

WINTER 2021/2022

# THE CMTA REPORT

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## DANCING 4 CMT!

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and Collaborations

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for CMTers

**17** > Applying  
for SSDI



## MEMBERS OF THE CMTA YOUTH COUNCIL AT THE BIG DANCE

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## THE CMTA REPORT | WINTER 2021/2022

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# CMTA

Charcot-Marie-Tooth Association

## Dear Friends,

When 9-year-old Kaya was diagnosed with CMT in 2020, her parents wasted no time in turning to the CMTA for help and information. Kaya's father William Chablani then underwent DNA testing and at the age of 53, he discovered that he too had CMT. Kaya and her family's greatest hope is that treatments are found to prevent/stop progression of CMT and that a cure will soon be within reach. But hope is more than just optimism: It is based on an expectation of positive outcomes. At the CMTA, we are fortifying our hope with action, doing everything in our power to find those positive outcomes. As you make your year-end giving decisions, we're asking you to join us in keeping hope alive for everyone living with CMT.

Families that live with CMT all share one hope: that their children and grandchildren will grow up without the fear of CMT hanging over them. They know that the CMTA will turn their hope into action by funding our critical Strategy to Accelerate Research (STAR) projects, which will eventually lead to treatments and a cure. Every donation, no matter the size, moves us closer to that goal.

Doreen Pomykala, 60, of Illinois, comes from four generations of CMT—her grandmother, uncles, sister, daughters and sister's children all have Type 1B. Doreen donates to the CMTA in the hope that her granddaughter won't need another major foot reconstruction surgery on top of the three she's already had. Doreen also hopes that future generations won't need braces, canes, walkers and wheelchairs to get around, or the extra time, thought and creativity that people with CMT need for the activities of daily living.

Alessandro Cacciani, 48, entrusts the CMTA with his charitable dollars in the hope that his wife won't have to watch him decline as his CMT progresses. He also hopes that a cure or treatment will mean that children don't have to wonder if every stumble or random pain is a sign that they have it—a constant fear for them.

*continued on page 5*



**A MESSAGE  
FROM THE CEO  
(AND DIRECTOR OF  
DEVELOPMENT)**



*Kaya and William*



*Doreen and family*



*Alessandro and family*

# YOUR DONATION MAKES A DIFFERENCE

**\$10**



Might pay for an information packet to be sent to a CMT Center of Excellence for a newly diagnosed patient

**\$30**



Can help fund the next generation of researchers

**\$50**



Will support patient registries and outcome measures needed for clinical trials



**\$100**

Might provide seed funding to leverage National Institutes of Health initiatives

**\$200**



Could support testing of wearable monitors needed for clinical trials

**\$500**



Might support small animal testing of new therapies

**\$750**



Might go to major biomarker testing initiatives needed for clinical trials

**\$1,000**



Could support small molecule testing

Every donation keeps hope alive for everyone living with CMT

**CMTA**  
Charcot-Marie-Tooth Association  
[cmtausa.org/curecmt](http://cmtausa.org/curecmt)

**\$2,500**



Could help find the genetic cause for an as-yet unknown type of CMT

**\$5,000**

Could support application of CRISPR-Cas9 to CMT research



**\$10,000**

Could go to clinical trials for CMT



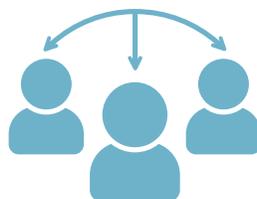
**\$20,000**



Might be used to support world-class pre-clinical testing

**\$50,000**

Might be used for major gene therapy initiatives with biotech partners



**Keep hope alive for everyone living with CMT!**

Please Note: The facts and figures are an estimate only. Donations are tax-deductible to the full extent allowable by law. This list is not intended to be comprehensive.

# MESSAGE CONTINUED

With our community's help, the CMTA has invested over \$17 million in CMTA | STAR research since 2008, making us the largest charitable funder of CMT research globally. But our work isn't done: Our strategy outlines investments of another \$10 million in the next few years to accelerate the search for CMT drugs and therapies.

Donations to STAR are bundled and used for a multitude of important projects. After a rigorous review process, the CMTA makes grants to researchers based on how "translatable" a proposed program is, in other words, how easily findings can be transformed into therapies.

So, for example, your \$500 year-end donation could help fund a \$664,261 award to CRISPR-Cas9 efforts by the Bruce Conklin lab, which will be the first application of CMT to axonal neuropathy (2A, 2E, 2F). A \$1,000 donation could help support a \$154,507 grant funding target validation for SARM1 and HDAC6 inhibitors in multiple types of CMT while a \$10,000 donation could be used to fund biomarker research to enable clinical trials for CMT1A, CMT2A, CMT1B and CMT1X. There are many ways for your donation to accelerate research.

The graphic on the facing page shows some of the ways your donations help fund critical research. And you can rest assured that we're using them wisely, earning Charity Navigator's highest 4-star ranking for meeting or exceeding industry standards with our exceptional performance and accountability.

As you make your urgently needed year-end gift, we ask that you give hope to everyone who lives with CMT. As the late actor Christopher Reeve said, "Once you choose hope, anything is possible."

With gratitude,



**Amy Gray**  
CMTA Chief Executive Officer



**Jeana Sweeney**  
CMTA Director of Development



**KEEP HOPE ALIVE  
FOR EVERYONE  
LIVING WITH CMT!**

**Donate by the end of 2021 and  
your contribution will be  
matched dollar for dollar,  
up to a maximum of \$500,000.**

Complete this reply slip and return with the enclosed envelope to **CMTA, PO Box 105, Glenolden, PA 19036**

**Please make checks payable to the Charcot-Marie-Tooth Association.**

**Donate online at [cmtausa.org/curecmt](https://cmtausa.org/curecmt).**

## YES, I WANT TO DOUBLE MY DONATION AND SUPPORT CMTA RESEARCH!

Here is my year-end gift of:  \$3,500  \$1,000  \$500  \$250  \$100  \$50  Other: \$ \_\_\_\_\_

Please charge my credit card:  Visa  MasterCard  American Express  Make My Gift a Monthly Donation

Earmark gift for:  Type 1A  Type 1  Type 2 and Unknown  Type 4  General CMTA | STAR RESEARCH

I am interested in learning more on how to make a major gift or a multi-year pledge to support STAR

Name \_\_\_\_\_ Card # \_\_\_\_\_ Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_ Billing Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Phone \_\_\_\_\_

email \_\_\_\_\_

Dedicate this gift to \_\_\_\_\_ Honoree's email: \_\_\_\_\_

My gift is  In honor of  In memory of: (Name) \_\_\_\_\_

# CMTA CONTINUES TO FILL RESEARCH PIPELINE WITH GRANTS FOR CMT4A, CMT1A AND SORD

The CMTA Board of Directors approved five more research projects and collaborations in the last two months, continuing its multipronged attack against all forms of CMT. Under the banner of STAR (Strategy to Accelerate Research), the CMTA works with the world's largest network of biotech research partners, research scientists and clinicians to develop new therapies directly with companies and to test them in its preclinical testing alliance.

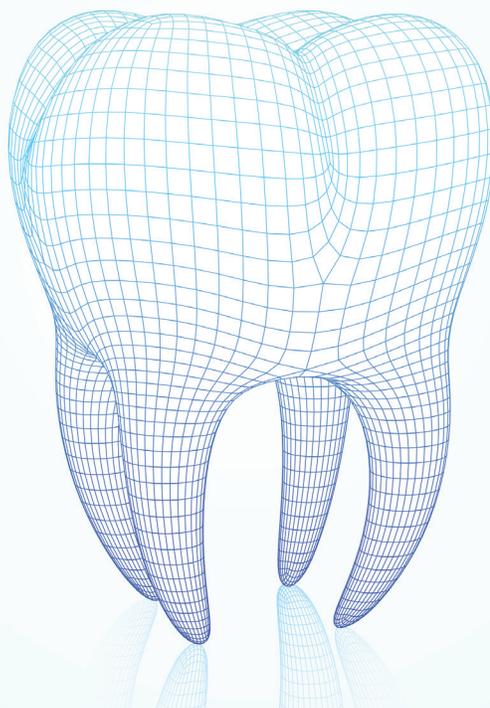
## 1A Project Uses Cells from Tooth Pulp

On Nov. 4, the board announced that it had awarded \$98,985 to Esther Wolfs, MSc, PhD, at Hasselt University in Belgium to develop new cell-based disease models of CMT1A (the most common form of CMT) extracted from the pulp of teeth that can be used to test the efficacy of drug candidates in a lab dish.

Dental Pulp Stem Cells (hDPSCs), which are extracted from teeth removed during dental procedures, are easy to isolate and provide a viable, bankable alternative to induced Pluripotent Stem Cells (iPSCs), which are derived from blood or skin cells.

Wolfs' approach will not only provide insight into the molecular pathways involved in CMT1A, it will also enable the CMTA's preclinical testing alliance to quickly test the effects of a potential therapeutic. The initial study's first goal is to demonstrate that the hDPSCs can form myelin—the protective coating around the “wire” of the nerve—in a dish. The second goal is to show that the cells can be transformed to express CMT1A disease markers as seen in Schwann cells from patients.

Currently, no human stem cell models accurately mimic Schwann cells from CMT patients, and that lack has been a considerable roadblock. New research tools to rapidly identify potential CMT1A therapeutics and to study what causes the disease at a cellular level are urgently needed. A reliable system that accurately reports the function in the affected Schwann cell will directly facilitate the identification of potential new drug targets and speed the design of new therapeutics. If successful, the work will be translatable to other CMT Type 1s that also result from a genetic defect in the myelin-producing Schwann cell of peripheral nerves.



## Grant to Taysha for CMT4A Gene Therapy

On Nov. 2, the CMTA announced a venture philanthropy grant to Taysha Gene Therapies for a CMT4A gene therapy project. Taysha, a patient-centric, pivotal-stage gene therapy company, is focused on developing and commercializing AAV-based gene therapies for the treatment of monogenic diseases of the central nervous system in both rare and large patient populations.

Taysha and the CMTA will jointly fund the project at UT Southwestern under the direction of Drs. Xin Chen and Steven Gray, co-principal investigators. (UT Southwestern and Drs. Chen and Gray hold a financial interest in Taysha. Dr. Gray serves as Chief Scientific Advisor for Taysha and is on the CMT Foundation Advisory Board.)

The goal of the project is to directly deliver the GDAP1 gene with adeno-associated viral 9 (AAV9) to stop the neuropathy that happens in CMT4A. The findings from this project will be critical in advancing research that will potentially lead to clinical trials for CMT4A patients.

**TAYSHA**  
GENE THERAPIES

For more information about the CMTA's research initiatives visit our website at [www.cmtausa.org](http://www.cmtausa.org)

## CMTA and Applied Therapeutics to Collaborate on CMT-SORD

The board announced Oct. 26 that the CMTA is collaborating with Applied Therapeutics to investigate a potential therapy for a newly discovered type of the SORD (sorbitol dehydrogenase) gene.

Applied Therapeutics, a clinical-stage biopharmaceutical company, is developing novel drug candidates against validated molecular targets in indications of high unmet medical need.

The primary goal of the collaboration is to help identify patients who may be eligible to participate in upcoming clinical trials and to provide insight into clinical trial planning through the CMTA's Patients as Partners in Research initiative. Through this collaboration, patients will be able to get free SORD testing, either from a nurse who comes to their homes or at their doctors' offices. The patient perspective will help shape trials to come.

A team led by Dr. Stephan Züchner at the University of Miami recently discovered SORD. Züchner's team, including Drs. Andrea Cortese, Grace Zhai, Adriana Rebelo and many others, found that mutations in the SORD gene cause an axonal form of CMT that is recessive. The newly discovered type is caused by a mutated SORD gene that raises sorbitol levels so high they cause nerve damage. Researchers found that treating fruit flies with a type of drug called an aldose reductase inhibitor reduced their high levels of sorbitol to near normal. It is estimated that 3,000 to 4,000 people in the United States and 4,000 patients in Europe have this type of CMT, making it the most common recessive form of the disease.

AT-007 is an oral aldose reductase inhibitor in development for SORD. Because the drug is still in clinical trials, it's called an "investigational drug." AT-007 blocks the enzyme that precedes

sorbitol dehydrogenase to prevent sorbitol from being formed in the body.

In a recent pilot study in eight SORD patients, AT-007 reduced sorbitol levels by 66 percent in the blood, with a range of individual patient reductions from 54 percent to 75 percent. AT-007 has also been studied in healthy volunteers as well as adults and children with another rare disease called galactosemia. Applied Therapeutics is planning to initiate a larger registrational study in SORD patients with sites in the United States and Europe toward the end of this year. The hope is that the registrational trial will support approval of the first drug to treat SORD.



## CMTA and ToolGen to Investigate Use of CRISPR for CMT1A

The CMTA and ToolGen announced a collaboration Oct. 7 to investigate the use of CRISPR gene editing technology for CMT1A.

The primary goal of the collaboration is to facilitate the development of a novel gene-editing therapy for CMT1A that will suppress overactivity of the causative disease gene, PMP22. CMT1A affects some 1.5 million people. The CMTA's Strategy to Accelerate Research (STAR) connects leading CMT clinicians and researchers with pharmaceutical partners committed to developing treatments and a cure for CMT. Strategic alliances with pharmaceutical partners like ToolGen support drug development efforts to deliver therapies to CMT patients.

CMTA's CEO Amy Gray said, "We are excited to establish this partnership with ToolGen as they work to advance gene editing technology to treat CMT1A. Attracting research partnerships with companies like ToolGen is a central part of our strategy to accelerate the development of treatments for the CMT community. Since launching STAR 12

years ago, the CMTA has been able to establish research partnerships with almost 40 pharmaceutical and biotech companies, and leading research labs around the world."

The testing alliance with ToolGen gives it access to the CMTA | STAR preclinical testing alliance, including scientific and clinical advisors, animal testing of the approach in the CMTA preclinical testing alliance network and assistance with the planning of clinical trials in the United States.



## CMTA to Collaborate with Addex Therapeutics on CMT1A Treatment

The CMTA announced Sept. 22 that it will collaborate with Addex Therapeutics, a clinical-stage pharmaceutical company, to investigate a potential therapy for CMT1A.

The primary goal of the collaboration is to evaluate the benefit of Addex Positive Allosteric Modulators (PAMs) targeting the GABAB receptor in rodent models of CMT1A. The GABAB receptor has previously been shown to be instrumental in controlling the overexpression of Peripheral Myelin Protein-22 (PMP22) in a rat model of CMT1A. Elevated PMP22 is closely associated with the sometimes disabling peripheral neuropathy that accompanies CMT1A.

CMTA CEO Amy Gray said, "Strategic research partnerships with great companies are proof that the work done by CMTA researchers is paramount to understanding the disease and developing medicines for the CMT community."

The testing alliance with Addex will include joint study planning aimed at the chronic dosing of select GABAB PAMs in rodent models of CMT1A, followed by detailed assessments aimed at measuring the improvement of key outcomes. These outcome measures include markers, motor function, electrophysiology and peripheral nerve histology.

# INVESTIGATORS IDENTIFY NEW THERAPEUTIC TARGET FOR SOME FORMS OF AXONAL NEUROPATHY

Several types of axonal CMT are caused by dominant mutations in genes that code for a class of enzymes called tRNA synthetases. Until now, it has been unclear how these mutations lead to peripheral neuropathy, but two recently published studies suggest a mechanism that could result in a treatment.

The tRNA synthetases are involved in cells' first step in making new proteins. A paper from Erik Storkebaum's lab in the Netherlands (Zuko et al., *Science*, Sept. 3, 2021) found that these mutant tRNA synthetases may stall the protein production process by failing to release the products of their biochemical reactions. Without those products, protein synthesis cannot proceed.

The second paper (Spaulding et al., *Science*, Sept. 3, 2021) describes the discovery by Robert Burgess (a member of the CMTA's Scientific Advisory Board) and colleagues at The Jackson

Laboratory that these impediments to protein synthesis lead to the activation of the integrated stress response in motor and sensory neurons. This pathway is usually beneficial: If a cell is starved for nutrients

or infected with a virus, the integrated stress response shuts down the production of new proteins until the stress is gone. This prevents the build-up of half-finished proteins or new viruses.

By contrast, stalling protein production in neuropathies associated with tRNA synthetases activates the integrated stress response, decreasing protein production even further. It's like having a car with sticky brakes and using

the emergency brake; it makes the situation worse, not better.

However, there may be a way to block the emergency brake. The integrated stress response can be activated in different ways, but in these neuropathies, it is activated by a protein, GCN2, that senses the stalled protein production. Using mouse models of CMT2D, which is caused by mutations in Glycyl tRNA Synthetase, or GARS, the Burgess lab tested whether blocking the integrated stress response would be useful.

GARS mutant mice are normally smaller than control mice, have length-dependent nerve degeneration and have muscle

weakness and fatigue that closely resemble human CMT2D. When the gene for GCN2 was deleted in the CMT2D/GARS mice, the neuropathy was much milder. The mice were bigger and stronger, had less nerve degeneration and had more normal

neurophysiology than mice with GCN2. Importantly, the integrated stress response was completely absent in the mice without GCN2. To test this further, the Burgess lab also used an experimental drug that inhibits GCN2. This was also beneficial, with results that were almost as good as the complete genetic deletion of GCN2.

The Burgess lab also showed that the integrated stress response



Robert Burgess

**“IMPEDIMENTS TO PROTEIN SYNTHESIS LEAD TO THE ACTIVATION OF THE INTEGRATED STRESS RESPONSE...”**

is activated in a mouse model of dominant intermediate CMT type C, caused by the mutations in Tyrosyl tRNA Synthetase (YARS). The hope is that this mechanism will extend to other tRNA synthetase-associated neuropathies as well, so that the same drug therapies will work on multiple forms of CMT.

It is important to note that the integrated stress response has been examined in other forms of CMT, such as CMT1B, but with opposite outcomes. In mouse models of CMT1B it is beneficial to preserve the integrated stress response and keep protein production low in Schwann cells. In CMT1B mice, inhibiting the integrated stress response makes things worse because the Schwann cells accumulate mutant “misfolded” proteins that lead to demyelination and neuropathy.

CMT is a complicated disease, with different types having radically different mechanisms. GCN2 inhibitors will not be a one-size-fits-all solution for CMT, and while more work will be required to create a drug suitable for clinical use, Spaulding's findings establish GCN2 as a good therapeutic target for CMT2D and possibly other tRNA synthetase-associated subtypes of CMT.



## CMT AWARENESS MONTH 2021 WAS A HUGE SUCCESS,

thanks to the many community members who took part both online and off—holding walks, signing up for giveaways, sharing information and honoring their loved ones by buying STARs (emblemizing the CMTA’s Strategy to Accelerate Research) in their names for a Wall of Fame.

To quantify the awareness raised, 36,580 first-time visitors accessed the CMTA website during September. The educational highlight of the month was a series of videos that provided an inside look at some of the CMTA’s strategic partners in the pharmaceutical, biotech and contract research organizations.

Continuing the theme, the CMTA highlighted community members featured on their local news stations in an email campaign called “Fame Friday.” Among those spots, Syracuse Branch Leader Mike Casey was featured on his local TV station, where he promoted his Walk 4 CMT, educated the audience and created awareness about CMT. Maine high schooler Aiden Darling told the Portland TV station how he overcame his CMT to play lacrosse as a high school senior and hundreds of news stations and radio stations nationwide aired a CMTA public service announcement featuring Jeffery Cave, Cathy Stanford, Rylee Sweeney, Carter Huber, Jordon

Sarageno, Alexandra Winant, and the family of Advisory Board Members David and Elizabeth Misener.

Two great giveaways marked Awareness Month: Mary Hebert from Maine (pictured left) was the happy winner of a pair of Turbomed AFOs and Kayla Roco is currently enjoying a pair of Cosysoles slippers and a body warmer.

Awareness Month may be over, but the search for treatments and a cure continues. Help keep the momentum going by volunteering for a CMTA event, writing and sharing social media posts about CMT and talking to people about your CMT journeys.

**JOIN OUR COMMUNITY AT**  
<https://www.cmtausa.org/get-involved/>



**AWARENESS  
MONTH RAISES  
\$390,000 FOR  
CMT RESEARCH**

# TeamJulia 2021 Marks 15 Years and Over \$1 Million Raised for Research

After 14 years and over \$1 million raised by swimming for CMT, TeamJulia '21 joined forces with the New Jersey statewide walk on Sunday, Sept. 19. The team walked in their own neighborhood and invited others to join them by participating in their own “virtual” swims/walks to help spread awareness. So far this year, \$65,000 has been raised, with more donations coming.

Herb and Rachael Beron created a swim event when their daughter Julia was diagnosed with CMT 2E. In the years since, it has left a lasting impact on both the CMTA community and Type 2 research efforts. Herb, a CMTA board member, said, “Julia, and thousands of other teenagers and young adults with CMT, share a dream. They want to run, jump and dance like the other kids do, but for many of them even the simplest activities of daily life can be challenging.

“Through the CMTA Strategy to Accelerate Research (STAR), we are doing everything we can at the CMTA to ensure a brighter future for Julia and everyone who is affected by CMT,” he added.

CMTA’s 2E program has seven research partnerships and/or projects underway. This year, the money raised will again be directed to research on CMT Type 2E, to help fund both existing and newly announced programs. In addition, a generous family also passionate about CMT Type 2 research will be matching funds generated by TeamJulia up to \$100,000! There is still time to support the Beron Family and their efforts by participating virtually or donating here: [www.cmtausa.org/julia](http://www.cmtausa.org/julia).



## CMT 4 ME PODCAST AIMS TO LIGHTEN LOAD OF THOSE LIVING WITH INCURABLE DISEASE

The CMTA announced the launch Sept. 21 of CMT 4 Me, an emotional, heartfelt and humorous podcast for the 3 million people who live with the degenerative neuromuscular disease and the millions more who support them.

In addition to its research work, the CMTA provides a wide-ranging array of services for the patient community, with everything from local support

groups to educational resources to publications to the country’s only summer camp for kids with CMT.

CMT 4 Me adds to the CMTA’s already extensive menu of patient services by providing a platform where people with CMT can give voice to their challenges—and share ways to overcome them. The podcast is also intended to spread awareness of this “rare” disease, which affects one person in 2,500. Topics will include research updates, fundraising, unique stories and interviews with members of the CMTA community, including board members, branch leaders and CMTA team members.

The podcast started Sept. 14 with an episode titled “The Epic Battle Between Samurai and CMT,” featuring Yohan Bouchard, a 28-year-old with CTM1A. Episodes, which can be found at [cmt4me.buzzsprout.com](http://cmt4me.buzzsprout.com) will air every three weeks thereafter, with podcasts scheduled for Oct. 7 and 28, and Nov. 18.

Podcast co-hosts Chris and Elizabeth Ouellette are the founders of the Vermont Cycle (and Walk!) 4 CMT, which has raised \$1.7 million for STAR research over its eight-year history. They are also on the CMTA Board of Directors. Elizabeth pointed out that the audio format makes podcasts “a great way to create more engagement and awareness around CMT. “With screen fatigue on the rise,” she said, “audio recordings are a convenient way to reach people all over the world, offering the freedom to listen while multi-tasking.

Chris said he’s been “thoroughly inspired by the spirit, determination and tenacity of our guests. The CMT narratives you hear on this podcast will touch you profoundly, giving you reasons to move beyond limitations, taking you to the next level of your personal journey.”

**Got an idea or tip for the podcast? Email [info@cmtausa.org](mailto:info@cmtausa.org).**



# FIRST ANNUAL DANCE 4 CMT RAISES \$27,590

The CMTA has sponsored walks for CMT, swims for CMT and bike rides 4 CMT, but until Saturday, Oct. 23, the world had never seen a Dance 4 CMT. The Youth Council changed that, raising \$27,590 with the First Annual Global Youth Dance 4 CMT on Zoom.

“Dance like nobody’s watching,” they say, and that’s just what the 70 participants from five countries did, filling their tiny squares with swinging arms, swaying hips and pumping fists.

A couple of dancers stood out: Blue-haired Ava was a whirling dervish, dancing as if her life depended on it, then slowing down when her father joined her to softly twirl her around. Two teens in unicorn costumes filled another square, while Youth Program Director Jonah Berger played master of ceremonies in still another one, clad in his usual work attire of wig, feather boa and Elton-John style sunglasses. The dress code for the evening also included glow stick necklaces, face paint and tutus like the orange one sported by Community Outreach Director Laurel Richardson. CMTA CEO Amy Gray sported a big red star on her face, giving off distinct David Bowie vibes.

The dance was planned as the highlight of a Youth Council weekend retreat because, as Jonah put it, “There is no energy stronger than the Youth Council. They inspire and excite the rest of the youth community in a way that cannot be replicated.”



Jonah said organizers were prepared with several ideas for additional activities during the dance in case they needed to fill the time and keep it going. They weren’t needed: “From the first note of the first song, the Tribe of the Funky Feet danced like a cure depended on it! An hour and a half felt like a minute and a half, and this amazing community had an absolute blast together. As we always do.”

Ashlyn Montisanti, 17, from Massachusetts, said, “Words cannot describe how amazing the first Dance 4 CMT was. I was blown away to see how much the youth helped fundraise for a cure. Not only did we raise money, but we had a blast doing so. From dressing up to singing, and, of course, dancing, I had such a great time. I cannot wait for the next dance!”

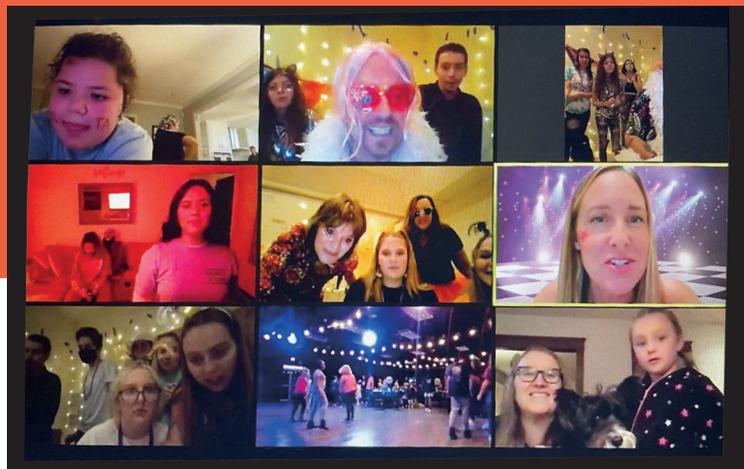
Kyarra Chaparro, 20, from Pittsburgh, said the dance was a great way to raise money and get back together with Camp Footprint friends. “It was so fun to be dancing with the tribe, especially after we crushed our fundraising goal.”



Renowned CMTA rapper Aron Taylor performed a new song he wrote specifically for the event, titled “Dance 4 CMT” (watch his performance at <https://youtu.be/ITHuGu4FzEE>). Among the song’s lyrics:

*When we hit the flo’  
We may not always be dancin’, yo  
  
Sometimes our legs give out below  
We’re more likely to stub our toes  
  
We need surgeries, that’s how it goes  
We need leg braces and custom Os  
  
We’re not fragile, just injury prone  
We’re more likely to break our bones*

While the first hour of the dance was solely for CMTA youth, the Zoom doors



opened for adults for the last half hour. DJ Joe Krukar, a Camp Footprint counselor, accommodated the oldsters with golden oldies like “Stayin’ Alive,” “Foot-loose” and ABBA’s “Dancing Queen.”

Dawn Goddeau said the Dance 4 CMT gave her 13-year-old son Liam “reason to believe in the good of people as they donated to help bring about a world without the disease.”

The evening’s upbeat energy allowed dancers to focus on their moves, without caring if they stumbled, Dawn said, adding, “In the dance of life we must embrace our stumbles knowing that they make our dancing special and unique.”



Youth Council Members Riley Williams (left) and Erin Black

# INNERVATORS HONOR ROLL

**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](http://www.cmtausa.org/cmta-innervators)

Tracy Adamson  
Scott Allen  
Christian Ayoub  
Aaron Baker  
David Balbi  
Kelly Banner  
James Barker  
Chevelle Bazo  
Brendan Bennett  
Robert Bourn  
H. Brand  
Deborah Breuer  
Nancy and William Buchanan  
William Buchanan  
Cynthia Carroll  
William Chandler  
Peter Cherpes  
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Rebecca Willis  
Zachary Willis  
Robert Willis  
Daniel Woltjer  
Chansik Yang



## THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS...

### In Memory of:

#### Greg Beeman

Ms. Val Hobson  
Ms. Sue Hoover  
Mr. Jeff Hurley  
Sharon Koegl  
Ms. Kristine Rooney

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Ms. Marisol Samhan Espinel

#### Ben and Gabe

Ms. Stephanie Powers

#### Edward Bidwell

Mr. Stephen Bidwell

#### Erin Black

Ms. Peggy Twohig

#### Henrietta and Dennis Cook – "Happy 50th Wedding Anniversary!"

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Lois and Arnold Demuzio  
Lynda and David Herendeen  
Joseph and Bonnie

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Mr. Robert Saxon, Jr.  
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#### Taylor and Noah Teague

Mrs. Vicki Brakefield

#### Isaac Walls

Mrs. Gayle Sanders

### JAMES FIORENTINO AND FAMILY CHOOSE TO GIVE MONTHLY FOR SEVERAL REASONS:

*"First and foremost, since our son has CMT we want to support an organization that will truly impact his future. Speaking of impact, it's great to see such a large part of our donations go towards research and education. Far too many organizations spend a significant amount of donations on administration and overhead, so happy CMTA is not one of them. Thanks to the great work that is happening at CMTA, we hope someday soon we'll hear about a cure or the ability to slow or stop the progression of CMT."*

# Country Music Superstar Alan Jackson Reveals He Has CMT

Country music superstar Alan Jackson rocked the CMT community Sept. 28 when he revealed on NBC's "Today" show that he has been living with the disease for a decade. Jackson said that while he's been reluctant to talk about his CMT publicly until now, his symptoms have been getting more and more obvious. "It's just good to put it out there in the open," Jackson said, adding, "In some ways, it's a relief."

"I know I'm stumbling around onstage, and now I'm having a little trouble balancing even in front of a microphone. I'm just very uncomfortable," Jackson told "Today" host Jenna Bush, adding "I just wanted the fans and the public to know. I don't want 'em to think I'm drunk onstage because I'm having problems with mobility and balance."

For Jackson, like so many others, his CMT manifests in muscle weakness, discomfort and pain, especially when he stands for lengthy periods, as he does when performing. While Jackson has been living with his diagnosis for 10 years, the Country Music Hall of Famer has continued to tour all over the country and around the world. In 2021 alone, he played a slate of concerts and staged a massive event in his small Georgia hometown that drew over



PHOTO FROM ALANJACKSON.COM

20,000 and raised more than \$2 million to help victims of a March tornado that ripped through the town.

Jackson hopes to continue performing. "I never wanted to do the retirement tour like people do and then take a year off and then come back," he says, expressing admiration for his personal heroes Merle Haggard, George Jones, Loretta Lynn, Willie Nelson and Charley Pride. "They never retired, just played as much as they could or want to. I always thought I'd like to do that, and I would like to do that if my health will let me."

"I'm not saying I won't be able to tour. I'll try to do as much as I can," Jackson said, adding, "I don't want people to be sad for me; it's just part of life."

CMTA CEO Amy Gray emphasized the importance of celebrities with CMT speaking out about the disease, saying, "The CMTA firmly believes that awareness like this will lead to more progress in the pursuit to develop treatments for the disease."

## Peaks Island Walk Raises \$8,428 For STAR Research in Ninth Year

Maine Branch Leader Mary Louie's mother, "Big Mary," was one of eight brothers and sisters, five of whom have CMT. "Little Mary" has some 50 cousins, and at the first Peak's Island Walk 4 CMT in 2013, most of the 30 participants were related. Today, it's still very much a family affair, but the numbers have grown to more than 100 participants, and the family has grown to include virtually everyone in Mary's orbit.

The Peaks Island Walk 4 CMT on Sept. 12 started, as usual, with a ferry ride across the Casco Bay in Portland. Participants gathered at the lovely Peaks Island Inn for registration and introductions, then took off on a three-mile walk around the tiny island. Back at the inn, they enjoyed a delicious lunch, a 50/50 raffle and fantastic swag.

The Peaks Island Walk, like all Walks 4 CMT, was just one more example of how a community rallies around a cause. Communities aren't always geographical—sometimes they're simply a group of people with a common goal. Mary's community, which includes the members of her daughter's ice hockey team, turned out in full force for her event, though there was some good-natured grumbling from Mary's cousins about her "bossiness."



# Check Your Feet Daily, Footcare Expert Advises CMTA Zoom Audience



*Footcare expert Dr. Greg Stilwell told participants in a CMTA Zoom meeting Oct. 20 how to keep their feet in the best condition possible.*

Stilwell, a member of the CMTA Advisory Board, was diagnosed with CMT1A as a teenager and became a podiatrist after seeing the many surgeries his mother and brother, both of whom have CMT, endured.

It's important to check your feet daily, Stilwell said, because the high-arched feet typical of CMT can easily lead to calluses. While calluses initially protect your feet from abnormally high pressure points, they eventually become dangerous little rocks in your shoes. These thickened areas can cause ulcers, infections and long-term wound care problems. Corns and calluses need to be managed regularly, he said, whether one goes to a salon and has a pedicurist shave them down or a podiatrist does it. He warned against using any sharp implements on the feet. Rather, he advised, use moisturizer, emery boards, a pumice stone or a callus roller.

Stilwell said that keeping the skin soft and pliable will help ensure that the

friction and shear caused by orthotics or AFOs can be controlled. He advised CMTers to use organic, high-quality lotions and oils like argan and sea buckthorn oils and to massage them into calluses and toes before putting on socks.

Socks should be made of wicking fibers like bamboo, polypropylene or hemp and be cushioned at both the heels and toes, Stilwell advised. White socks are no longer necessarily the best, he said, noting that dye lots have improved greatly. His suggested brands include Smartwool, ThorLo, Bombas and Dr. Comfort. There are also special socks with padding, for ankle foot orthotics (AFOs) and to gently squeeze the legs for better blood circulation (compression socks).

According to Stilwell, foot drop—muscular weakness that makes it difficult to lift the front part of the foot—can initially be managed with rocker shoes, which have a thicker sole and rounded heel. But as the muscle balance and weakness worsen over time, a custom brace or AFO, which normally incorporate some sort of foot orthotic, can help one maintain stability and balance.

Because high arched feet need cushioning, and most orthotics are meant for flat feet, Stilwell suggested

buying two pairs of gel insoles—one to cut up and the other to build up. In some cases, over-the-counter orthotics work just fine.

People with flat feet and high arches often need specific shoes with extra depth, correct width and fit and modifications for more stability. When shopping for shoes, one should look for a rigid heel counter and a removable insole.

Preventing hammertoes is key, Stilwell said. The CMT-associated deformities can be either flexible or rigid. Most start out flexible, meaning that the toes can be easily straightened out and no arthritis has yet formed in the knuckles of the toes. But longstanding deformities can become fixed, or rigid. The abnormal joint positions start to cause wear and tear, resulting in bone spurs and osteoarthritis.

Soft tissue surgeries like a tenotomy can help straighten a flexible hammertoe, while rigid toes have to be resected. Many surgeons believe the CMT hammertoe should be fused straight because the incessant muscle imbalances going into the toe will continue as the muscles weaken further and cause greater imbalance, leading to a recurrence of the deformity.

Silicone toe straighteners like “CorrectToes” can help prevent hammertoes by separating the toes, Stilwell said, noting that toes functioning individually strengthen the small muscles of the feet.

Stilwell recommended that CMTers do toe exercises—rotating the ankle in a circle, pulling on toes while twisting the foot with the other hand and pulling the toes toward the nose to stretch the Achilles tendon and calf.

The podiatrist also recommended Nordic pole walking, which increases strength and mobility when walking. It's especially good for people with pelvic or back issues.

**To see Stilwell's full presentation, visit [cmtausa.org/stilwellfootcare](http://cmtausa.org/stilwellfootcare).**

**THE STAND STRONG ORTHOTIC** (which Stilwell invented) benefits a high-arched foot, fits many foot types and sizes and helps stabilize the foot comfortably. The reusable orthotic sticks to the soles of the feet and can be worn with heels, sandals and flip-flops. Stilwell is currently working with the University of South Florida on a new iteration of the arch and needs feedback from CMTers. He's offering 20% off the orthotic with the code CMTDEAL1020 at [www.StandStrongArch.com](http://www.StandStrongArch.com).



# I AM NOT A CMT WARRIOR: ONE WOMAN'S OPINION

BY KATE LAIR

I'm about to say something that will probably be unpopular, but I feel strongly about it so I'm sharing anyway. I really despise it when people talk about illness/impairment/disease/disability in terms of being a "warrior" or "battling" or "fighting."

I fully understand that for certain individuals this language is empowering and motivating. I get that. Whatever helps YOU cope with whatever YOU have to deal with should be your choice. But you'll not hear me talk about myself in these terms, and here's why:

**1** When we talk about "battling" a disease/illness/impairment there is implicitly a winner and a loser. Either the disease wins or you do. It's reductionist and binary. In some cases, it might be true: If someone manages to achieve remission after a stage 3 cancer, you could say they "beat" cancer. However, with most chronic illnesses—like CMT, MS, ALS, Parkinson's, lupus, diabetes and COPD—there's usually no clear winner/loser. Instead, the illness/disease/disorder is a part of you—always. It's not YOU, it's not even the most remarkable thing about you, but it is part of you. So "battling" the disease is "battling" yourself.

**2** If the disease progresses and health continues to deteriorate, this thinking puts the onus on the individual and not the disease. When we talk about someone "losing a battle with cancer," it subtly places the blame on the person who died, as if they should have fought harder. Nobody means it that way of course: You don't go to the funeral of a loved one who died from cancer thinking the person who died is at fault. But if we discuss illness as a battle to be won, then the implication is that the loser didn't fight hard enough.

It's convenient for people who are temporarily able-bodied to think of illnesses in this way because it gives one the illusion of control. "If I take care of myself, if I just fight harder, I'll be okay." It is this line of thinking that brings me to my third point.

**3** "Fighting" a disease/illness/impairment—especially if it's chronic and/or progressive—is often counterproductive to living well with the disease. When you think of illness/disease as a battle to be won or lost and any setback is a loss, then you risk feelings of failure, shame and worthlessness. This language of "fighting" or "battling" or being a "CMT warrior" isn't necessarily conducive to long-term physical, mental and emotional well-being. With illness/impairment/disease, acceptance and adaptation win the day. Even with acute illnesses, adaptation is key. If you get the flu, for example, what happens when you "power through" and try to do all the things you can do when you don't feel like death? Usually, you get sicker, you risk pneumonia, and recovery takes longer. If you accept that the illness is there and the best way through it is to rest, drink fluids, take your meds and recover, you get better faster and are less likely to get a secondary infection.

It's true with chronic illness too. When you stop thinking of CMT as a disease



*Kate, a former disability claim case manager, brings a wealth of knowledge and experience to the CMT patient community as a member of the CMTA's Advisory Board. Katie shares her professional expertise on page 17.*

you have to conquer and instead accept the reality of the situation and then adapt to it, you expend your (limited) energy on living your best life AND you save yourself a LOT of mental and emotional anguish. That's not to say that you don't work hard to maintain as much independence as you can or continue to enjoy the things you love, or that you don't experience rage and grief over the changes thrust upon you. All that still happens, but if we let go of this idea that we're supposed to "fight" our disease at every turn, we can accept and adapt a whole lot faster, which enhances quality of life.

So, you won't hear me describe myself as a "CMT warrior." I'm not fighting the disease. It's a part of me, and it's going to progress. These are facts. Instead, with each progression, I cycle through the stages of grief and eventually end with acceptance followed closely by adaptation. Because it is my ability to adapt that keeps me living my best life.

# TWO NEW YOUTH COUNCIL MEMBERS ANNOUNCED

The CMTA Youth Council welcomed two new members in September, including the first overseas member. The Youth Council is a volunteer group ages 15-21 who help plan and implement the CMTA's youth initiatives; the newcomers bring the total number of members to 13.



**Eli Landau-Pope, 20**, is from London. Though the time zone difference means some late-night meetings, Eli says she is honored to be the first international representative on the Youth Council. She has CMT Type 1A and attended Camp Footprint for the first time in 2019. As a member of the social media and engagement committees, she will be focusing on global outreach and involvement.

**Abigail Thompson, 16**, also has CMT Type 1A and lives in Latrobe, PA, where she is a high school junior. She works on the Youth Council's engagement and special projects committee. Abigail joined the Youth Council to help empower the youth of the CMTA community and hopes for a future without CMT.



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— Aika, Doctor of Physical Therapy  
and 2-time Paraclimbing World  
Champion (RP3)

# ADVISORY BOARD MEMBER TELLS CMTERS

## How to Get Social Security Disability Income

**D**iagnosis does not equal disability when making a claim for federal benefits, CMTA Advisory Board Member Kate Lair told a Zoom audience Aug. 31. Rather, she said, an applicant's doctor-supported documentation of functional impairment will make or break a claim for Social Security Disability Income (SSDI).

Kate, who has CMT1A, knows whereof she speaks. After graduating with a master's in sociology, she held nonprofit and private sector jobs in a variety of fields, including individual disability insurance and employer-sponsored long-term disability insurance. When her CMT forced her to retire at the age of 38, she successfully applied for benefits on her first try, which is rare enough to qualify as a holy grail in the disability community. Even she found the documentation overwhelming.

Lair first clarified the difference between public and private disability policies: The former are covered by SSDI, while private policies can be individual or employer-funded. Individual policies generally cover self-employed people like doctors and lawyers and small businesspeople: The chances of someone with CMT obtaining an individual policy after diagnosis are low because they are deemed too big a risk.

The other private option is an employer-funded policy, and Lair stressed the value of this benefit in career decisions. One typically signs up for workplace insurance when starting a new job and the cost is minimal—maybe \$5 per paycheck. Short-term policies cover things like pneumonia or a broken leg, which could require a month or two of leave. When the short-term plan ends, typically after six months, long-term disability kicks in. One normally has to reapply for long-term benefits, and the application process is generally more rigorous. Long-term policies almost always run from the time short-term benefits run out up to normal retirement age, which varies according to one's year of birth.

Employers will make employees apply for SSDI, but they will also help them get it because the total amount of the benefit is capped and Social Security

has to split the cost with the employer. Most long-term policies cap disability at 60 percent of income so someone with a \$60,000 income would be entitled to \$3,000 per month. Social Security would pay \$1,500, and the private long-term policy would pick up the rest.

Lair acknowledged that the expense of going to a neurologist—and the fact that there are no treatments for CMT—keeps some patients from doing so. “But your physician is your best ally in proving a claim,” she told participants. “And if they don't know you, they can't support you.” Seeing a doctor once or twice a year means you'll have documentation of your illness on hand if you need to apply for benefits, she added.

The physician supporting your claim doesn't have to be a neurologist, she told the audience. A primary care doctor can also do it. Orthopedic surgeons generally won't support SSDI claims, Lair said, because they're in the business of fixing people, though their documentation is great for short-term claims.

In general, Lair said, “Be open and honest—you don't need to embellish your impairment in order to be believed.” She cautioned CMTers used to minimizing their pain not to answer questions thinking about their best days but about their worst days. If you can't stand for an hour without support on those days, say so.

Medical records are another key element in a successful claim, Lair said. While the Social Security Administration (SSA) requires applicants to sign HIPAA (Health Insurance Portability and Accountability Act of 1996) forms to get those records, a busy doctor's office might not respond as quickly as you might like. Lair requested records from her doctors on her own and sent them in with her application. “It's a lot of work,” she said. “It might cost you money, but tying everything up in a bow for the SS examiner can streamline the process.”

The SSA will also ask for extensive occupational records, Lair said, so it's

good to throw a resume in the application packet. “More information is usually better,” she said: It helps the SSA make a decision.

In addition to proving a disability, applicants must prove they have enough work credits in the system for it to pay out. The only way to find out is to go to [www.ssa.gov](http://www.ssa.gov) to see how many credits you have and what your payout might be. “That number will be way lower than you thought it would be,” she told the audience.

Applicants also must have worked recently enough to be entitled to draw benefits. For example, a mother who left the workforce for 10 years to raise small children might not have enough if she doesn't return to the workforce before filing a claim. “If you chose to leave the workforce for some reason other than impairment and you wait too long to go back in, you may be denied,” she told listeners. There's no hard and fast numerical test for this, but as a general rule if you haven't worked in the

last five years, you're probably not going to be eligible for SSDI, she said.

Lair cautioned that there is a six-month waiting period before an applicant can collect a dime in benefits.

That's where short- and long-term disability can be particularly useful, replacing lost income until SSDI benefits kick in. Even when the waiting period has passed, if the SSDI office is overloaded or is having trouble getting your medical records—or if you live in a state that denies everyone's first application—it might be a year or two before any benefits are disbursed.

People can work while getting SSDI—they just can't work full-time, which is defined as 30 hours per week. Working part-time while waiting to hear about an application might make approval more difficult, she said, because the claims examiner might think if you can work 20 hours a week, you can work 10 more.

**“THE PHYSICIAN  
SUPPORTING YOUR CLAIM  
DOESN'T HAVE TO  
BE A NEUROLOGIST....  
A PRIMARY CARE  
DOCTOR CAN ALSO DO IT.”**

**To see Kate Lair's full presentation, visit [cmtausa.org/lairdisability](http://cmtausa.org/lairdisability).**



# BRANCH MEETING NOTES

## NORTHERN ALABAMA

Five people gathered virtually for the Northern Alabama Branch meeting on Sept. 21. This was only the group's second meeting, so members got to know each other, discussing their common CMT symptoms and sharing what's helped them manage their disease.

## TORONTO, CANADA

The Toronto Branch welcomed guest speaker Josée Mathieu from the Ottobock prosthetics company to its virtual meeting on Sept. 11. Josée presented the company's line of carbon fiber ankle foot orthotics (AFOs), specifically the WalkOn and WalkOn Reaction Plus line of braces. These braces help users with dorsiflexion weakness to walk and support people with less severe forms of CMT, but may not be appropriate for everyone. While these AFOs have to be purchased from and fitted by a registered orthotist, other off-the-shelf models require little customization.

## DENVER, CO

The Denver Branch had a virtual meeting Sept. 23, with a wide-ranging discussion that included Awareness Month and members' experiences with local resources, mostly orthotists and podiatrists. One member shared her recent experience with major foot surgery performed by CMTA Advisory Board Member Dr. Glenn Pfeffer in Los Angeles and the recuperation required afterward.

## JACKSONVILLE, FL

Six members of the Jacksonville Branch met on Sept. 11 to catch up and to do some planning. They discussed the branch survey results and determined the best meeting times and future meeting topics. They also began planning for 2022 meetings and a branch fundraiser. Their next meeting will be with Mayo Clinic neurologist Dr. Elliot L. Dimberg, a neuromuscular neurologist who has worked closely with the branch since its inception.

## CHARLOTTE, NC

On Oct. 7, the Charlotte Branch had an informative and engaging meeting with Dr. Urvi Desai, neurologist and director of Charlotte's new CMTA Center of Excellence. Dr. Desai has a multidisciplinary team consisting of occupational, physical, speech and respiratory therapists, genetic counselors and social workers. She is currently accepting new patients. Dr. Desai's clinic is one of 50 sites worldwide selected for the CMT1A clinical trial for Pharnext's PXT 3003.



Dr. Desai

## RALEIGH (RTP), NC

Fifteen members of the Research Triangle Park Branch were treated to a virtual presentation by genetic counselor Courtney Downtain from GeneDX, on Sept. 25. She explained many aspects of genetic testing, including eligibility requirements and reasons to have it done, and shared that the cost of genetic testing has dropped dramatically over the last few years.



Branch leader Jeanne Boehlecke shared "CMT Tips" at the beginning of the meeting.

## WESTCHESTER, NY

The Westchester Branch met virtually on Sept. 18, with 21 people in attendance. CMTA Advisory Board Member and psychotherapist David Tannenbaum was the guest speaker. Trying a different format, the branch went around the Zoom room to give everyone the opportunity to talk and share. This gave everyone the opportunity to ask questions or just talk about their feelings. David responded in a comforting, sincere and heartfelt way, with a touch of humor.

## CHESTER COUNTY, PA

Ten members attended the Sept. 11 virtual meeting of the Chester County Branch. Fitness instructor and CMTA community member Julie Barnett spoke with the group about staying active with CMT and shared some exercises—both sitting and standing—that can be done at home. She encouraged everyone to start small and build from there. Julie also suggested joining the CMTActive group on Facebook to stay in touch with others in the CMT community who like to stay physically fit.

## PITTSBURGH, PA

The Pittsburgh Branch met virtually on Sept. 15 with seven people in attendance. Julie Tarle, the CMTA's special events manager, attended to help the group plan the Pittsburgh Walk 4 CMT. They finalized details of their walk and planned future branch meetings.

## SEATTLE, WA

Members welcomed guest speaker Eric Weber, an orthotist from Hanger Clinic, to their Oct. 10 branch meeting. He shared information on the latest and greatest bracing options for people who struggle with drop foot and balance issues. Members also discussed how best to support each other and agreed to try a monthly in-person discussion group to talk about how everyone deals with CMT in their daily lives.

# SAVE THE DATE

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# FIRST STEPS: A Big Hike in Tiny Chunks

BY MICHAEL LITZKY

It was the early days of COVID. Santa Clara County was under quarantine: no driving out of the county, no parking at trailheads. Perfect day for a hike that started at our front door.

Before CMT set in, I backpacked all the time, though the ability to do big hikes had slowly drained away. But I'd be miserable without my nature time and I'm happiest with a big project. So my sweetie Geri and I set out to hike from our front door in Mountain View, CA, up into the coastal hills, a hike of some 20 miles along city streets and county park trails.

In tiny chunks, of course.

We reached a corner where Hans Avenue met Gretel Lane. "Look," I pointed, smiling.

Geri smiled back. "Cute."

My walking sticks clicked annoyingly on the sidewalk. I could have left them home for a walk on pavement, but they help with curbs. My leg braces keep my foot flexed so it doesn't drop and make me trip over flat sidewalks. But I can't point my toe down to cushion the step from the curb. I've got to ease down with my back leg, turn and reach sideways with the front foot and transfer my weight carefully.

Not every step is fraught. Much of the time you'd only know I have CMT from my flat-footed, lurching gait. We passed a school with windows where bright tempera colors on butcher paper said, "Welcome to Ms. Johnson's Class!!" We came to Bubb Park, a play area floored with springy rubber mats, and a huge grass field where fat squirrels raced along a fence between the park and people's back yards.

That was enough of a goal for the first day. But a week later, we picked up the hike and walked on.

## Calling in the Past, Hiking On

When I start the next section of a big hike, I like drive to where I left off the previous time so it feels like one continuous hike. I shyly told Geri about wanting this.

She nodded with amused delight. "Let's do it. Is this where we were? I didn't track it."

"Well," I admitted, "I didn't mark it exactly either. It's more a spiritual sort of thing, joining this hike to last week's hike."

"Got it."

We stood where I imagined our feet were a week ago and she took my hand while I spoke memories from our last hike. She lifted an eyebrow: ritual complete? I nodded and we started forward on the paved path through Bubb Park, Geri taking pictures of flowers as we walked. The little details she notices help me appreciate them more.

## First Falls

The first sign of my CMT was 30 years ago, when I realized I couldn't stand on my toes to reach the jam on the high shelf. Slowly my backpack got too heavy to carry but I could still do day hikes, so I took on a big project. I would hike every completed section of the 385-mile Bay Area Ridge Trail (in tiny chunks, of course).

When I started that hike, I could go up and down steep hills without pain. I remember the moment that changed, as I descended a mountain.

Was there a puddle or the tiniest dip in the fire road? All I knew was my right foot skidded forward and I fell hard on my left knee. Knee throbbing, palms stinging, I tried to see how I had fallen.

Three hundred yards farther on, as the fire road plunged steeply, my downhill foot skidded on loose gravel and I fell again. Same knee, gashed this time.

I've never been tough and stoic: I screamed as I fell. I'm also way more superstitious than I like to admit. Two identical falls in five minutes felt like a warning.

When I got to my feet I was shaking. And suddenly, that steep downhill was the hardest thing I'd ever faced. I was



Michael Litzky on his big hike.

PHOTO BY GERI WEITZMAN

so afraid of falling again that I practically inched down it. And still, several hundred feet further, I fell a third time.

After that day, downhill stretches, which used to be the reward for making it to the top of a steep hill, became an endless agony of trembling legs and aching calf and thigh muscles. How could things have changed so much in one day?

Downhill remains harder to this day but I don't think it had to get so hard so fast. Those three falls made me walk with cautious tightness, which made things far worse, though I seldom fell after that.

I'm amazed I hiked the whole Ridge Trail given that every hour climbing was matched by two agonizing hours coming down. But I did it. And since then I've come up with ways to make downhills more bearable, such as relaxing my ultra-tense muscles—or just sitting down and sliding!

## Park to Park

Today, the "trail" through Bubb Park went beside a few redwood trees on a little mound. I was so eager for real hiking that I left the paved path and walked up the teeny ridge to the teeny hill and

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# 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 had a fairly mild case of CMT throughout my early years, but now that I've reached my 40s, I feel the progression speeding up. I have always been skilled at compartmentalizing my feelings so they don't live at the surface and weigh me down emotionally. I'm wondering how to strike a healthy balance between putting my emotions about my CMT progression on the shelf and keeping them near the surface so I'm not in denial.

## David Replies:

This is a great question! I was always secretly envious of anyone who could put their emotions on the shelf for any period of time. My feelings were often so strong, particularly around my CMT, that they were simply all-consuming. This was not a great way to live, so I began my quest for balance. In psychology, compartmentalizing is defined as a defense mechanism used to suppress thoughts and emotions.

There are of course certain benefits to compartmentalizing. A firefighter who has a family depending on him still has to rush into a burning building and perform under intense pressure. Being able to compartmentalize helps him do his job. A mother who loses a loved one or goes through a painful divorce still has to try to function normally for her children.

Managing your mental health is another healthy advantage of compartmentalization. Immersing yourself in the movies you're watching, reading a book, taking a long relaxing bath or taking a slow walk in nature can help you disconnect from acute stress.

However, there are also serious disadvantages to compartmentalization. If you are obsessing about your CMT or constantly worried about every little change in your body, you might find it more comforting to go about your daily routine as if you're "just fine" and never confront the emotions you're feeling. But your loved ones can sense the disconnect and feel like you are pushing them away.

We worry that if we allow our upsetting feelings to surface, we will be overwhelmed or drown in them. In truth, when we can be honest with ourselves and name what we are feeling, regardless of how upsetting, our emotions will lighten and fade by themselves. Yes, difficult emotions will return, but by acknowledging them quickly, we can shift them, making room for other feelings.

In bringing some light to what we are experiencing emotionally, we regain some control, and there is less chance of feeling overwhelmed. Unexpressed feelings that build up can lead to depression or numbness. What we resist persists. When we act as if everything is fine while feeling just the opposite inside, we shut out the people who can truly be comforting. Allowing someone to truly see us is the best antidote to feeling alone.

So balance would be a combination of being aware when we need to shelve our upset for the moment and coming back to it as soon as there is an opportunity to look at our emotions in a nonjudgmental and compassionate way.

## HIKING WITH CMT

*continued from page 19*

wound left and right around the redwoods. It wasn't really a challenge, even for me, but I used my sticks anyway.

We passed houses with native plant gardens: spiky aloe, deep green swaths of deer grass and beds of crystal granite. When we had to cross a four-lane street, I pressed the walk

signal with the tip of my walking stick.

We crossed to Cuesta Park, our goal for this day and sat where we could barely see the city. Just trees, blue sky mottled with cloud, and hills a mix of dark green and toast brown rising in lazy folds.

"If we just keep doing this hike, we'll reach those hills," I said happily.

We gave each other a thumbs up.

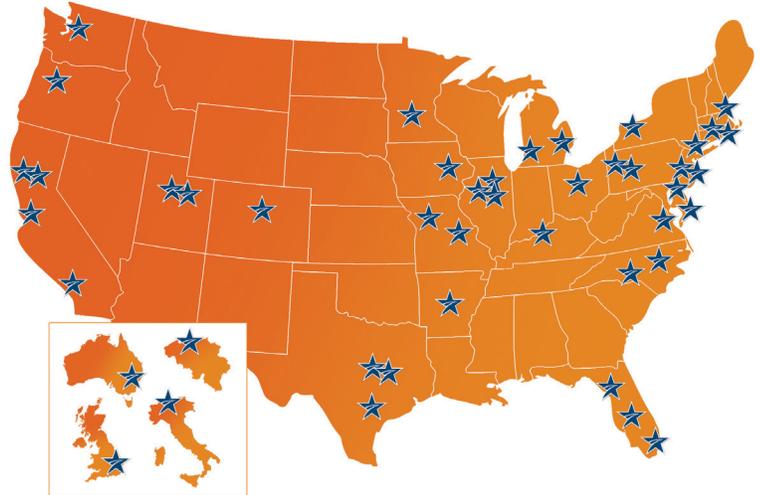


*Michael Litzky is an author, storyteller and a math/science tutor who lives in Mountain View, California.*

*Find more articles about this hike and about hiking with CMT on his website, [www.FictionAndMore.com](http://www.FictionAndMore.com).*

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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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Email the CMTA at [info@cmtausa.org](mailto:info@cmtausa.org)

**CMT PATIENT  
MEDICATION ALERT:**



**Definite high risk  
(including asymptomatic CMT):**

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

**Moderate to significant risk:**

Amiodarone (Cordarone)  
Arsenic Trioxide (Trisenox)  
Bortezomib (Velcade)  
Brentuximab Vedotin (Adcetris)  
Cetuximab (Erbix)  
Cisplatin and Oxaliplatin  
Colchicine (extended use)  
Dapsone  
Didanosine (ddI, Videx)  
Dichloroacetate  
Disulfiram (Antabuse)  
Eribulin (Halaven)  
Fluoroquinolones  
Gold salts  
Ipilimumab (Yervoy)  
Ixabepilone (Ixempra)  
Leflunomide (Arava)  
Lenalidomide (Revlimid)  
Metronidazole/Misonidazole (extended use)  
Nitrofurantoin (Macrochantin, 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-Fluorouracil  
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.** It 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.

People 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](http://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.**