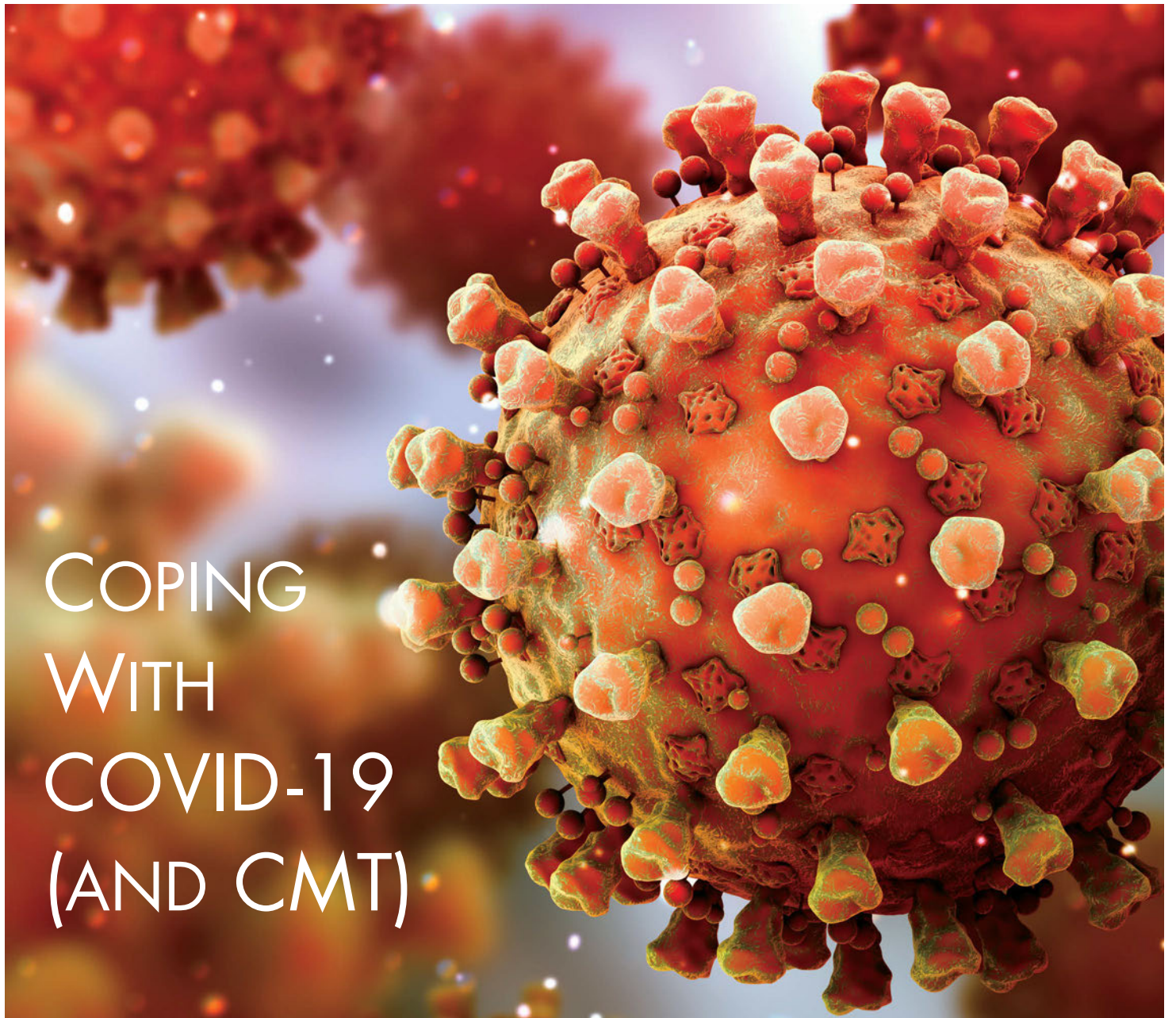


THE

CMTA Report

SUMMER 2020

www.cmtausa.org



COPING WITH COVID-19 (AND CMT)

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Gene Identified

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With Stress

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Fusion Explained

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 Laurel Richardson *Director of Community Outreach*, laurel@cmtausa.org
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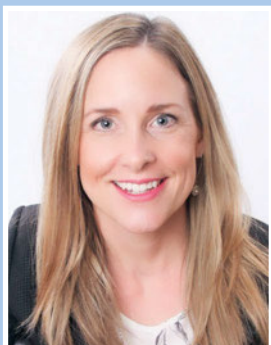
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 Dana Schwertfeger *Contributing Editor*

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Email the CMTA at
 info@cmtausa.org

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A MESSAGE FROM THE CEO



DEAR FRIENDS,

First, the good news: A team led by Dr. Stephan Züchner at the University of Miami has discovered a new type of CMT that may be treatable with drugs already approved for diabetes. If those drugs show promise, it may be possible to accelerate the clinical trial timeline and skip straight to Phase 2 since the drugs have already gone through Phase 1 testing for other indications.

Researchers think that at least 3,000–5,000 people in the United States—and more than 60,000 worldwide—have this type of CMT, making it the most common recessive form of the disease. “We’re very optimistic about the therapy going forward,” Dr. Züchner said, noting that the drug basically cured CMT in fruit flies. “This is a remarkable discovery only possible due to large scale genomic data aggregation from volunteering CMT patients,” he added.

There is no bad news, but because we’re all still dealing with the pandemic, we are continuing to seek out and bring you helpful information for dealing with it. Resident psychotherapist David Tannenbaum offers advice on getting a handle on fear, the first step to a life with much less worry.

Dr. Mario Saporta, director of the Center of Excellence at the University of Miami, shares what happens when CMT patients turn to telemedicine, and Dr. Ashraf Elsayegh answers the question: Are CMT patients at increased risk from intubation and mechanical ventilation?

Since COVID-19 has forced us to move so many CMTA community services online, we asked Laurel Richardson, our director of community outreach, to share what’s happening online, everything from chair dancing lessons on Facebook Live, to virtual walks, Zoom support meetings and much, much more.

Finally, because it is summer, albeit a strange one, we bring you two stories that speak to the essence of the season—one by an author who found the courage to wear shorts at the ripe old age of 28 and the other about a group of kids who created a classic lemonade stand to raise money for CMT research.

All of us at the CMTA are staying active, staying committed, staying hopeful and staying focused on our main goal—the eradication of CMT. We hope you’re doing the same.

All my best,

A handwritten signature in black ink that reads "Amy Gray". The signature is written in a cursive, flowing style.

AMY GRAY, Chief Executive Officer

University of Miami Researchers Find New CMT Type That May Be Treatable with Diabetes Drugs

University of Miami researchers led by Dr. Stephan Züchner have discovered a new type of CMT that may be treatable with the same drugs used to reduce elevated sorbitol in people with diabetes.

The initial discovery was made by Andrea Cortese, MD, and Adriana Rebelo, PhD, who worked with a large group of CMT2 families convened by the Inherited Neuropathy Consortium, with support from the National Institutes of Health, the CMTA and many others.

The newly discovered type is caused by a mutated SORD (sorbitol dehydrogenase) gene that raises sorbitol levels so high they cause nerve damage. Researchers found that treating fruit flies with a diabetes drug (aldose reductase inhibitors) reduced their high levels of sorbitol to near normal.

An estimated 3,000–5,000 people in the United States—and more than 60,000 worldwide—may have this type of CMT, making it the most common

recessive form of the disease. Dr. Züchner and his colleagues are looking to screen undiagnosed CMT patients to identify as many patients as possible in preparation for clinical trials.

“We’re very optimistic about the therapy going forward,” Dr. Züchner said, noting that the drug basically cured CMT in fruit flies. “This is a remarkable discovery only possible due to large scale genomic data aggregation from volunteering CMT patients,” he added.

Dr. Züchner, MD, PhD, is a professor of human genetics and neurology and chair of the Dr. John T. Macdonald Foundation Department of Human Genetics at the University of Miami Miller School of Medicine. He is also a member of the CMTA’s STAR Advisory Board. He and his team—Rebelo, associate scientist at the Hussman Institute for Human Genomics, and Cortese, a visiting scholar from University College of London—discovered the SORD mutation “hidden” from the gene analysis software that most



Dr. Stephan Züchner

researchers use. Using a different strategy, the researchers found the relevant variations hidden behind a “pseudogene.” Pseudogenes mirror the DNA sequence of their active counterparts, but have no function.

After identifying the gene, the team identified 45 individuals from 38 families who had the specific mutation. With gene and patients identified, the next step was finding the necessary animal model.

Serendipity intervened in the person of R. Grace Zhai, PhD, senior associate dean for basic science research and associate professor in the Department of Molecular and Cellular Pharmacology at the Miller School. Her lab is right across the street from Dr. Züchner’s and the two of

(continued on page 6)

Readers interested in being screened for the new type should fill out a Patients as Partners in Research profile. The criteria for screening are:

- 1) you have received a diagnosis of CMT, but genetic testing did not reveal with certainty the responsible gene;**
- 2) your parents never had CMT symptoms.**

This piece was adapted from an article by Damian McNamara in Inventum, published by the University of Miami Miller School of Medicine. The full article is available at physician-news.umiamihealth.org/innovative-genetic-research-may-lead-to-treatment-for-inherited-form-of-peripheral-neuropathy/.

A DIAGNOSIS WORTHY OF A TATTOO

BY VITTORIO RICCI

When I found out that my type of previously unknown CMT had been identified, I was very excited—partly because I was finally going to know the truth after six years of being in the dark—and partly because I'd been planning on getting my first tattoo to commemorate the occasion.

In the past, I visited Dr. Shy's CMT Center for Excellence in Iowa to track the progression of my disease in order to determine its severity and to undergo more genetic testing. The scientists there had been sequencing my genome and comparing it to all the other patients in the Inherited Neuropathy Consortium registry in an attempt to find the mutation that caused the neuropathy.

My third trip to the clinic in the summer of 2018 had a different purpose: The mutation had been discovered on Chromosome 15 in a region titled SORD1. Intrigued by the diabolical-sounding name, I flew out to Iowa for my first-ever skin biopsy to confirm the diagnosis. It was also the

first time I almost passed out during an exam (due to dehydration), so suffice to say it was quite a rollercoaster experience. The biopsy confirmed that one section of DNA base pairs was missing in my SORD1 region.

The results of the study were officially published in May in *Nature Genetics*. The article details the methodology of the study and explains how the mutation inhibits enzyme function and eventually leads to the breakdown of peripheral neurons, which was fascinating to the bioengineering student in me.

Having participated in the study, I read the article with the notion that I already knew what it contained. I had been privy to the progress of the study and how the mutation leads to neuropathy. I was just excited to see it officially published. Toward the end of the article, I was surprised to read about potential treatments. There are drugs currently in clinical trials that could jump-start the afflicted enzymes, effectively preventing further damage.

I don't think I've completely wrapped my head around the diagnosis and prognosis for a potential treatment. One thing I've learned over the years is that big events can take a while to set in. I've spent the past six years reading, listening and speaking about big goals—getting a diagnosis, finding a treatment. It seems surreal to learn the full truth of my condition after so many years of questioning. It's just another example of the great things the CMTA community has accomplished and of the many more to come.

Another great thing to come? My tattoo—the DNA code that includes the SORD1 mutation on my lower leg. ★

Vittorio, 22, is a rising senior at Northeastern University. He is currently interning at Abnelym Pharmaceuticals. Vittorio and his family, which includes Boston Branch Co-Leader Jill Ricci, have raised well over a quarter of a million dollars for CMT research since 2012.



Vittorio accepting a Youth of Tomorrow Award with his mother Jill.

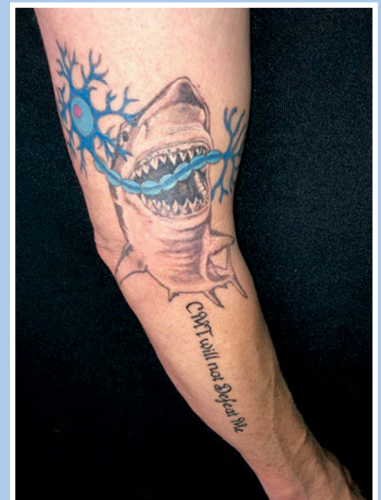
SHOWING THE CMT COLORS

Vittorio Ricci isn't the only one to rep his CMT on his body. Recently, 63-year-old Dave Loy got his very first tattoo—a shark with a nerve cell in its mouth and the words “CMT Will Not Defeat Me” on his arm. As he said, it is not small. He got it because he wanted to let people know about CMT—and that it's not going to beat him.

“Within 24 hours of getting the tat, I had five people ask me about it and within the last week that number has grown to 13,” Dave said, adding, “It has opened the door for me to tell them about the disease.”

This isn't Dave's first venture into creative self-expression to benefit the CMT community. When he lived in Iowa he had a vanity license plate that said CMT1A. People often asked about the plate, giving him the chance to talk to them about the disease. His hope, then and now, is that using exciting ways to spread the word will encourage others to find their new way of telling people about CMT.

Dave, who is retired on disability, lives in Independence, Missouri.



NEW CMT TYPE

(continued from page 4)

them ran into each other over lunch. When he told her about his team's discovery, she said he could introduce the gene mutation into her fruit fly model.

Dr. Zhai and colleagues were able to genetically manipulate flies to raise sorbitol levels, causing precisely the same kind of damage observed in people. The fruit flies with neuronal damage behaved differently, but when treated, showed an "amazing reversal" of their altered movements, Dr. Zhai said, adding, "This is truly remarkable. In my career I work on neurodegenerative diseases, and I've never seen such complete suppression of the phenotype. We are very excited about this."

After modeling CMT in fruit flies, the next step was to test the

theory using skin cell fibroblasts from CMT patients. The team found that just as in the fruit fly model, when relevant genes were inactivated, they saw accumulation of the sorbitol and a reversal with the addition of the medication.

According to Dr. Züchner, SORD neuropathy will represent one of the first examples of a treatable hereditary neuropathy. The experience with SORD neuropathy reinforces the power of international collaborations, which can accelerate the journey from gene identification to effective treatment, he said.

"This story is really unique. Because we can measure the sorbitol, we will be able to determine effectiveness of treatments and even can determine pathogenicity of DNA variants," Dr. Züchner said. Measuring sorbitol levels in a

blood sample could flag people at risk and could also help physicians monitor their response to treatment over time.

The core study team included INC members Dr. Michael Shy, MD, from the University of Iowa, and David Hermann, MBBCh, from the University of Rochester, both of whom are also on the CMTA STAR Advisory Board, and Dr. Rosemary R. Shy from the University of Iowa. Dr. Mario Saporta, MD, assistant professor of neurology at the Miller School, also participated in the study. He built and runs the premier CMT clinic in Florida and is a member of the CMTA STAR Advisory Board. "Without the support of the Inherited Neuropathy Consortium and the CMTA, this work would not have been possible," Dr. Züchner said. ★

VIRTUAL CYCLE (AND WALK) 4 CMT



The 7th annual **CYCLE (and WALK!) 4 CMT** is going **VIRTUAL** this year. Help find a cure for **CMT** by registering (**FREE!**) for this year's **VIRTUAL CYCLE (and Walk!) 4 CMT**.

Cycle or walk anywhere/anytime between now and **August 30, 2020** to beat **CMT**, while earning the best-looking swag ever! We've set up the **VIRTUAL** platform so that everyone, everywhere can participate.

Register or donate at: cycle4cmt.com



COPING WITH COVID-19

How do I deal with the mental stress of the current pandemic AND my CMT at the same time?

CMTA Advisory Board Member David Tannenbaum replies:

This is a strange time for the world in many ways, but those of us with CMT have had to deal with strangeness and adversity all of our lives. “We grow through adversity,” a wise man once said. I was young when I first heard that and I needed to get a lot older to truly understand what it meant. I strongly believe that adversity pushes us to go deeper within ourselves and gives us an opportunity to develop the coping skills we need to be our best. The uncertainty and fear of the COVID-19 crisis is not all that different from the uncertainty and fear we face in living with CMT. In some ways, having CMT has prepared us for COVID-19. Those of us who have already adjusted our lives to moving around less than others may have experienced less of a dramatic change than others. COVID-19, like our CMT, is forcing us to slow down and separate the essential from the non-essential. We are thinking about what is truly important in our lives.

Uncertainty and fear are feelings that I have ardently explored all my life in an attempt to avoid being paralyzed by them. Even more than my physical limitations, my fears of the future were the cause of much stress and anxiety. How many times has some change

in my body signaled “My life is over” and left me gripped by panic? Too many! Getting a handle on fear and truly understanding the nature of fear can be the beginning of a life with much less worry. I will share with you what I have learned.

I have learned that fear is usually based on some narrative that we create in our mind. It is often a story about the future or the past. Fear cannot survive in the present moment. Our mind is constantly creating scenarios. All the thoughts that go through your mind are not who you really are. They are the product of your conditioning over a lifetime. Your suffering is usually a product of your fearful thoughts and not the situation.

Simply recognizing and observing this stream of thinking—without judging or holding on to these thoughts—is a way to release them and bring you back to the present moment and the peace that is underneath all these habitual behaviors.

You can have these thoughts without identifying with any one thought. Worry arises from thinking about the future that you can't control. In the present moment you can take an action or realize there is nothing you can do. Try to separate your-

self, the observer of the thoughts, from the actual fearful thoughts. A great way to interrupt the obsessive stream of worry thoughts is to simply take a deep breath and listen to yourself breathe. It's impossible to listen to your breath and your thinking at the same time.

The gradual recognition and observation of your negative thinking is an ongoing practice. You won't be able to catch yourself every time but it gets easier. Just pay attention and observe your thinking. Take this time of COVID-19 to work on yourselves and appreciate the joy in simple things. Being home a lot reminds us to feel grateful that we actually have a home in which to shelter. Having our ability to go to concerts or eat out taken away is frustrating, but being able to cook at home and enjoy our food is golden. How much more are we able to appreciate our friends and family when

we are unable to see them. A neighbor offered to shop for me. I was so touched by that gesture. Accepting help with gratitude is something I have had to learn. Experiencing solitude is very different than loneliness. With the Internet we can stay connected, but in our solitude

we have an opportunity to get to know ourselves without all the distractions that we usually have. And just maybe when we let go of all the self judgment and comparisons, we will actually like what we find! ★



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.

In some ways, having CMT has prepared us for COVID-19.



CMT Patients Turn to Telemedicine For Treatment During Pandemic

BY MARCIA SEMMES

Dr. Mario Saporta, director of the CMTA Center of Excellence at the University of Miami's Miller School of Medicine, conducted his last face-to-face physical evaluation of a new CMT patient on March 11. On March 25, he began seeing new patients for the first time via telemedicine. By the end of April, the clinic was back up to pre-pandemic levels.

The terms telehealth and telemedicine are often used interchangeably, but telehealth is an umbrella term referring to the use of a virtual platform to deliver health information, prevention, monitoring and medical care from healthcare practitioners like nurses and physical therapists. Telemedicine is generally understood to mean a virtual appointment with a doctor.

According to Dr. Saporta, the clinic's format is much the same as

it was pre-pandemic: He "sees" new patients in one-hour time slots on Mondays. On Wednesdays there are multidisciplinary follow-up appointments lasting two to three hours that include time with a nurse and other specialists, each spending 30 minutes with the patient. Afterward, the team connects to review recommendations. Follow-up appointments are a little easier, he says, because the patients are already known to the team.

New patients are sent instructions on connecting to Zoom along with a reminder to make sure their computers or mobile devices are fully charged. They're also instructed to place their video devices eight feet from the side of their beds or sofas so they can remain fully visible to the doctor during the physical assessment. The doctor also watches patients standing and walking.

The new-patient letter asks

recipients to have available a flashlight, a safety pin or paper clip for testing pinprick sensations, a cotton ball or Q-tips to test light touch sensations, a card or coin to test hand dexterity and strength, a plastic cup or glass and a blood pressure monitor.

They are also asked to have a caregiver or family members present during the assessment to help with things like the pin prick tests. Dr. Saporta jokes that he awards those helpers honorary neurology degrees.

Saporta said his team is also experimenting with using “telerehabilitation” in which therapists assess functional ability and weakness progression, then devise a rehabilitation plan for the patient. “The rest is education,” he said.

While telemedicine can’t accomplish genetic testing, kits can be sent to patients with instructions for taking mouth swabs or saliva samples, which can then be mailed directly to the genetic laboratory. And because genetic testing labs operate separately from other testing labs, they’ve not been overwhelmed with testing for the coronavirus.

The complex web of insurance and regulatory issues to permit telehealth have largely been resolved at this point. HIPAA (the Health Insurance Portability and Accountability Act of 1996) regulations were relaxed in March to allow providers to use virtual platforms like Zoom and Skype for visits with patients. After the pandemic was declared a national emergency on March 13, the U.S. Department of Health and Human Services waived federal licensing regulations to permit out-of-state physicians to treat patients via telemedicine.

Telemedicine visits are now covered by Medicare regardless of whether the patient lives in a rural area and the Centers for Medicare



Dr. Mario Saporta, director of University of Miami’s CMTA Center for Excellence says the clinic’s format is much the same as it was pre-pandemic.

and Medicaid Services is no longer enforcing a requirement that patients have an established relationship with a physician in order to receive telehealth. Most health insurance companies including Aetna, Cigna and UnitedHealthCare are covering virtual visits during the pandemic.

Saporta believes that telehealth is here to stay. Patients seem to like it, he said, particularly those who come from more than three hours away, as more than

half the clinic’s patients do. The platform works particularly well for CMT, he said, because it is a slowly progressive chronic condition, as opposed to a something like MS where patients have sudden, acute flare-ups. “It’s very rare for CMT patients to throw us a curveball,” he added.

All in all, Saporta said, “Given the constraints we are facing the system works very well at keeping both patient and doctor healthy and safe.” ★

As The CMTA Report goes to press, some states and insurers are beginning to restrict telemedicine appointments. Before you arrange one, check to make sure it’s covered.

SIX CENTERS OF EXCELLENCE SURVEYED

An informal survey of six other Centers of Excellence revealed that all of them have moved to telemedicine appointments since the pandemic began. The respondents were Dr. Kevin Felice with the Hospital for Special Care, Dr. Raghav Govindarajan from the University of Missouri–Columbia, Dr. Ryan Jacobson at Rush University in Chicago, Dr. Jun Li at Wayne State, Dr. Rebecca Traub at UNC Chapel Hill and Dr. Sasa Zivkovic at the University of Pittsburgh.

Only two of the respondents had ever done telemedicine appointments before the pandemic began: one had done a few telemedicine appointments, though not for CMT patients and one had previously done inpatient video consults. Four of the six had zero experience with telemedicine up to that point.

Appointments covered a wide variety of subjects, including diagnosis, genetic testing and counseling, reviewing test results, disease progression, adjusting medication for symptom management and pain management. The doctors found it very helpful to observe patients walking and standing in their home environment in order to assess their current needs. They also praised telemedicine for the convenience it offers patients, particularly those at high risk for coronavirus and those who have to travel long distances.

Obviously, not everything can be covered in a telemedicine appointment. Respondents cited as examples EMG and NCT tests, the difficulty in performing a good neurological examination, PT and OT assessments, orthotics assessments and anything that requires a detailed exam.

All six plan to continue telemedicine appointments, subject to insurance carriers continuing to cover them.



CONNECTING OUR COMMUNITY ONLINE

Connection, connection, connection: It's what life is all about. As we continue to socially distance, the CMTA's top priority continues to be bringing the CMT community together via engaging virtual programs. We remain steadfast in our efforts to plan twice-monthly online events in the form of Zoom meetings, Facebook Live sessions and webinars. There is literally something for everyone: chair dancing, stretching and yoga, managing CMT, camp songs with Jonah and much more.

Many of our amazing branch leaders around the United States and Canada are planning virtual branch meetings as well. If you haven't made it out to a branch

meeting, now is the time to pop in and give it a try. These are small group meetings designed to support and educate patients and families, providing a place for them to chat with other people who share the challenges of CMT. To learn about upcoming virtual branch meetings please go to the "Events" section of our website found at www.cmtausa.org/get-involved/events/.

To learn more about CMTA virtual programs, please make sure to sign up for e-News, which you can do on the homepage of our website: www.cmtausa.org (look for the "Subscribe" button at the top). You can also learn about virtual events by following the CMTA's social media accounts on

Facebook (www.facebook.com/CMTAssociation) and Instagram (www.instagram.com/cmtausa/).

While there is no substitute for in-person connection, the Internet gives us the chance to build togetherness with our fellow CMTers during these uncertain times. I am thankful we have these digital options in place and I hope you will consider joining us for one of our many virtual programs. We would love to "see" you!

If you have any questions please reach out to me via email or phone: Laurel@cmtausa.org / 800.606.2682 ext. 112.

—*Laurel Richardson,*
CMTA Director of
Community Outreach



CMTA branch leaders plan upcoming meetings via Zoom



HOW TO ZOOM

While many people hadn't heard of Zoom before the COVID-19 quarantine forced social distancing, it's now being used for everything from dance parties to exercise classes to CMTA branch meetings and webinars. In short, it's become a pandemic lifeline.

Zoom is a web-based video conferencing tool that allows users to meet online, with or without video. Users can record sessions, collaborate on projects and share or annotate on one another's screens.

Zoom is not difficult to use. The first step is to set up an account at www.zoom.com. There are different membership levels. The lowest level is free and allows the subscriber to host unlimited one-on-one meetings with no time limit—great for talking with friends and relatives. Free subscribers can also host unlimited 40-minute meetings for up to 100 participants. For \$14.99/month, paid subscribers can host meetings of up to 100 people that last up to 24 hours. The paid version also allows the host to record meetings and schedule repeat meetings. Additional business levels allow more participants and other features like cloud storage for recordings, a customer success manager and discounts on webinars and Zoom Rooms.

When meeting "hosts" schedule meetings, Zoom sends out "invitations" to the chosen participants, who must also have accounts. Invitees simply click on the link in the email from Zoom, then join the meeting and click the link to enable audio. There's a choice of speaker view, which focuses on the current speaker, and gallery view, which allows attendees to see multiple participants at once, "Brady Bunch" style. Since only the head and shoulders of a participant is in view, many people go business on top, casual on the bottom. There are multiple bells and whistles—everything from screen-sharing to a variety of backgrounds that make users look as if they're calling in from places like a tropical beach or the moon. All in all, the Zoom setup is user-friendly and semi-intuitive.

Zoom is available on all major desktop and mobile operating systems, including Windows, macOS, Android and iOS.



Taking the Toronto Branch Online

Like most people, the co-leaders and members of the Toronto Branch were thrown for a loop by COVID-19.

Lockdown began March 14 in Toronto and our next in-person branch meeting was scheduled for March 21. Yikes! My co-leader, Linda Scott Barber, and I quickly pivoted and moved our meeting online.

We were tentative at first. We'd never hosted a digital meeting with our whole group and we were worried about whether anyone would show up. Equally nerve-racking was the potential for technical difficulties with some of our less tech-savvy members. Luckily, the CMTA provided online accounts to host the meet-

ings and we were able to quickly communicate everything to our members.

I'm happy to say that there was no need to worry. Our first meeting went off without a hitch. We had a small but engaged group who all appreciated the opportunity to connect and share with each other. It was wonderful, especially during those anxious and uncertain first weeks of lockdown.

Since that first tentative meeting we've upped our game and managed to host two more! While the first small engagement didn't have a guest speaker, our subsequent meetings have featured guest speakers and bigger turnouts. In April we had a nutritionist and at the beginning of

June a physiotherapist specializing in mindfulness training.

I have to admit that it hasn't been completely smooth sailing with all the meetings. There have been a few Internet and connectivity problems, as well as some members dropping out early to deal with family needs at home. I'm sure this sounds familiar to anyone who has Zoomed lately.

All in all, though, it's been great to be able to still meet together, connect with each other, learn from our guest speakers and share the good and the bad in our collective situations.

—Mike Dreidger,
Toronto Branch
Co-Leader



Intubation and mechanical ventilation have been in the news constantly lately. Are CMT patients at increased risk from these procedures?



Dr. Elsayegh, FCCP, is a pulmonologist at Cedars-Sinai Medical Center and a member of the CMTA Advisory Board.

Dr. Ashraf Elsayegh answers:

The average CMT patient is at no greater risk from intubation and mechanical ventilation than any other patient. The former refers to placing a tube in the throat into the trachea to help move air in and out of the lungs while the latter refers to the use of a machine to move air in and out of the lungs. These are life-saving measures and, if needed, can easily be done, usually with minimal side effects. Just having a diagnosis of CMT does not change that fact.

CMT patients who have significant problems with their

respiratory systems (particularly respiratory muscle weakness), may be at higher risk. These patients are more difficult to wean from the ventilator, making removal of the endotracheal tube more difficult. That sometimes places them at an increased risk of ventilator-associated pneumonia.

The risks of intubation—for any patient, whether otherwise healthy or chronically ill—include the side effects of the medications given to sedate and relax the patient enough to be able to intubate them, including allergic reaction to the medications,

hypotension or low blood pressure and cardiac arrest.

Difficulty with a particular airway may result in multiple intubation attempts, which can cause edema of the airway, making it more difficult to intubate the patient.

There is also the risk of injuring the trachea while trying to insert the endotracheal tube (breathing tube). Finally, post intubation, increased pressure in the chest cavity can result in further hypotension. Although most of these risks are rare, they can occur.

The main risks of mechanical ventilation include development of pneumonia (known as ventilator-associated pneumonia), a small risk of a collapsed lung, mucous plugging and difficulty removing the endotracheal tube. Again, these risks are not common, but they are possible. ★

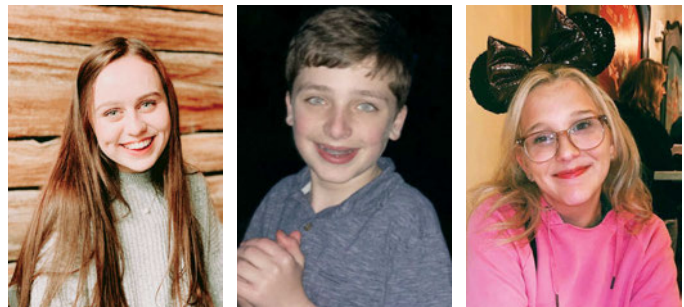
CALLING ALL DREAMERS!

The CMTA Youth Council is calling all youth with CMT (up to 21 years old) to share their thoughts on having CMT for a “Book of Dreams.”

Participants are guided through a series of questions, at first just basic information like age at diagnosis and type, then moving on to deeper, more insightful questions designed to elicit thoughtful and useful responses. For example, the survey asks “What is one piece of advice that you have for someone with CMT?” and what are the best and worst parts of living with the disease?

Participants are urged to be creative in answering questions like “If you were to write a story about your life with CMT, what would the title of the story be?”

Anyone interested in participating can go to bit.ly/CMTABookofDreams. As the Youth Council announcement says: “Don’t miss this chance to be one of the authors in a book that will be a permanent symbol of the youth perspective on CMT!”



Youth Council members on the Book of Dreams Committee: Riley Williams, Evan Zeltsar and Julia Beron

Keeping the Fun in Funathlon

Creativity Allows Annual Event to Continue for Its Sixth Year

Not even a pandemic can stop us! When the coronavirus rendered a standard Oxford Funathlon unworkable, event organizer Steve O'Donnell improvised and overcame. A scaled-down version of the annual event was held on June 6 with just Steve and his son Sean participating in the traditional swim and 20-mile bike ride. The remaining portion of the Funathlon went virtual as Steve invited participants from around the country to engage in their own athletic endeavors and then post them to the Funathlon website. The event raised more than \$200,000 for CMT research.

At 7:30 a.m., Steve and Sean dove into the Tred Avon river in beautiful Oxford, Maryland for a quick swim around the harbor. They were escorted on their swim by Clark Semmes in a kayak and Dennis McCartney in a rowboat, while a drone filmed them from above. Steve and Sean then jumped on their bikes for the traditional 20-mile bike ride around Maryland's beautiful Eastern Shore, escorted out of town by two Oxford Police Department squad cars with sirens blaring.

Meanwhile, participants all over the country were posting pictures of their own athletic achievements on the Oxford Funathlon website. Some of the 2020 Oxford Funathlon virtual participants included Chris and Jeana Sweeny, Benjy Hershorn, and 2-year-old Quinn Fernandes, who earned the "Hero Award" for her quarter-mile walk. The adorable tyke wore a cape and a sign that read "We're taking steps to find a cure for CMT." Quinn's



mother Molly reports that at one point she exclaimed, "I'm so fast!"

It's not too late to make a donation—just visit www.cmtausa.org/funathlon. To view the full album of pictures, visit <https://bit.ly/30s9uea>. Plans are already underway to make the



Quinn Fernandes wins "Hero Award" for her quarter-mile walk.

2021 Oxford Funathlon the biggest and best yet. Steve is also organizing Tee Off for CMT, a golf tournament to be held September 28 in Baltimore. For more information, keep an eye on the CMTA website at www.cmtausa.org. ★



Steve and Sean O'Donnell enjoy their 20-mile ride.

See Steve and Sean's swim and ride (and some amazing drone footage) at www.facebook.com/169513073068855/posts/3301746793178785/.

WHY WE GIVE:



Pru and Louis Ryan like to support organizations that “move the needle” in the right direction. They believe that the CMTA is one of those organizations. That’s why they are once again matching another CMT1B family’s gift for \$300,000, following an earlier \$500,000 match.

“We make annual gifts to the CMTA because we think that all the work they do is important,” Pru said, adding, “We like it that the CMTA supports many aspects of research and also many aspects of information and support for people who have CMT and families affected by CMT.”

The CMTA has grown by leaps and bounds both in terms of research and patient resources, Pru said. She and Louis particularly

like the CMTA’s Patients as Partners in Research initiative for the link it provides between CMT patients and the researchers trying to find a cure for them.

Pru’s CMT journey began relatively late in life. As a child, she was athletic and well-coordinated and the only foreshadowing of what was to come were several ankle sprains. Other than that, she enjoyed all the pleasures of a New England childhood—ice skating in the winter and hiking, tennis and soccer the rest of the year.

In her early forties, though, she developed increasingly pronounced pronation as the muscles in her feet weakened. She began wearing custom orthotics, which stood her in good stead for many years. After a New York neurologist diagnosed her older sister, Abby Wakefield, with CMT, Pru followed in her footsteps and was diagnosed at the age of 42. She was still relatively symptomless, but the

diagnosis didn’t come as a complete surprise, given her sister’s diagnosis and the fact that a neurologist told their mother that she had some kind of peripheral neuropathy back in the 1970s. In 2005, at the suggestion of Abby’s neurologist, she and Pru both had genetic testing, which gave them a more definitive diagnosis of CMT1B with an MPZ variant H39P.

In 2009, with the weakness in her lower legs and feet worsening, Pru visited Dr. Michael Shy’s clinic at the University of Iowa for the first time. Through him, she

became more aware of the work the CMTA was doing, and she and Louis began contributing on an annual basis. In 2013, Pru began wearing supramalleolar orthotics (SMOs), which surrounded her ankles and gave her much-needed support. By 2015, Pru was experiencing enough foot drop and lower leg fatigue that she moved to custom carbon fiber braces, which she wears along with her SMOs.

Pru, now 75, and Abby, now 81, along with Abby’s daughter Reeve Washburn, 56, made a family pilgrimage to Dr. Shy’s clinic in June 2014. Pru, who clearly enjoys the nitty gritty of medical research,

“We make annual gifts to the CMTA because we think that all the work they do is important.”

made a “CliffsNotes” edition of CMT basics for her sister and niece. She still has the paper towel that Dr. Shy used to explain the unfolded protein response.

Not long after that family visit, Pru and Louis became aware that another family was making a

substantial contribution for CMT1B research. Inspired by their example, the Ryans decided to match it.

Louis said that was a watershed moment for the couple. Although they had previously contributed to the CMTA’s annual campaign, they decided to make a more significant gift because they knew for the first time that they could be more focused in their giving. While they wanted to help everyone who has CMT, the idea that it could directly impact Pru’s subtype, CMT1B, was appealing. They

Pru and Louis Ryan

also liked the fact that the CMTA has the highest possible rating, 4 Stars, on Charity Navigator.

The couple's latest gift is not uniquely focused on Pru's specific variant, but the Ryans wanted to make sure that MPZ H39P—one of the more common variants—was included in the research package they're helping fund. "It only makes sense to research something that affects more people," Louis said, but at the same time the CMTA can help patients focus their giving. "The exciting

thing about this package is that developing protocols to prove effectiveness will benefit all forms of CMT," Louis said.

Pru is now retired from her career as a paralegal and Louis from his position as general counsel of a media company, but they continue to be involved with various not-for-profit organizations, both as board members and donors. Pru has some hearing loss in addition to the muscle wasting and weakness in her hands and legs, but she handles it with

aplomb and hearing aids that connect to her cell phone and televisions.

The couple will celebrate 50 years of marriage this fall. Pru says that Louis' strength and creative, out-of-the box thinking have helped her endure while his "interest in, passion about and thoughtful attention to philanthropy have had a profound effect on me and have helped guide my philanthropic decisions." They have both helped move the needle for the CMTA. ★

CMTA CENTERS OF EXCELLENCE

www.cmtausa.org/coe

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 Neuropathies Consortium (INC)—a group of academic medical centers, patient support organizations and clinical research resources sponsored in part by the CMTA. The centers will become even more important as the CMTA begins clinical trials, which will 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.

CMTA CENTER OF EXCELLENCE

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Lucile Packard Children's Hospital at Stanford (Palo Alto)	Drs. John Day and Ana Tesi Rocha
Massachusetts General Hospital (Boston)	Dr. Reza Seyedsadjadi
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University of Antwerp (Edegem, Belgium).....	Dr. Jonathan Baets

*These Centers of Excellence are not part of the INC.



QA ASK AN EXPERT

Sara Kevern, RD, CNSC responds to questions about nutrition.



Sara Kevern is a registered dietitian and nutrition support specialist at Stanford Health Care and Stanford Children's Health.

What is the best diet for someone with CMT? I've read about the Wahls protocol, the paleo diet and keto, just to mention a few. I'm so confused!

No diet has been proven to show improvement in CMT symptoms or disease process. Everyone has unique dietary needs for energy levels and weight maintenance. The best diet to manage CMT symptoms is one that is nutritionally balanced to give muscles all the necessary macro- and micro-nutrients to optimize their function. Weight maintenance is also important in order to maximize the ability to move pain-free and with as little fatigue as possible.

Everyone is different and CMT affects people in very different ways. For some people, a ketogenic diet may be beneficial for weight loss but may be too deficient in carbohydrates, leaving them fatigued. Wahls protocol is a modified paleo diet, which may have benefits for some, but again may be too low in carbohydrates for others.

While one size does not fit all, a diet low in processed foods, low in sugar and high in fruits, vegetables and healthy fats is a very

important starting point. This means cooking from scratch, eating five to seven servings of fruits or vegetables per day and incorporating foods like avocados, olives, nuts and cold-water fish into your diet while limiting processed carbohydrates and sugar. Protein is necessary but shouldn't be consumed excessively, as this can lead to weight gain. Choosing a variety of protein sources such as cold-water fish, poultry, grass-fed red meats and beans is important to get a variety of nutrients.

If you are incorporating these basic diet guidelines but still feel unhappy with your current energy levels or mobility, it may be worth meeting with a neuromuscular registered dietitian to help develop a more customized nutrition plan.

Are there any foods or nutritional supplements to help treat my chronic CMT-related fatigue?

Constant fatigue is almost inevitable with CMT, but optimizing nutrition can help minimize it. Food provides energy for all cells in the body, and the types and amounts of certain foods can influence the way your body uses that energy.

With CMT it is important to eat enough carbohydrates for your muscles to have a steady fuel source, but too many simple carbohydrates can result in feeling more tired. Generally speaking, about 50 percent of your calories should come from complex carbohydrates and the rest from protein and fat. However, this varies from person to person and you may need to experiment with your own diet to find the best amount of carbohydrates

for you. Simple carbohydrates like sugar, candy, syrups/honey and refined grains can leave you feeling more tired. Ever hear the term "sugar crash?" That term comes from the tired feeling you get after eating an excess of simple carbohydrates. These foods digest too quickly and cause a spike in your blood sugar. You may feel energized at first, but once your body burns off that sugar you're likely to feel more tired. Focusing on food sources of complex carbohydrates such as beans, legumes, fibrous fruits, whole grains, starchy vegetables and dairy is a better way to get your carbohydrates without a sugar crash. Aiming for foods with less than 5g sugar per serving and more than 5g fiber per serving is best.

In addition to complex carbohydrates, micronutrients play an important role in providing your body with usable energy from food. Micronutrients are vitamins, minerals and antioxidants. B vitamins are the most important players in the energy production game and they are very easy to get from food. The top food sources of B vitamins are leafy greens, salmon, eggs (with yolk), shellfish, poultry, beef, fortified whole grains and sunflower seeds.

There are no specific supplements to take for fatigue. Focusing on a varied diet with adequate carbohydrates and a wide variety of fruits and vegetables will likely meet all of your micronutrient needs. If you feel like you're not meeting all of your vitamin and mineral requirements, a daily multivitamin provides the best bang for the buck and will provide all the vitamins and minerals you need without excess. ★





**Life as we knew it has stopped,
but if we work together we can keep moving forward.**

The CMTA community has always come together behind our cause—a world without CMT. Community members organize our walks, support each other in branch meetings and raise money for research—one walk, bake sale and car wash at a time.

These are challenging times, but we know we can get through the months ahead by doing what our CMT family does best: *coming together for our shared cause.*

Because the coronavirus has forced the cancellation of all in-person meetings and fundraisers, the CMTA staff and Board are coming together and personally donating or raising more than \$1 million to support the CMTA's overall mission.

We ask you to join us as we gather resources from within. We understand that times are hard, but if you're in a position to join our initiative, we ask you to do it today—every gift matters, no matter the size. **TOGETHER** we can keep moving toward our goal.

It's worth noting that the recently passed federal stimulus bill includes an "above the line" charitable deduction of up to \$300, which allows you to deduct charitable donations even if you don't itemize.

The CMTA's strength is and always has been its supporters. Please join us in a show of strength today. And please continue to take care of yourself and one another. Together, we will get through this.

YES, I would like to join the CMTA Staff and Board in support of the CMTA's mission!

Complete this reply slip and return with the enclosed envelope.

Enclose check payable to the Charcot-Marie-Tooth Association. Donations can be made online at cmtausa.org/ourcause.

- \$1000 \$500 \$300 \$250 \$100 \$50 Other: \$ _____
- I am interested in learning more on how to make a major gift or a multi-year pledge to support STAR.
- Please charge my credit card. Visa MasterCard American Express

Name _____ Card # _____ Exp. Date _____

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Adaptive Training for All Ages

BY SHELLY TAYLOR AND PAYTON RULE

IMPROVED STRENGTH AND STAMINA FOR SHELLY

Growing up, I could not understand why I was such a stumble bum, as people called me. I was never good at sports because my ankles sprained so easily. I was the last one to be picked for any team in school PE and running was very hard for me. Later, when I got married and had children, I began trying to find the cause of my athletic issues, and after many years I was diagnosed with CMT/HNPP. Finally, I had a name for what was going on.

I first heard Payton Rule talk about the Disabled Athlete Sports Association for adaptive training at a St. Louis Branch meeting in

2015. Thanks to Payton, the branch leader, I started going to DASA personal training in 2016 and I have seen improvement in my fitness. Of course, my HNPP hasn't gone away, but my strength and stamina have improved. Before DASA, I scheduled no more than one doctor's appointment per week, then had to rest and recuperate the rest of the week because it took so much out of me. When I had a week without appointments, I spent it in my pajamas. I still have pajama days, but not as often.

My DASA trainer, Kimi Kemp, has helped me so much. It was tough to set up a program for me because I am a 67-year-old senior and my HNPP was progressing faster and farther. But

as Kimi got to know me, she switched the program to match my needs. One week I might have a flare-up on one part of my body and the next week on a different part. Kimi and the other DASA trainers were patient and very knowledgeable about CMT. They really listened to me so they could set up the correct program for the time I was there.

I have muscles now where I did not have any before. Yes, I have gained weight but it is muscle that helps me to do more every day—blow drying my hair, brushing my teeth, walking through the house without tipping over as much, doing a little cooking, getting dressed mostly by myself and even occasionally doing some chores around the house like dusting, vacuuming and sweeping. My legs are now strong enough that I can turn over in bed, whereas before I had to struggle using only my arms. I am not as fatigued when I travel. My quality of life has improved immensely.

—Shelly Taylor

PAYTON'S POV: WORKOUTS ENJOYABLE AND EMPOWERING

I have enjoyed playing sports and staying active my whole life. My CMT 2E diagnosis at age 5 and the resulting balance and strength challenges did not stop my parents from signing me up for a whole host of sports including T-ball, basketball and tennis. While I absolutely loved playing these sports and learned many important life lessons, I struggled to play competitively alongside people without CMT.

My parents eventually came across an organization called the Disabled Athlete Sports Associa-



Shelly Taylor works out at DASA



Payton Rule (right) with DASA trainer Kimi Kemp

tion (DASA) that offers adaptive recreational and competitive sports for kids and adults with physical disabilities. My mom surprised me one day by signing me up for their adaptive workout program.

I am not going to lie: When I first heard I had been signed up for an adaptive program, I was not excited. I pictured myself in a room lifting extremely light weights and doing careful, light exercise that would not challenge or excite me at all. In addition, I had always heard that CMTers cannot gain much muscle, so as far as I was concerned, this would be boring and pointless.

I could not have been more wrong. I left my first workout sweating and out of breath, and I was sore for days. But I kept going back week after week and eventually something crazy happened: I started to feel stronger. Activities that had been difficult—like getting off the floor and navigating stairs—became significantly easier.

When I first heard I had been signed up for an adaptive program, I was not excited.

I began falling less and had more energy. I have had CMT symptoms my whole life, but at the age of 17, I was able to function better than I ever had.

The program has benefited more than just my body. I find my workouts both enjoyable and empowering. Kimi is also my trainer and she pushes me just as hard as any personal trainer pushes any able-bodied client. She is also always willing to try and help me achieve any goal I set, no matter how crazy it may seem. Right before I started training with Kimi, I had set a goal for myself to complete a half-marathon. This was a goal that many questioned and perhaps doubted I would reach. However, Kimi's response was an immediate "Awesome! Let's do it. I'll train you." With Kimi's help, I was able to complete a half-marathon a little over a year later.

I have been training one-on-one with Kimi for four years now and don't plan to stop any time

soon. Exercise has been the best treatment I have received for my CMT. I am so thankful for the support and empowerment I have received from DASA and Kimi and am excited to see what the future holds. ★

Shelly, 67, recently moved to Norfolk, Virginia, where she plans to continue working out. Payton, now 21, is a rising junior at Washington University in St. Louis, where she is pre-OT and studying philosophy, neuroscience and psychology.

DASA is a 501 (c)(3) nonprofit specializing in therapeutic sport and fitness opportunities. Trainees are encouraged to seek their highest level of independence and become involved to the fullest extent with their non-disabled peers and their community as a whole. With programs for both children and adults, DASA seeks to promote physical fitness, self-confidence, family values, and a positive, team-building environment designed to encourage personal growth throughout all aspects of life. To learn more about DASA, go to www.dasasports.org.

DASA is located in St. Peters, Missouri. For a list of similar organizations in other parts of the country, go to www.challengedathletes.org/adaptive-sport-organizations/.

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The Surgical Correction of the CMT Foot: IS SURGERY RIGHT FOR YOU?

PART 3 OF 4:

THE ROLE OF JOINT FUSION

BY GLENN B. PFEFFER, MD

A surgical joint fusion, or arthrodesis, is a procedure that joins the bones of a joint together. It is one of the oldest procedures in orthopedics and has been used for arthritis and deformity correction since the 19th century.

Today, the most common reason for a fusion is joint arthritis, which occurs when the cartilage that covers the bones of a joint becomes damaged by trauma, disease or age. Age-related arthritis is called osteoarthritis. Healthy cartilage is white and glistening and allows the bones of a joint to move smoothly. Arthritic cartilage is greyish, thinned and pitted, and interferes with smooth joint motion. The joint becomes progressively stiff, inflamed and painful.

Surgical fusion of an arthritic joint will take away the pain, but it will also take away the motion. It involves removing the compromised cartilage and stabilizing the remaining bones with metal screws, plates or staples. The surgery is done on an out-patient basis, followed by six weeks in a non-weight bearing cast on the operative foot and another four weeks in a walking cast. Remarkably, during this time the bones grow together, fusing the joint. It may sound horrible, but it is one of the most common and best pain-relieving surgical procedures performed on the foot and ankle.

There are 33 joints in the foot, and it is possible to fuse a few of them without any significant loss of function.

The most common reason for a fusion in a CMT patient, however, is not arthritis but deformity correction. When needed, it is an operation with superb results, but severe deformity is a completely preventable problem. If the muscle on one side of a joint is weak and the other is strong, as commonly happens in CMT, the joint gradually becomes deformed and eventually fixed. This does not happen overnight and it is preventable if caught early enough. A brace can help if the joints are still flexible and can be held in the correct physiologic position by the brace. But all too often the foot deformity progresses despite the

brace, as discussed in the first two parts of this series. If you take your clenched fist and put it into your pocket for several months, your fingers probably won't open again. The soft tissues contract and the joints become fixed. The longer one waits, the more impossible it becomes. Anyone whose foot is not flat on the ground when walking needs to have a surgical correction before it becomes fixed and a fusion is the only option. Big problems start small.

I recently operated on a 15-year-old boy with CMT who, but for the surgery, would have needed a triple arthrodesis in a few years. He and his family had been told for years that nothing could be done for him and that braces were his only option. Over time, his

(continued on page 22)



Dr. Pfeffer is an orthopedic foot and ankle surgeon and co-director of the CMTA's Center of Excellence at Cedars-Sinai Medical Center, Los Angeles. He is also a member of the CMTA's Advisory Board.

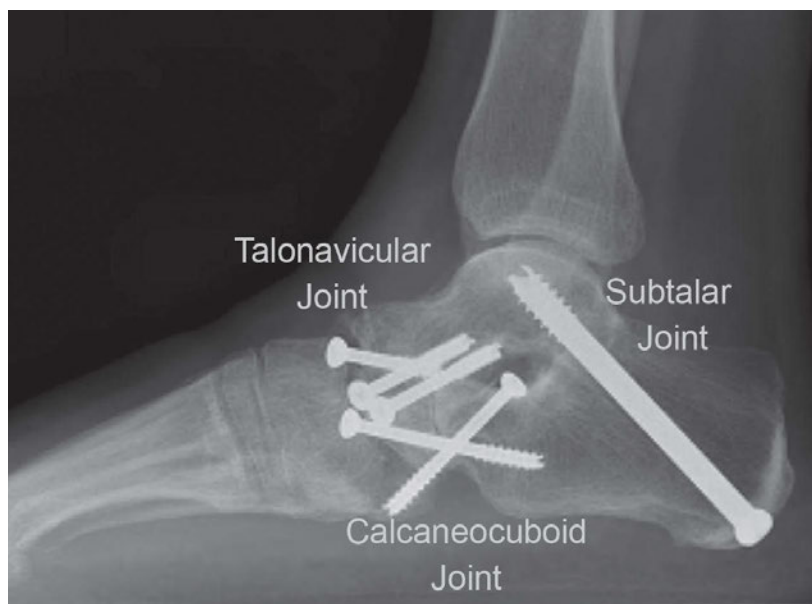


Figure 1: A triple arthrodesis fuses three major joints in the hind foot.

JOINT FUSION

(continued from page 21)

foot became more deformed and almost fixed in its crooked, painful position. Fortunately, he came just in time for his deformity to be corrected without a fusion. While a fusion, if needed, would have straightened out his crooked foot, the preservation of motion is preferable, especially in someone with so much life ahead.

If a fixed deformity has developed, patients can still be helped with a triple arthrodesis, a procedure in which the three major joints in the hind foot—the subtalar, talonavicular and calcaneocuboid joints—are fused (figure 1) in a corrected position so the foot is flat on the ground. It's not ideal, but it's much better than having a rigid foot that doesn't lie flat and causes pain with every step. Ankle motion is preserved and the patient can walk with no obvious limp from the fusion.



Figure 2: A subtalar fusion fuses only one joint.

The good news is that a triple arthrodesis is rarely needed anymore, especially in people under 30. It seems like the word that early intervention can prevent more serious problems is getting out. The procedures discussed in parts 1 and 2 in the previous two *CMTA Reports* will balance a

crooked foot while preserving motion. While a triple arthrodesis can be transformative, the more motion one can keep the better. Anyone told they need a triple arthrodesis should first consider a second opinion with an orthopedic foot and ankle surgeon to see if it can be avoided.

Joint instability, rather than deformity, is probably the most common reason for a fusion in my practice. When the muscles that control a joint are paralyzed, the joint loses function and becomes unstable. This can happen with any joint, but it is particularly problematic when the paralysis in a CMT patient involves both peroneal muscles. The peroneals are the muscles and tendons on the outside of the ankle that keep it stable and prevent it from collapsing inward with each step.

Typically, the peroneus brevis (PB) is weak, while the peroneus longus (PL) remains strong. In that case, a tendon transfer of the PL to the PB provides sufficient lateral strength and stability (see part 2). When both muscles are paralyzed or very weak, however, a subtalar fusion may be the best option. Only one joint is fused—the one comprising the talus and calcaneus. One

or two screws are used to stabilize the fusion (figure 2). This provides complete stability to the hind foot and prevents the foot from constantly twisting inward while walking. Some of my happiest patients have had a subtalar fusion, especially when combined with soft tissue releases and ten-

don transfers. Since only one joint is fused, more motion is preserved than would be with a triple arthrodesis. The most common problem of any fusion surgery is that the bones don't fuse and a non-union develops. Fortunately, that is very rare.

Fusions of joints other than those discussed above are rarely needed in CMT patients. A fusion of the ankle should rarely be done, especially not for a drop-foot. Modern ground-reaction energy-storing braces only work when the ankle moves. An ankle fusion takes away the chance of ever using one of these braces. Only in rare cases of extreme deformity or arthritis should an ankle fusion be considered. Most ankle deformity can be corrected without a fusion and patients with CMT often tolerate ankle arthritis quite well because of the decreased feeling that results from the neuropathy.

In summary, a fusion of one or more of the joints in the hind foot can correct the severe deformity or paralysis that causes joint instability. If the surgery is done well, the patient will do well and may be able to get out of a brace completely. An ankle fusion for a drop-foot, however, should usually be avoided. In that case, a ground reaction brace will provide better function. ★

In the final part of our four-part series, we will discuss the surgical correction of crooked toes.

On a personal note, I want to thank all of my patients. I dislocated my ankle on Easter, broke three bones, and required surgery. In my darkest hours, your examples of bravery and perseverance gave me strength. I'm still improving but back to work with three CMT surgeries this week. Stay safe out there.

—Glenn

 Follow Dr. Pfeffer on Instagram at @Charcotmarietoothsurgery.

The Courage to Wear Shorts

BY MONICA THOMAS

I didn't buy my first pair of shorts until I was 28 years old. Summer after sweltering summer, I hid my atrophied legs and leg braces beneath layers of denim and cotton. I let sweat pool on the backs of my knees until it trickled into my AFOs, where my skin was burning hot. Being physically uncomfortable every summer of my adolescence and adulthood was just something I did, as second nature as eating and breathing.

It wasn't always that way. When I was a kid, I wore the shorts my mom bought for me. I loved the purple ones that matched my butterfly-printed leg braces. I hadn't yet been conditioned to be ashamed of my body. But thousands of stares and "What's wrong with you?" later, I tucked my legs away in an attempt to make other people more comfortable. Because let's face it, able-bodied people are often uncomfortable around visible disability. I took on their discomfort and wore it like another suffocating layer of clothing around my legs.

And then, in the summer of 2018, I went outside on the hottest day of the year. I wore the thinnest maxi dress I owned, and still it felt like my legs were in their own personal sauna. I looked on with envy as other women passed me in miniskirts and shorts. I wish I could wear that, I thought. And then, a brand new thought presented itself. Who told you that you couldn't?

And the answer was obvious: I did. Sure, society told me I shouldn't. Every stare, every question, every ad reinforced the idea that there were standards for beauty that my body didn't meet. But what did I think of my body? I was still pondering this new thought when my husband and I pulled our car into my sister's driveway later that day. She came out to greet us wearing denim shorts and white Keds. Her AFOs were fully visible. She looked adorable. She looked confident.

The next day, I ordered four pairs of shorts online. Clearance. Final sale. No going back. When the package arrived the following week, I was nearly feral tearing into it. I tried on each pair and wheeled myself in front of my full length mirror to have a look. Each time, I smiled. Each time, I felt beautiful. Each time, I felt the layers I had surrounded myself in fall away as I learned to love all of myself, atrophied legs included.

Being physically uncomfortable every summer of my adolescence and adulthood was just something I did, as second nature as eating and breathing.

I kept the shorts on that evening when my husband and I went for a stroll in the park. I couldn't stop smiling as I felt the fresh summer air stream over my exposed legs. People stared the exact same amount they always had, and it gave me

a final, solidifying thought on the matter: It had never mattered if I covered my legs or not. My disability didn't hide itself under a pair of jeans. People are always going to look, always going to question. And it is not my problem. Their discomfort can sit



COMFORTABLE, AT LAST!

with them; it is no longer welcome in my lap.

For the rest of that summer, I wore shorts everywhere. I stopped thinking about it at all. And then one afternoon at the park, a pair of middle school girls (the most terrifying age), came up to me. I braced myself for a "What's wrong with you?" as they stopped in front of my wheelchair.

"We love your outfit!" one of them exclaimed.

"Oh, thank you!" I replied in shock.

They continued down the path and I continued down mine. Clearance. Final sale. No going back. ★

Monica, 30, is a writer and social media manager at a small public library in Muncie, Indiana.

WALKS ARE HAPPENING AND ...ALL WE NEED IS YOU!



Virtual or in-person, we are still Walking 4 CMT! Check with the walk location in your area to see how they are choosing to walk.

Led by CMTA volunteers, the CMTA's National Walk 4 CMT campaign provides multiple opportunities to raise awareness and funds to improve the lives of those living with CMT. Join thousands of people across the country by visiting Walk4CMT.org to find an event near you. If there is no walk near you, consider starting your own—we'll help!



Funds raised by the Walk 4 CMT campaign help to support the CMTA's mission of finding treatments and, ultimately, a cure for CMT.



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Thanks to my ToeOFFF[®],
I have been able to
EMPOWER PEOPLE to
challenge their limits and
FIND NEW HEIGHTS
no matter the obstacle!

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



CMTA BRANCH NEWS

LOS ANGELES

A dozen people welcomed guest speakers Alison Sterite, DPT, and personal trainer Tara Lyn Emerson to the Los Angeles Branch's virtual meeting on May 30. Sterite presented on different types of physical therapy, the goals behind each and how to differentiate between normal soreness from exercise and pain caused by overdoing it. She shared some stretches that are generally helpful for CMT patients. Emerson talked about her own CMT journey and how she focuses on exercises she is able to do. Branch member Julie Lightner shared her experiences volunteering with the annual Angel City Games, which include adaptive sports workshops. The 2020 Angel City Games will be virtual and branch members are invited to sign up—it's free! Lastly, branch member Lexi Dineen announced that she has started a blog about her journey with CMT at theabilityblog.com/.

★

CENTRAL FLORIDA

Five members of the Central Florida Branch welcomed guest speaker Laurel Richardson to their first virtual branch meeting on May 30. Laurel, who is the CMTA's director of community outreach, talked about moving education and meetings online and steps the CMTA is taking to stay connected with the community during this time.

★

NAPLES, FL

Four members of the Naples Branch held their first virtual meeting on Zoom recently, chatting about how everyone is doing and feeling during the pandemic. They also talked about the challenges of CMT. They all enjoyed the virtual format and will use it again.

★

TAMPA BAY AREA, FL

Two guest speakers addressed the Tampa Bay Branch's virtual meeting on June 6. Dr. Michelle Arnold spoke about CMT and hearing loss, and Laura Russell provided information regarding social work support for Dr. Nivedita Jerath's neuromuscular clinic at AdventHealth Orlando. More than a dozen regulars tuned in via Zoom. The next meeting will be held online on September 12 and the Tampa Bay Walk will be held on November 14.

★

GREATER MINNEAPOLIS, MN

The Greater Minneapolis Branch held its first Zoom meeting on June 11 with six people in

attendance. Laurel Richardson gave attendees an insight into the CMTA's STAR research program, history and community programs. She also talked about the importance of being seen at a Center of Excellence, like the clinic at the University of Minnesota led by neurologist Dr. David Walk. Laurel also talked about the CMTA's Patients as Partners in Research initiative, a critical way for patients to get involved in the research process.

★

SYRACUSE, NY

The seven people who attended the Syracuse Branch's first meeting on Zoom were pleasantly surprised at how easy it was. They discussed the importance of staying positive, walking aids and footwear. During the footwear discussion, a former mail carrier gave his suggestions for what brand to wear and where to shop for them. Members also discussed the importance of maintaining a positive outlook through the pandemic, which is made easier by knowing "We are not alone."

★

CLEVELAND, OH

Several members of the Cleveland Branch attended their first virtual meeting May 21. Guest speaker Laurel Richardson shared information about the STAR research program, education and events in the community, and also provided detailed resources about how community members can get involved and communicate with the CMTA.

★

TULSA, OK

The first Tulsa Branch Zoom meeting went well, with several new members in addition to those who came to the inaugural meeting in 2019. Several members are from Oklahoma City and the branch has 36 Facebook friends. Some members expressed happiness at being able to meet on Zoom, not only because of COVID-19, but also because traveling is difficult for many. The group

hopes to keep growing and adding members from all over Oklahoma.

★

BUCKS COUNTY, PA

Eleven members welcomed CMTA Advisory Board Member David Misener to the Bucks County Branch's Zoom meeting May 16. David is a board-certified prosthetist and orthotist who has practiced in Albany, New York, for more than 20 years. Both he and his son have CMT 1B, so he truly understands the unique challenges faced by others who have the disease. David shared various options for orthotics and bracing to assist with challenges such as poor alignment, foot drop, ankle instability and propulsion. David's wealth of knowledge, along with his personal and professional experiences, left members feeling understood and optimistic about finding solutions to improve their stability and mobility. Given concerns regarding COVID-19, the members agreed to postpone their annual Buffet Dinner & Raffle fundraiser, but they will hold an outdoor potluck picnic this summer.

★

CHESTER COUNTY PA

Sixteen people gathered via Zoom for the Chester County Branch meeting on May 3. Guest speaker Bernadette Scarduzio shared her CMT journey and some of the work she's done as a CMT advocate, including a documentary about her life with CMT that is free on Amazon Prime. She talked about her work making New Jersey beaches accessible with mats that go over the dune to the shoreline. She shared her quarantine exercise routine and gave tips about getting insurance to pay for physical therapy. Members also discussed pain management adaptive devices and one member shared a spreadsheet of helpful tools. The tentative date for the branch's Walk 4 CMT is September 9, depending on what happens with social distancing rules in the upcoming months. The next meeting will take place in late August.

LEMONAID FOR CMT

Tanner, Reagan and Sloane Fearson were swimming at their local pool in Fenwick Island, Delaware, when an announcement came over the loudspeaker: Neighbor Steve O'Donnell was raising money for a rare disease called CMT. They'd never heard of it, but when they heard that a neighbor needed help, they immediately decided to put up a lemonade stand to raise money for CMT research. It was all their idea and no one pushed them—not their parents and not Steve. The youngsters' big hearts and hard work raised \$45 for CMT research and the CMTA is beyond grateful.



Entrepreneurs Tanner, 11; Reagan, 9 and Sloane, 5

To learn about upcoming virtual branch meetings please go to the "Events" section of our website found at www.cmtausa.org/get-involved/events/.

CMT: Let It Empower You

BY RILEY WILLIAMS

Fundraising has always intimidated me: I was nervous and worried I wouldn't be successful and wouldn't know how to answer the questions "What is this fundraiser for?" or "What is CMT?" Before I got involved with the CMTA, I struggled to answer. Once I got active, though, these questions began to seem exciting.

By the time I was diagnosed with CMT at 13, I was desperate for answers and often felt hopeless. That all changed after my parents talked me into going to Camp Footprint for the first time in 2017. There I conquered my fears, broke out of my shell and, for the first time in my life, felt like a "normal" kid. It was the best feeling in the entire world. The more involved I got with the CMTA, the more my passion grew. I saw what could happen by transform-



Erin Black (L) and Riley Williams (R)

ing something destructive into something that gave me purpose. Since then, Camp Footprint has become my heaven on earth. It's where I met my best friends, who also happen to be fighting this disease. I have become a member of the CMTA Youth Council, and I have shared about my CMT.

As a member of the CMTA Youth Council, one of my responsibilities is to fundraise. Each of us is tasked with raising \$1,000 annually. Hearing about this goal

initially took me back to the hopeless place I thought I had left years ago. The more I thought about it, though, the more it brought to mind the phrase, "Let it empower you." It's a simple phrase, but it embodies my entire battle with CMT. This disease is what you make of it: If you choose to let it take your joy, it

will, but it can also become your source of joy. It can become your purpose.

Shortly after this, I began thinking of ways to hit my fundraising goal. Some of my friends have created shirts to raise money for the CMTA, and I decided to do the same. I went online, wrote out my story and designed my shirts. Before I knew it, people were actually buying them. The support I received was overwhelming. Within a month, I had hit my fundraising goal and the number of new people who had learned about CMT truly gave me chills. My friends and family were soon wearing the shirt, which both raised awareness and told a story.

My fundraiser showed me how many people truly care and want to learn more about this disease. It showed me how much you can accomplish when you stop letting fear get in your way. The question that once seemed so daunting now gives me so much joy to answer. So now when you ask me, "What is CMT?" my answer is, "It is something that empowers me." ★

Riley, 17, is a rising senior in Baton Rouge, Louisiana.



Looking for a creative and fun way to support the CMTA? Why not use your time to move, dare or celebrate 4 CMT and raise critical dollars to help the CMTA's mission in finding a treatment for CMT. It's super easy—create a personal page with your OWN VIRTUAL CHALLENGE, and ask family and friends to support you and the CMTA!

Just OWN it....today, and every day!

cmtausa.org/ways-to-give/justownit



CMTA Branches

Most CMTA Branches can be accessed
online at www.cmtausa.org/branches

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Interested in starting a branch in your area?

Contact CMTA Director of Community Outreach
Laurel Richardson at laurel@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)
α-Interferon

Negligible or doubtful risk:

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



The Charcot-Marie-Tooth Association

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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's 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.