there’s always someone to talk with
Those we could never replace
Friends we laugh with and cry with till
Tears run down our faces.

We sometimes need help with our braces
Our snaps and zippers and such
And sometimes it feels like a little too much.

But since we all found each other
We don’t have that sense that we lack
Because we know our Ohana
Always has our back!

So, once again Queen Corona has split us apart;
But if we remember our tribe
And each of us keeps doing our part
We may in fact be miles apart
But we’ll continue to live in each other’s hearts.

Things have not been easy lately
But we all should feel great pride!
For we are all Camp Footprint
And we take it all in stride.

So set up your tents
And your sleeping bags too
And gather your chocolate
and marshmallow goo

Our circle of friendship draws tighter
It’s that time again, can you feel it?
For our Ohana to gather together
And all yell out very loudly
CAN YOU DIG IT????????

Rob Weis has been a part of the Camp Footprint staff for five years. He lives in Florida where he is a cardiac technician. Rob says “I would pick up trash if they needed me to, just to be a part of Camp Footprint!”

CMT-ASSOCIATED GENES AND THEIR RELATED SUBTYPES:

THE DEFINITIVE GUIDE

Until now, there has been no definitive list of all the CMT-associated genes and their related subtypes. But thanks to CMTA Advisory Board Member Kenneth Raymond, that's about to change. Raymond, a passionate amateur geneticist, compiled a comprehensive and complete catalog of CMT-associated genes and their related subtypes and is publishing it online with updates annually or as needed.

The field of genetics moves so fast that commercial labs offering CMT genetic testing services often can't keep up. It's not uncommon for a CMT genetic test to fail to identify an underlying genetic cause for CMT. There are a number of reasons a genetic test might fail to identify an underlying cause, but the most significant is that commercial labs don't include the full catalog of discovered CMT-associated genes. The lack of a complete list of all known CMT-associated genes and subtypes that can be used to identify what is included in a CMT genetic test leaves everyday CMTers and practicing clinicians in a sea of uncertainty.

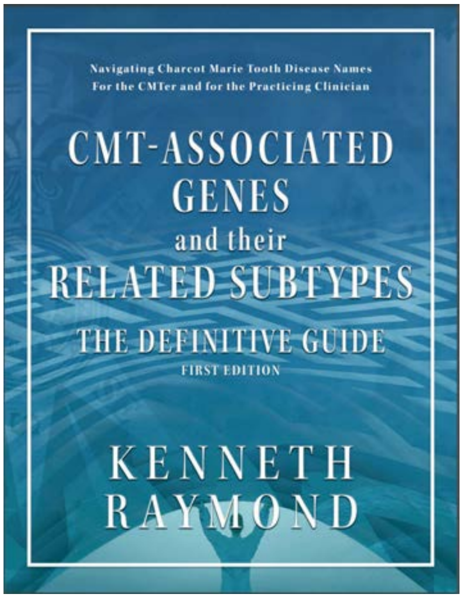
A writer, a CMT blogger, a CMT patient community advocate, and a CMTer diagnosed with 1A in 2002 at 29 years old, Kenneth Raymond has made it his passion to learn and absorb as much about CMT as he possibly can. Along this journey, he has developed an ability to translate the complexities of CMT into easily relatable narratives that are presented from the patient perspective.

"CMT-Associated Genes and Their Related Subtypes: The Definitive Guide" provides an up-to-date catalog of all CMT-associated genes and related subtypes discovered to date. The guide does not discuss symptom and phenotype descriptions for the many individual CMT subtypes. Rather, it is a comprehensive accounting of the identified CMT subtypes and an inclusive listing of all discovered CMT-associated genes, including the underlying data, current as of publication.

Scientists discovered the first CMT-associated gene in 1992 and have continued to identify new genes every year since. The number of CMT-associated genes discovered in the last 10 years eclipses the number of genes discovered in the first 20 years of gene discovery. Each new CMT-associated gene discovery creates a newly named CMT subtype. The ever-changing and evolving manner in which scientists name new CMT subtype discoveries also creates confusion for CMTers.

CMT is the acronym for Charcot-Marie-Tooth disease, which encompasses a wide variety of inherited motor and/or sensory neuropathies, each represented by a different acronym. There are 14 different Type categories of CMT, into which 155 individual CMT subtypes are sorted. These 155 CMT subtypes are associated with 120 different genes, plus an additional five chromosomal locations scientists suspect as having a gene with a CMT-causing mutation, though the exact gene is not yet identified.

The six basic types of CMT are CMT1, CMT2, CMT4, CMTX (X-linked CMT), CMT-DI (Dominant Intermediate CMT), and CMT-RI (Recessive Intermediate CMT). The additional eight categories are dHMN (Distal Hereditary Motor Neuropathy), dSMA (Distal Spinal Muscular Atrophy), GAN (Giant Axonal Neuropathy), HMSN (Hereditary Motor and Sensory Neuropathy), HSAN (Hereditary Sensory and Autonomic Neuropathy), HSN (Hereditary Sensory Neuropathy), SMA-LEP (Spinal Muscular Atrophy–Lower Extremity Predominant), and a category referred to as [Gene Name]-CMT (stated as [Gene Name]-associated CMT, as in SORD-associated CMT). Each of these is a CMT type, as well as a category into which the subtypes are sorted.



Navigating Charcot Marie Tooth Disease Names
For the CMTer and for the Practicing Clinician

CMT-ASSOCIATED GENES and their RELATED SUBTYPES
THE DEFINITIVE GUIDE
FIRST EDITION

KENNETH RAYMOND

GET YOUR FREE COPY of "CMT-Associated Genes and Their Related Subtypes: The Definitive Guide" at www.cmtausa.org/download/23552/.

Knowing the six basic categories of CMT is easy because of the CMT acronym attached to them, but the remaining acronyms can be confusing. The guide discusses how each of these non-CMT acronym categories constitutes CMT and why experts consider these categories CMT.

The guide not only provides a full catalog of all discovered CMT-associated genes and their related subtypes, but also a full bibliography of all original source publications that established each gene as a CMT-associated gene and its related subtype(s). This guide discusses the chaotic and confusing saga of the multiple CMT2A subtypes and the critically important retraction of the KIF1B gene as a CMT-associated gene. This guide also discusses the limitations of genetic testing for CMT and gives a statistical overview of the current state of CMT gene discovery and named subtypes, plus much more.

2021 CAMP FOOTPRINT

continued from page 9

STAFF

David Sellers is both parent and counselor, part of a father-daughter team: His daughter Audrey has CMT and was also a camp counselor this year, David's fourth as a counselor in the Upper Boys Cabin.

"I feel so very thankful to be a part of camp; each year it fills my soul with joy to be able to help and to witness the campers enjoying each other's company, sharing their stories, coming out of their shells, and finding their camp family. I am so impressed with the camp administrators, the staff, the other counselors, the Youth Council and with the campers themselves."

David, a middle school teacher, said, "I know how hard it is to get students involved over Zoom, so I am amazed by how engaged the campers were: Many campers stayed on Zoom all day, fully engaged and excited about what was going on. It is a testament to just how much the campers need this time with others who also have CMT."


The Seekers

Bridget Savant, the camp's resident chair-dance instructor, said "Camp Footprint 2021 was such a special experience that … I just don't know how we could top ourselves virtually!" Program staff worked for eight months to prepare. "It was a full production that required immense teamwork and many creative think tanks," Bridget said, noting that on top of normal camp activities staffers transitioned to a virtual setting and added nightly scavenger hunts, avatars, plot lines, guest speakers, costumes, Camp-in-a-Box, decorations—all for more participants than ever before.

"Spending the week pulling this off with my fellow program staff team in Pittsburgh, after two years apart and so much prep work, meant the absolute world to me. These people are my friends, my family, and my tribe. I can't thank the CMTA enough for the beautiful opportunities Camp Footprint gives us all to share our CMT journey with some of the best people on the planet."

YES, PLEASE PUT MY CONTRIBUTION TO USE IN THE FIGHT AGAINST THE PROGRESSIVE AND DEVASTATING EFFECTS OF CMT.

Please earmark my gift for STAR Research towards:

○ Type 1A Dollar-for-Dollar Match ○ Type 2 Dollar-for-Dollar Match ○ STAR Research (All CMT Types)

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○ Check enclosed, payable to the Charcot-Marie-Tooth Association. Donate online at cmtausa.org/donate2star

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GAIT TECHNIQUES TO HELP MAINTAIN WALKING STABILITY

BY ROBERT H. MEIER, CO

Maintaining stability while walking is an incredibly complex process made up of three main components: appropriate range of motion, adequate strength to control that motion and a functioning proprioceptive system—the neurological component—to control that movement. This article will explore all three factors and then discuss walking techniques that can help maintain stability.

Range of motion makes an important contribution to stability. The foot-ankle complex is especially important during walking because it becomes flexible at ground contact to become an effective shock absorber. Loss of flexibility or excessive motion can create significant challenges for individuals with neuromuscular conditions. Every effort should be made to incorporate custom foot orthotics, if needed, that help feet maintain their appropriate range of motion. An AFO, if needed, should be a carbon composite type with an open heel area to allow feet to function more normally when walking.

Strength is important to maintain stability and for the propulsion that is essential for walking. Muscle strength controls the motion that's available at the joints used for walking. Strength can be lost due to neuromuscular conditions or disuse atrophy. Stretching tight muscles is imperative for conditions that cause those muscles to shorten. Simply walking in the composite AFO/foot orthotic combination mentioned earlier can help the foot maintain or even regain some strength.

The final element is the proprioceptive system, which provides primary muscle activation in response to a muscle being stretched—the so-called stretch reflex mechanism. If a muscle isn't being stretched for whatever reason, the muscle activation system fails to activate that muscle, which then tends to atrophy or become weaker.

Keeping these systems functioning can be challenging for those with certain neuromuscular conditions. There are, however, some walking techniques that can optimize the function of these systems and help maintain or slow the progressive loss of gait stability. As always, the exercises must be performed in a safe environment, taking each individual's limitations into account.

Hip excursion. Part of gait is transferring the body's center of gravity from one leg to the other. Standing with feet shoulder-width apart, move the hips from side to side. An excursion (distance moved) of just two or three inches indicates a relatively weak pelvic girdle. An excursion of six or eight inches indicates a relatively more stable pelvic girdle.

Alter head position while walking. Move it up, down, to the right and then to the left. Altering head position can alter and strengthen the proprioceptive input system and can help challenge the system to keep it functioning properly.

Alter vision while walking. Close one eye, then the other. Look up, down and to the sides while walking in a safe environment. Altering the visual input system puts additional emphasis on the proprioceptive system to keep it functioning at a more normal level.

Alter speed while walking from slow to fast. Riding a bike very slowly is difficult; riding faster is actually a lot easier. Although walking very slow may seem safer, walking faster can make walking easier due to the inertial forces of the body moving through space.

Alter step length from short to long and back again. Going to the extremes of very short to very long can equip the body to reactively alter step length depending on an unexpected gait situation.

Alter base of support from feet wide apart to feet crisscrossing each other while walking. The normal distance in the base of support is about four inches. A wider base may become necessary as balance reactions are diminished, but that leads to more trunk motion and greater energy expenditure while walking.

Alter trunk posture while walking from slouched over to an exaggerated upright trunk. Each person should experience what feels most stable to them.

Walk to the beat of music to enhance a more consistent and symmetrical, and therefore safer, walking rhythm.

Walking tends to be habitual. We walk how we walk without much deviation from our normal gait. Experimenting with these walking variables in a safe environment can help individuals maintain or perhaps even increase their stability during walking.

Robert has been active in the fields of orthotics, therapeutic exercise and biomechanics since 1978 and has been conducting education programs since 1982. His special interest is in applied closed chain biomechanics and muscle function. He holds six patents involving orthotics and applied biomechanics for spine and lower extremity applications.

DR. MICHAEL SHY WINS PRESTIGIOUS AWARD FOR EXCELLENCE IN PERIPHERAL NERVE RESEARCH

The Peripheral Nerve Society (PNS) awarded CMTA Board Member Michael Shy, MD, its prestigious Alan J. Gebhart Prize for Excellence in Peripheral Nerve Research during an awards ceremony at the virtual PNS Annual Meeting on June 27.

The unrestricted $30,000 cash award recognizes an active PNS member's ongoing contributions to improving the lives of people with peripheral neuropathies throughout the world.

Presenting the award to Dr. Shy, PNS past president Dr. Richard Lewis praised his unique contribution to CMT research. Lewis, who worked with Shy at Wayne State more than 20 years ago, said that he made it clear from the start that "he was going to devote his career to treating patients with Charcot-Marie-Tooth disease and do everything possible to understand the basic pathophysiology of the disease and work to find treatments and ultimately a cure for as many of the genetic causes of CMT as possible."

Two decades later, Lewis said, "I can only look back with astonishment at what he has done to achieve these goals. He is without a doubt, the driving force behind so much of the basic and clinical research that has been done and is being done on CMT. He has created a remarkable network of centers and trained an amazing array of clinicians and researchers in inherited neuropathies. He has been a wonderful mentor and collaborator to so many."

CMTA WELCOMES SOFTWARE CEO PETE FOLEY TO BOARD OF DIRECTORS

The CMTA announced the appointment of Pete Foley to its already stellar Board of Directors in June.

Originally from Pittsburgh, Pete attended Yale University, where he played on the basketball team before graduating with a BA in economics and political science in 1984. He currently lives in San Francisco with his wife Adrienne and their two children. Pete spent the last 35 years as an entrepreneur in the technology industry: He founded his first company in 1987 and is currently CEO of ModelOp, a venture capital-backed enterprise software company.

Foley, who has CMT, said he is "excited to join such a talented team focused on addressing the challenges of finding treatments and a cure for CMT. They have made a lot of progress, especially within the last few years, and I hope to help add to the momentum of the board and team."

CMTA Board Chair Gilles Bouchard said, "It is with great pleasure that the CMTA Board of Directors welcomes Pete. He is a very successful entrepreneur with a proven capacity to deliver results and has expressed a contagious passion for applying his energy and talent for the benefit of all those affected with CMT."

The CMTA Board of Directors is a dedicated cadre of business owners, executives, doctors and lawyers charged with overseeing the organization's operations and strategy. Each is personally affected by CMT. Because they are all invested in the mission, they are singularly committed to the organization and give generously of their time and talents.

PARENTING KIDS WITH CMT

One of the best things about the CMTA's online sessions is the opportunity they provide for community members to share their knowledge and tips for dealing with a multitude of issues. The recent Zoom meeting on "Parenting Kids with CMT" was no exception.

Gail Buuck, the mother of a 49-year-old son with CMT2A, shared her experiences with the group, including her most important tip: "Teach your child to self-advocate." She acknowledged that it's hard for parents to sit back and not do anything while their children struggle, and she advised them to "Sit on your hands if you have to in order to prevent yourself from taking over." It may take the child a little longer to ask for help, complete a task or solve a problem, but it will be worth it in terms of the independence it builds, she said.

Gail's son John started showing symptoms when he was a toddler, and he was finally diagnosed at the age of 4. There was nowhere to go at the time, Gail said: There were no support groups and the CMTA wasn't yet in existence. The advice back then was just to live with it. Ignoring that advice, the Buucks found the Courage Center in Minneapolis, a not-for-profit whose mission—then and now—is to empower people with physical disabilities to reach their full potential in every aspect of life.

John Buuck, now 49, with his mother, Gail

The first step in teaching children to self-advocate is to teach them about their disability. When John got braces, Gail told him that wearing them was no different than wearing a pair of eyeglasses. Once they understand it, empower them to speak for themselves. Make sure they understand the difference between being assertive and being aggressive and how to avoid the latter.

Teach children to use their voices to ask for help, Gail says. Make sure they talk to their teachers about any problems like bullying or needing more time to take a test. Gail advised her son to talk not just to his teachers, but to everyone, right up to telling the waitress what he wanted to eat in a restaurant.

Gail, a former elementary school teacher, recommends getting children to talk to their teachers early. Fourth graders don't feel like babies anymore, so that's a very important year to make sure they are empowered to speak for themselves since their parents won't always be there.

"TEACH YOUR CHILDREN TO SELF-ADVOCATE"

Gail also taught her son to focus on what he could do, not what he couldn't do and to "Learn to ask." That meant that when John lost manual dexterity at the age of 7, he knew to ask for a different cup or lighter fork, for example.

Later, when John's school wanted to put him in Special Ed PE, he refused, then talked them into letting him fulfill his PE requirement with swimming. John was very "self-adapting," Gail says, and when it was clear that sports other than swimming were out, he pivoted to speech and debate and model UN.

John was in a wheelchair by the time he was 12, Gail recounts, and while he was nervous about his friends'

> **“ARM YOUR CHILDREN WITH CMT KNOWLEDGE AND SHARE THAT KNOWLEDGE WITH YOUR CHILDREN’S PEERS.”**


Laurel Richardson with her kids, 18-year-old Sophie and 16-year-old Jack, and her husband Chris

reactions to the wheelchair, the first day he had it, he ended up in detention for racing it in the school hallways.

Gail knew she had taught her son to self-advocate one snowy day in Minneapolis. John was stuck outside in the cold for a solid hour because the snowplows had blocked the path he needed to access the sidewalk. After a custodian helped him inside, he went straight to the principal’s office to make sure that it never happened again—for him or anyone else.

Three CMTA staffers also shared their perspectives on parenting children with CMT. Laurel Richardson, the CMTA’s director of community outreach, talked about the initial choice to have children. Laurel was diagnosed with CMT1A at the age of 6. She wasn’t terribly symptomatic until she was an adult, and her then-future husband was the first person she told about the disease.


Director of Development Jeana Sweeney with daughter Rylee

Laurel said that it never even dawned on them not to have biological children, in part because her father, who also had CMT, was a very positive role model. Laurel’s kids are 16 and 18 now and have thus far chosen not to be tested because they are asymptomatic.

Participants on the call had varying opinions on the right time to test. For some, it was when their children needed services. Others decided on early testing so that they could be proactive in their child’s care, by starting occupational therapy early, for example.

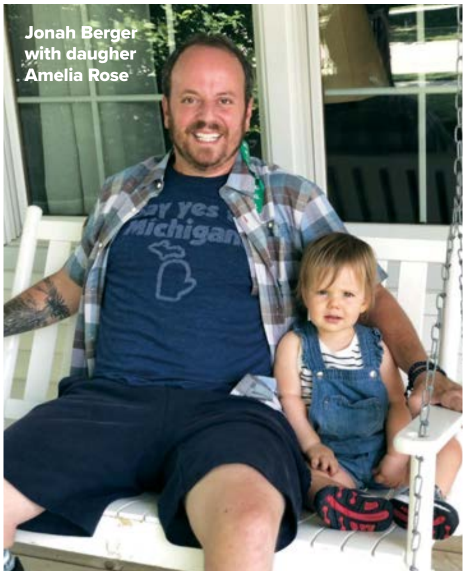
Jeana Sweeney, the CMTA’s director of development, agreed that there’s no right answer to the question of when to test and recommended that parents make an old-fashioned list of pros and cons. On the pro side, she noted that knowing their type could help ease a child’s anxiety about keeping up on the playground. Early knowledge could also empower them to find a physical activity that suits their abilities. They will also need a diagnosis when a treatment becomes available and when making the decision to have kids themselves.

Jonah Berger, the CMTA’s national youth programs manager, says the joke around his house is that you can tell if his wife, a nurse, is on duty by the state of his 2.5-year-old daughter’s hair. Jonah’s manual dexterity is not quite up to hers—he has CMT1X–and their daughter’s hair styles suffer as a result.

Jonah was diagnosed at the age of 5, so he grew up with the knowledge that he had CMT. His parents were always very positive about it, he says, and they conveyed that positivity to Jonah. As a result, he was able to run three triathlons and climb the highest mountain in Colorado.

Jonah advised participants to arm their children with CMT knowledge and to share that knowledge with their children’s peers. His mother, for example, came to his class every year from kindergarten to sixth grade to explain CMT to his schoolmates.

Asked what to do when a child resents the parent for passing CMT on, Jonah said that while it’s tempting and natural to try to place blame, it’s not productive. He suggested working on a shift in attitude, adding, “It’s not about what happens to you; it’s about how you deal with it that matters.”


Jonah Berger with daugher Amelia Rose

WHEN CMT GOES TO SCHOOL: STRATEGIES FOR THE BEST SCHOOL YEAR YET

BY SARAH KESTY

CMT varies in its expression in each individual, so it follows that its impact on students' school experience will vary as well. While some of our kids need accommodations only for PE, those whose hands are affected may also need support for writing. With such a wide range of disability impact, how do you best prepare your child and the school for a successful school year?

Start by explaining CMT to your child's school. Teachers are humans and very busy ones at that! The best way to empower the school staff is with information, but not too much. Clarity and simplicity are key in your outreach to schools. Consider the basics:

- CMT is a neuro-muscular disease that _______
- My child was born with CMT and was diagnosed at age _______
- One way CMT impacts my child is ______
- In class, you might notice ______
- Ways you can help my child are ______

Analogies are also a great way to explain CMT in a memorable and accessible way. You can describe CMT as causing traffic in the electrical highways of the nerves to the muscles. This traffic slows reactions and can make moving more challenging.

It's important to emphasize to the teachers that they need to listen to your child's self-advocacy. Fatigue is a big concern for many of us with CMT, and it can appear like laziness to outside observers. Encourage your child to speak up when he or she needs a break or is feeling extra pain or sluggishness. You can even develop a signaling system for your child to alert teachers without alienating or embarrassing themselves. For example, I have hand signals my students can show me when they need to express different things. They're something I set up with each child as a vehicle for communicating without interrupting the class or bringing unwanted attention to the student.

When informing (or reminding) the school about your child's CMT, remember to include the nurse. The school nurse can provide terrific support in allowing your child a space to rest, storing and giving out pain medications (please don't keep them in your child's backpack) and advocating for your child in your absence.

Nurses can also help you develop a safety plan, should a fall or other accident happen at school. If your child has an Individualized Education Plan or 504 Plan, include the nurse in its annual development. Every state's paperwork has space to document health concerns, and the nurses need to be aware.

Just as important as explaining CMT to your child's teachers is empowering your child to explain CMT to others. It took me nearly 30 years to be comfortable enough with my CMT to share it with others. If your child isn't ready to talk about it, that's okay. Don't push your child or shame him or her for not being ready to embrace CMT; that path is deeply personal and follows no particular timeline. Your child will, however, need to be able to self-advocate and express his or her needs effectively.

Discuss ways to explain CMT to trusted adults. Phrases could include, "I have a nerve and muscle condition that sometimes makes me feel..." or "I have a medical condition that means I sometimes need....” It doesn’t have to be more detailed than that. But your child does need to be well-rehearsed in saying the phrases so he or she is willing to speak up when the time comes. Rehearsal is a great way to increase confidence in a low-pressure situation.

Similarly, your child may need some responses ready in case other kids ask about some of the visible symptoms, bracing or assistive technologies. I love to teach kids to respond with, “Everyone has something. My something is that I ______ What’s yours?” It’s a good way to answer with fewer emotions and then pass the question back to the asker. Sometimes this creates a great conversation; other times it confuses a potential bully. Either way, having a response ready will empower your child to handle social situations, student curiosity and potential bullying that can happen during the year.

Lastly, encourage your child’s teacher(s) to practice empathy and awareness in class. You can offer to share lessons or resources (www.cmtausa.org/kesty-empathy) or connect the teacher with empathy programs like RedRover (www.redrover.org/readers/). The idea is to create a classroom environment where students are safe to be their unique selves and share the vulnerabilities of being human.

I know from personal experience that living in a body with CMT can be tough. School doesn’t have to be. Taking a thoughtful and empathetic approach to start the school year can pave the way for great success and personal growth this year. Remember, you have the CMTA community for support and guidance.

CMTA Advisory Board Member Sarah Kesty is an educator, speaker and author who helps CMTA members make the best of their children’s school experiences. An experienced advocate who has CMT herself, Sarah helps families navigate school support systems with confidence and clarity. Her website is www.sarahkesty.com and her children’s book is called “Everyone Has Something!”

special edition **access cmt** it’s awareness month

NEWSPEOPLEPLACESEVENTS

Happy CMT Awareness Month!

As we celebrate awareness month, we welcome you to a Special Edition of Access CMT Awareness Month. We will be bringing you all the best in CMT news, personalities and entertainment from patients living with CMT around the world.

We invite you to tune in or be part of the show, as we will be showcasing stories about the brave, innovative and doggedly persistent members of our community. To us, they are the real celebrities.

To be part of Access CMT,
visit www.cmtausa.org/aware.

special edition access cmt be an awareness month STAR

BUY A STAR.
BE A STAR.

There's no shortage of shining stars in the CMTA firmament. That's what drives us to work harder, longer and smarter, through good times and bad. That's why—to us—you and your loved ones are the real celebrities. So today and throughout Awareness Month, we are asking you to put yourself or your loved one's name in the CMT Hall of Fame!

All STARs purchased this month ($5 each) will be inducted into the CMT Hall of Fame and shared on September 30.

Go to www.cmtausa.org/cmtstar to purchase yours today!

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THE NEURO SWING AFO:
ONE ORTHOTIST’S OPINION

BY DAVID MISENER

As a prosthetist/orthotist with CMT, I encourage my patients to Continue Moving Today (CMT). That means working your muscles daily, eating healthy and being happy doing what you want to do. Over a year ago I got quite excited about wearing a newer AFO—the Neuro Swing—that made perfect biomechanical sense for individuals with CMT. What’s perfect? A brace that allows the muscles to work properly with a full range of motion. Muscle weakness or range of motion loss compromises what can be done with our bodies, requiring a device to support, align and/or assist motion.

I am fortunate that my chosen field allows me to try many different designs and styles of devices. Historically, I have used the silicone AFO custom-fabricated by Dorset Orthopedic in the UK. This device allowed for simple drop foot and medial lateral support. It was exceptional around water, and it was very discreet to use. As my condition progressed, I required greater support and assistance from bracing. I progressed to using carbon devices for everyday use and the silicone AFO solely for water sports. I have enjoyed the Blue Rocker from Allard with a custom foot orthosis to direct, control and manage my biomechanics. Over time the Blue Rocker has improved, and I now wear the Blue Rocker 2 1/2 on my left side. I use the Phat brace on my right side due to additional bracing needs.

The Neuro Swing AFO is made by Fior & Gentz (www.fior-gentz.us/neuro-swing-orthosis/neuro-swing-afo.html). According to the manufacturer, it is the only custom-designed orthosis that matches the pathological gait of persons affected by neurological disorders with the accurate orthotic treatment providing dynamic balance and stability. It does so via a patented ankle joint that provides three independent adjustment possibilities that can all be changed separately without influencing the others.

I can tell you from my experience that it felt like no other device. It gave me incredible standing stability: I could stand straighter; I could stand with my eyes closed for an extended time; and my balance was better in crowds and on grass, gravel, stairs and ramps. It took some time to learn how to walk properly with them, and I enjoyed positive comments from friends and family on how I looked standing and walking. Then snap, the right AFO broke! A complete fracture of the ankle stirrup. I examined the left AFO and it too was failing.

This is one of the pitfalls of adopting technology early. The joints themselves—which are the heart of the device—seemed to be fine. But the company needed to make production improvements in fabricating the AFO.

Since my Neuro Swing broke, I have seen a significant improvement in the devices coming from the manufacturer and now believe the brand is worthy of being added to the list of successful devices to be used with CMT. There will always be more maintenance with a hinged AFO and that is to be expected. I generally tell people that all bracing is a compromise. Imagine a scale considering the positives and negatives of each device. Some people will select one style to meet their lifestyle, while other may select something different.

> THERE WILL ALWAYS BE MORE MAINTENANCE WITH A HINGED AFO…

I believe the Neuro Swing is a great choice for CMTers in certain circumstances. As CMT progresses, traditional carbon AFOs need to be stronger and stronger to support and align the body. At some point, the carbon AFO becomes too strong to describe it as dynamic: It essentially becomes a solid ankle AFO. I believe this is more harmful to maintaining muscle strength and range of motion.

This is where the beauty of the Neuro Swing comes into play. The large adjustable joint gives it the strength to hold the ankle for standing stability and to move while walking. This allows for a more normalized walking pattern. It also makes it easier walking up and down hills and ramps and simply getting out of chairs because your ankle can flex.

With all of the positives of the Neuro Swing, why am I wearing different bracing? Like most things in life there are positives and negatives to each device. I often say an orthosis is like a tool: Some tools are better for certain jobs. I was a little disheartened when I broke the Neuro Swings and it does take considerable effort and cost to repair them. That’s a future project, but for now I am happy achieving my goals using my current systems. In the end, no bracing is perfect; it is all a compromise allowing us to improve our activities of daily living. Do what you can do to be the best you can be. Don’t let CMT stop you from doing the things you want to do … within reason.

CMTA Advisory Board Member David B. Misener, BSc (HK), CPO, MBA, is an American board-certified prosthetist and orthotist who has been practicing in Albany, New York, since 1998. He is one of three owners of Clinical Prosthetics and Orthotics, which has office locations ranging from Saratoga Springs to Poughkeepsie, NY.

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ACCORDING TO THE DICTIONARY, an innervator is a nerve stimulator. According to the CMTA, an Innervator is an action-oriented donor who gives monthly to the organization, sustaining STAR (Strategy to Accelerate Research), our premier research initiative, as well as important community initiatives like Camp Footprint, Patient/Family Conferences and educational programs. All of these programs require steady, reliable support from committed donors. Please join the Innervators today!

www.cmtausa.org/cmta-innervators

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> *"I am a CMTA Innervator because my dream is to further our scientific breakthroughs and, right around the corner, find a cure. Giving monthly allows me to help the CMTA with the necessary funding to make the dream come true."*
>
> *—INNERVATOR ROBERT WEIS*

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CMTer Jamal Hill Takes Bronze at Paralympic Games

Jamal Hill took the bronze medal in the men's 50-meter freestyle at the Paralympic Games in Tokyo on August 29, breaking his own record with a score of 25.19 seconds. Denis Tarasov of the Russian Paralympic Committee won silver with 24.99 seconds and Simone Barlaam of Italy won gold with 24.71.

At 26, Jamal is ranked #1 in the US Paralympic 50 Free and #3 in the world. He had hoped to add four medals to his total in 2020, but the games were postponed until 2021.

In addition to being a Paralympic athlete, Hill is working towards a much larger goal: He wants to teach 1 million people to swim. According to his website, roughly 360,000 people lost their lives to drowning in 2016, and drowning ranks fifth on the Centers for Disease Control's list of the causes of unintentional injury or death. He founded Swim Up Hill in an attempt to lower the global drowning rate. "My mission is to have an impact. I want to be more than just an athlete," he says.

Read more about Jamal at www.swimuphill.com and the Winter 2020 issue of *The CMTA Report*.

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BRANCH MEETING NOTES

SARASOTA, FL

About a dozen Sarasota branch members met for an informal lunch on May 22 at a Denny's Restaurant while following COVID protocols. Everyone was fully vaccinated and felt comfortable gathering in a small group. There was plenty of lively conversation and the branch is looking forward to having in-person branch meetings again soon.

CHICAGO, IL

Jonah Berger, CMTA national youth programs manager, and Rai Ganesan from the CMTA Youth Council joined the Chicago Branch meeting May 8. Members started with a check-in to see how things have been going in their lives, then heard about the latest CMTA research news, the resources at the www.cmtausa.org website and the many Zoom meetings the CMTA offers. Jonah and Rai, two passionate and inspired individuals, shared their stories of living with CMT and talked about the Youth Program's beginnings, what's happening now and what they see for its future.

LAS VEGAS, NEVADA

The Las Vegas branch welcomed Douglas Eck, PT, DPT, MHI, to its June 12 branch meeting on Zoom. Dr. Eck is a neurologic physical therapist and expert in rehabilitation and health maintenance for a variety of neurological diagnoses and a board-certified Neurological Clinical Specialist (NCS). He is passionate about helping people improve their symptoms with physical therapy training. He gave a wonderful presentation and took time to answer questions.

NEWBURY, NH

Jeana Sweeney, CMTA director of development, joined the Newbury branch on August 18. Jeana is a passionate CMT advocate and spent time talking about her CMT journey. She also shared highlights of what's happening in CMTA-STAR research and how to be involved as a patient partner in research studies. Other people also shared their CMT stories and talked about living with CMT. The branch also discussed its upcoming Trivia Night fundraiser on September 10.

NEW MEXICO

Ten people joined the New Mexico Branch's Zoom meeting on July 31, including four new attendees from out-of-state. Branch leader Gary Shepherd opened the meeting by reporting on a CMTA branch leader training meeting with Dr. Svaren, chair of the CMTA Science Advisory Board and a long-time CMT research scientist, who conducted a Q&A session on CMT research. The group also viewed several video segments recorded by a physical therapy specialist who is extremely CMT-knowledgeable. Three CMT patients demonstrated the various exercises and stretches that were presented. The segments covered: Balance, Endurance, Flexibility, Strength and Walking Balance. The group had a discussion after each segment. The next Patient/Family Conference will take the place of the branch's next meeting on November 6.

BUCKS COUNTY, PA

Sixteen people came out for the Bucks County Branch's Summer Picnic on August 21, including six new people who had never attended a branch meeting. Members thoroughly enjoyed gathering safely outside as a group and catching up in person for the first time in over a year. The weather, food and outdoor activities were all great.

PITTSBURGH, PA

The Pittsburgh branch met (via Zoom) on July 21 to discuss the 2021 Pittsburgh Walk-4-CMT. Julie Tarle, special events manager for the CMTA, and the members decided to hold an in-person walk this year at Blueberry Hill Park on September 26 while following COVID safety protocols.


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VIRTUAL - SATURDAY, NOVEMBER 6

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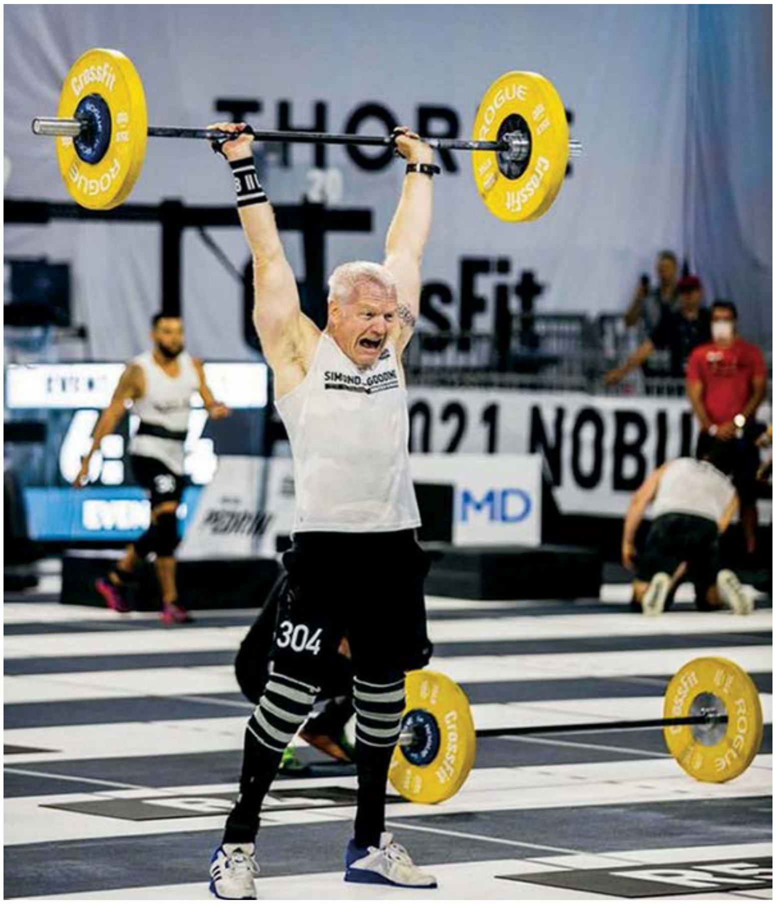

UK CMTer Takes Division Second at CrossFit Games

At 45, George Simonds-Gooding was the oldest competitor in the neuromuscular division of the NOBULL CrossFit Games in Madison, Wisconsin, July 27 to August 1, but neither his age nor his CMT slowed him down. In what he describes as one of the proudest moments of his life, he finished his division in second place.

Thirty athletes took part in the first-ever Adaptive Division at the NOBULL CrossFit Games. Of the 30, five men and five women participated in the Neuromuscular Division.

According to CrossFit, "All of the competitors gave an impressive showing, making a clear statement that fitness is attainable for anyone, no matter what limitations may stand in the way." Sport changes lives, whether that be through physical and mental health, battling back disease, or forming connections with the community, the company said in a statement, adding, "These athletes are no different, making the same—if not stronger—argument for the sport of fitness."

For those who don't know, CrossFit is an exercise program that incorporates elements from several sports and types of exercise. As George put it, "A good CrossFit athlete is a Jack-of-all-trades, whether it be running, weightlifting, Olympic lifting, gymnastics, plyometrics—the list is endless! CrossFit also encourages a holistic approach through good nutrition to reduce the risk of many lifestyle-related diseases." All exercises can be scaled to the individual athlete's age, fitness level, and physical condition, making it perfect for the inclusion of the Adaptive Division, George said. To win second in his category, George had to compete in seven different events:

- A three-mile run
- A workout featuring 15-foot rope climbs and 275-pound deadlifts
- One rep max power clean (lift barbell to shoulders from floor)
- Workout including bike erg, toes to bar and weighted squats
- A 300-meter swim
- A workout including pull-ups, an indoor ski machine and skipping rope
- Box jump overs and thrusters (lifting a 115-pound barbell overhead)

George owns a gym in Eastfield, UK, and fitness has been his life since he was diagnosed 10 years ago. He had always enjoyed and tried to compete in sports but never reached the levels he aspired to. He couldn't improve his 100-meter sprint time, and he wasn't very good at soccer. In his teenage years, though, he found the gym and rugby. While he never earned a regular first-team position at his last rugby club and had plenty of sprained ankles over the years, he discovered that he enjoyed strength training.

At the age of 35, some of the muscles in George's hands began to waste, and after numerous tests, he was diagnosed with CMTX. Shortly after diagnosis, he discovered CrossFit at a local gym.

George says CrossFit has been a good outlet for his need to stay fit, especially after his ankles became too unstable for rugby. He opened the Park Side Gym, home of CrossFit Earlsfield, with a partner in 2019. It's "been challenging but we've got through the pandemic," he says, showing once again the fortitude that all CMTers possess.

WHAT'S ON YOUR MIND? ASK DAVID.

David Tannenbaum answers questions from readers in his column "What's On Your Mind? Ask David" regularly in The CMTA Report. *David has an LCSW degree and has been a psychotherapist in New York City for the past 30 years, specializing 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.*

Dear David,

I am a 32-year-old female with CMT. I often feel anxious and scared. I have been depressed at times and even cut for a while. My family has never talked much about CMT. We all try to hide it. My dad swears he doesn't have it, but I think he does because he walks with a different gait. I'm afraid to go to doctors but feel I need to get some help so I can make life better for myself, my son and my brother, who has much more severe symptoms than I do. I wish this disease would just go away. Please help.

David Replies:

I often hear from members of our community who grew up in families that never talk about CMT even though it is such a prominent aspect of their lives. Then again, other issues involving strong emotional content are avoided as well. The end result is family members silently struggling alone, never quite connecting with one another and feeling isolated.

Emotions like fear, anxiety, anger and sadness are considered a weakness and we are often given the message to buck up and stop complaining. Eventually, we shut down emotionally and lose the ability to identify our feelings.

Sadly, the inability to know what we are feeling can lead to depression and anxiety. Once we can put a name to the feeling and accept it in a non-judgmental way, the feeling will soften and fade away on its own. Often, we are resistant to acknowledging feelings, even to ourselves. Cutting, as you probably know, is an attempt to experience physical pain when we are unable to tolerate our emotional distress. When families are not able to share their feelings about CMT, the children subliminally receive the message that CMT is something to hide or be ashamed of. This is something you want to avoid. I have seen parents unknowingly pass this unspoken shame down to their children.

Transform the energy of fear into action and taking care of yourself, your brother and your son. There is a lot of good information about living your best life with CMT. A good neurologist who understands CMT can be invaluable. Better yet, try to visit one of the CMTA Centers of Excellence near you (see page 25, or visit www.cmtausa.org/coe).

Be courageous and break the tradition of not speaking about your CMT. When you begin to share with others who truly understand what it is like to live and flourish with CMT, you will instantly feel better. Whether you connect with others through a support group or find a counselor online who understands about living with chronic illness, do something to take charge of your life. Remember that knowledge is power and learn how to live your best life. You will be setting a great example for your son and, most importantly, you will know that you are not alone.

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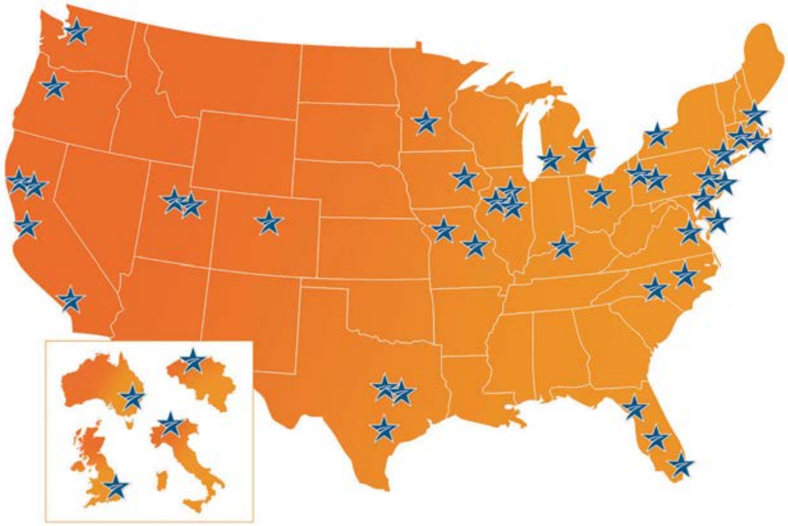
CMTA CENTERS OF EXCELLENCE are patient-centric, multidisciplinary CMT clinics where children, adults and families affected by CMT can be assured of receiving comprehensive care by a team of CMT experts. The Centers roughly correspond to the 21 international sites that make up the NIH Inherited Neuropathy Consortium (INC)—a group of academic medical centers, patient support organizations and clinical research resources sponsored in part by the CMTA. The centers are becoming even more important as the CMTA begins clinical trials, which 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. Much of that information will be supplied by the Centers of Excellence.



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CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):
- Taxols (paclitaxel, docetaxel, cabazitaxel)
- Vinca alkaloids (Vincristine)

Moderate to significant risk:
- Amiodarone (Cordarone)
- Arsenic Trioxide (Trisenox)
- Bortezomib (Velcade)
- Brentuximab Vedotin (Adcetris)
- Cetuximab (Erbitux)
- Cisplatin and Oxaliplatin
- Colchicine (extended use)
- Dapsone
- Didanosine (ddI, Videx)
- Dichloroacetate
- Disulfiram (Antabuse)
- Eribulin (Halaven)
- Fluoroquinolones
- Gold salts
- Ipilimumab (Yervoy)
- Ixabepilone (Ixempra)
- Lefluonamide (Arava)
- Lenalidomide (Revlimid)
- Metronidazole/Misonidazole (extended use)
- Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
- Nitrous oxide (inhalation abuse)
- Nivolumab (Opdivo)
- Pembrolizumab (Keytruda)
- Perhexiline (not used in US)
- Pomalidomide (Pomalyst)
- 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)
- 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 medications listed above are potentially toxic to CMT patients. Vincristine has been proven hazardous and should be avoided by all CMT patients, including those with no symptoms. Taxols also pose a high risk to people with CMT. The remainder of the medications listed above present varying degrees of potential risk for worsening CMT neuropathy. Before taking any medication or changing medication, all CMT patients should make sure the treating physician is fully aware of their medical condition.

WHAT IS **CMT?**

More than 3 million people worldwide have CMT, which is one of the most commonly inherited nerve disorders and affects the motor and sensory nerves.

CMT is slowly progressive, causing the loss of muscle function and/or sensation in the lower legs and feet, as well as hands and arms.

Men and women in **all ethnic groups may be affected by CMT.**

CMT is genetic, but it can also develop as a new, spontaneous mutation.

CMT can vary greatly in severity, even within the same family.

CMT causes structural deformities such as high-arched or very flat feet, hammertoes, hand contractures, scoliosis (spinal curvature) and kyphosis (rounded back).

CMT can also cause foot drop, poor balance, cold extremities, cramps, nerve, muscle and joint pain, altered reflexes, fatigue, tremor, sleep apnea, hearing loss and breathing difficulties.

CMT rarely affects life expectancy.

Some medications are neurotoxic and pose a high risk to people with CMT, notably Vincristine and Taxols. See full list (at left) of medications that may pose a risk.

More than 100 different genetic causes of CMT have been identified.

Many types of CMT can be determined by genetic testing. Please consult with a genetic counselor (www.nsgc.org) or your physician for more information.

Although there are no drug treatments for CMT, a healthy diet, moderate exercise, physical and/or occupational therapy, leg braces or orthopedic surgery may help maintain mobility and function.

The CMTA-STAR research program and extensive partnerships with pharmaceutical companies are driving remarkable progress toward delivering treatments for CMT, bringing us closer to a world without CMT.