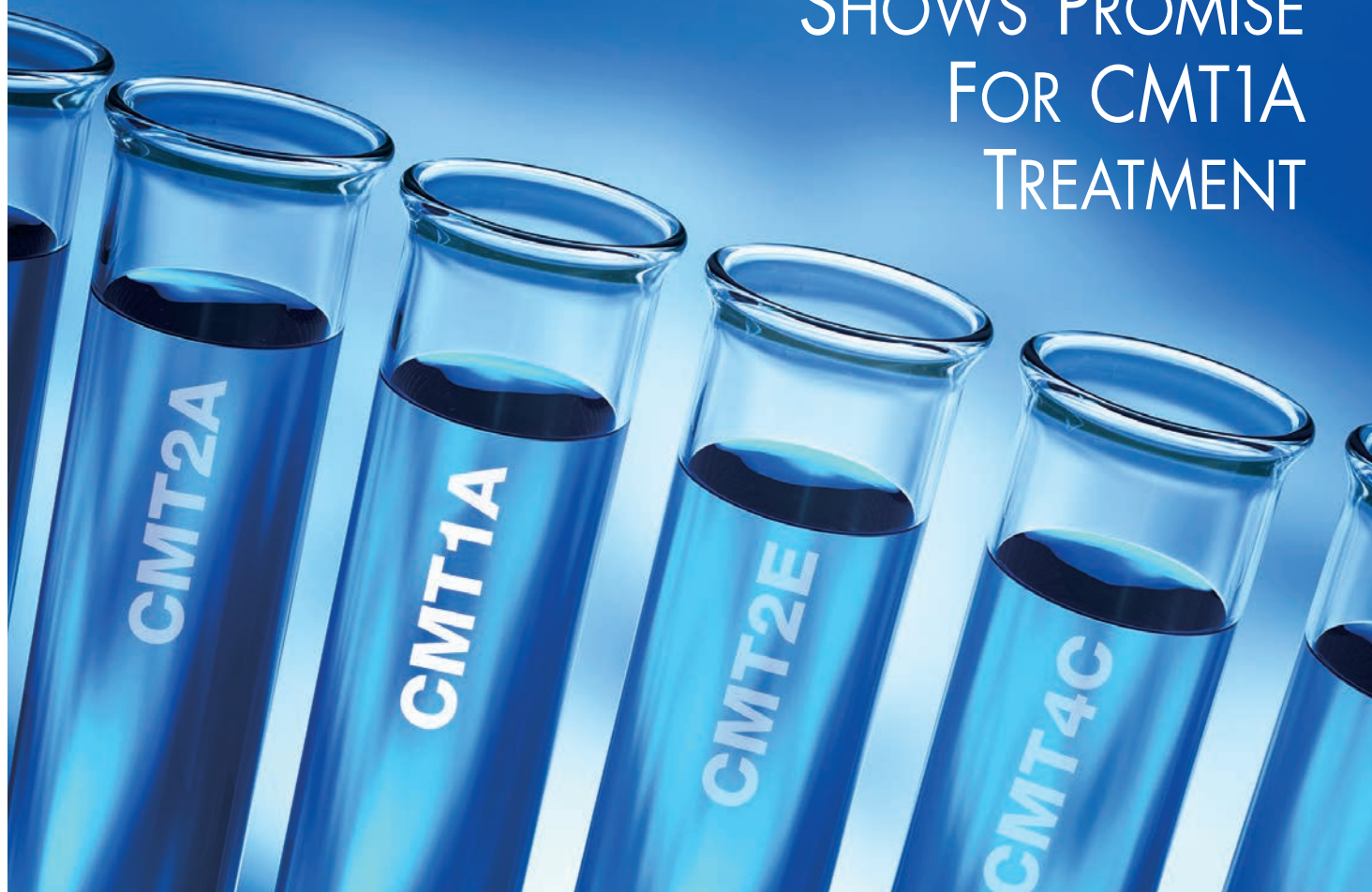


FALL 2017

THE CMTA Report

www.cmtausa.org

NEW RESEARCH
SHOWS PROMISE
FOR CMT1A
TREATMENT



6 > Camp Footprint
Makes an Impression

8 > Awareness Month
Nationwide

16 > Paratriathlete
Hits His Stride

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OUR MISSION: To support the development of drugs to treat CMT, to improve the quality of life for people with CMT and, ultimately, to find a cure.
OUR VISION: A World Without CMT.

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Campers find fun and friendship at CMTA's Camp Footprint
 See page 6

THE CMTA Report

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Email the CMTA at info@cmtausa.org

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A MESSAGE FROM CEO AMY GRAY & CHAIRMAN OF THE BOARD GILLES BOUCHARD

DEAR FRIENDS:

A breakthrough is defined as a sudden, dramatic and important discovery or development. In truth, breakthroughs are most often the result of relentless hard work and determination. That's what drove the CMTA's Strategy to Accelerate Research (STAR) to where it is today: on the precipice of delivering treatments for CMT, the progressive neuromuscular disease that affects more than 2.8 million people worldwide.

As you will read in more detail in this issue of *The CMTA Report*, thanks to CMTA-funded research, Ionis Pharmaceuticals has identified promising therapeutic approaches for CMT1A. Studies in two rodent models of CMT1A not only stopped progression of the disease, but also showed improvement of some symptoms.

It's a huge breakthrough—but we need more of them to get from drugs and therapies that work in animals to ones that work in people. We also need to develop additional potential drugs and therapies. To deliver the first treatments for CMT, we need funding for clinical trials and further drug development. And, while the 1A project is furthest along the path to drug delivery, projects addressing 90 percent of all cases of CMT, including types 1B, 1X, 2A, 2E and 4, are also delivering promising results using cutting-edge techniques like antisense oligonucleotides and gene therapies.

The CMTA has worked hard to accelerate breakthroughs in the past decade, committing \$8 million to bring together world-class academic and industry researchers, and using innovative and efficient research methods to prepare for drug delivery.

As detailed in this issue of *The CMTA Report*, the CMTA's drug discovery program is working exactly as planned, attracting new pharmaceutical partners



every year. But challenges remain. The safety and efficacy of these drugs must be validated. Key metrics must be developed to quickly demonstrate their efficacy in humans. Conducting clinical trials is expensive. That's why we're asking you to help the CMTA once more as we reach for our next breakthrough: translating the research and promising test results to a treatment that will slow, stop or even reverse the progression of CMT.

We're asking you to invest in Breakthroughs, which will target these final challenges. We don't have to tell you what a drug treatment for CMT will mean. You undoubtedly have your own living example—maybe a child who will fulfill her dream of becoming an Olympic gymnast or a grandfather who will be able to cast off his braces and walk on the beach with a grandchild who will never know the ravages of CMT. We simply ask you to think of that person as you consider your investment in Breakthroughs.

Sincerely,

Two handwritten signatures are shown. The one on the left is 'Amy Gray' in a cursive script. The one on the right is 'Gilles Bouchard' in a more stylized, bold cursive script.

AMY GRAY
Chief Executive Officer

GILLES BOUCHARD
Chairman of the Board

2.8

MILLION

STAR, the CMTA's research program,

is based on the concept that when the CMTA puts top researchers together with pharmaceutical partners that have relevant expertise and assets—and attracts donors willing to fund their research—scientific breakthroughs follow.

In the 10 years since the CMTA laid out STAR's parameters, the concept has proved successful time and time again. The CMTA now has more than half a dozen partnerships with pharmaceutical companies and has funded more than 70 projects.

What makes STAR unique is that it brings the world's top CMT researchers out of their silos to collaborate with each other, share results and discuss strategies. The CMTA holds those researchers accountable for achieving their stated goals—if they don't meet them, the funding goes elsewhere. STAR initially started with a focus on CMT1A, but it didn't end there. The CMTA has added projects over the years as the science and the funding for different subtypes has come together, always emphasizing the translational value of the work—how fast and effectively the research could be translated from basic medical research to treatments for CMT.

While the STAR Advisory Board (SAB) is responsible for setting the research agenda, the CMTA is a patient-led organization, and patients also have a voice. More than once, their ability to fund a project put it on the STAR agenda.

**CMT1A**

CMTA-funded researchers have identified promising drug candidates for CMT1A. One of them has not only stopped progression of the disease, but has also shown improvement of some symptoms. (*See article on page 12.*) The promise of symptom alleviation and the possibility of symptom reversal is real.

After creating the Strategy to Accelerate Research (STAR), the CMTA decided to focus its first efforts on CMT1A because researchers had already developed the basic building blocks needed. Animal models and cell lines—critical assets for drug development—already existed. The fact that CMT1A is the most prevalent form of CMT also played a role in the decision. With almost \$4 million committed to funding 1A research since 2008, STAR has:

- ★ Attracted strong alliances with pharmaceutical partners, including flagship partner Sanofi-Genzyme.
- ★ Launched partnerships that are in advanced stages of developing drugs to treat CMT1A. One treatment stops the progression of CMT1A in two models of the disease.
- ★ Collaborated with the National Institutes of Health (NIH) and pharmaceutical companies to develop the first drug-screening tests using CRISPR/Cas9 and genome editing.
- ★ Conducted the first large-scale drug screen for CMT1A at the NIH.
- ★ Conducted multiple screenings of drugs from the libraries of three different pharmaceutical partners. More than 2 million compounds have been screened.
- ★ Identified candidate biomarkers for CMT clinical trials, allowing potential new drug treatment results to be measured faster and with fewer patients.
- ★ Developed stem cell lines from CMT1A patients which will be used to validate promising compounds.

REASONS TO CARE

Be the **breakthrough** in their lives.

CMT2A

In 2010, the CMTA's scientific and medical experts turned their attention to CMT2A. Researchers and the Board of Directors approved a plan to grow CMT2A cell lines and animal models. With almost \$1.5 million in funding dedicated to 2A since 2011, STAR has:

- ★ Created two new rat models of CMT2A that are available for testing.
- ★ Created stem cell models of CMT2A that are being used to identify how MFN2 mutations cause neuropathy.
- ★ Created the first drug screen for CMT2A.

CMT1X

By 2013, the SAB had identified key researchers and projects for CMT1X. With more than \$130,000 in funding dedicated to 1X since 2013, STAR has:

- ★ Proved that drugs could be used to reduce inflammation that worsens CMT in a mouse with CMT1X.
- ★ Initiated a gene therapy approach to treat advanced symptoms of CMT1X.

CMT2E

Strong research, coupled with proper funding, launched an initiative to deliver treatments for CMT2E. With two key supporters, two key researchers and more than \$625,000 in funding dedicated to 2E, STAR has:

- ★ Supported the development of the best mouse model of CMT2E.
- ★ Developed both mouse and human stem cell models of CMT2E, which are being developed for drug screening.
- ★ Initiated the testing of compounds on nerve cells derived from the animal and patient models.

CMT4C

In 2014, the time was right to address the recessive types of CMT. The SAB mapped out a pathway to address CMT type 4C, and once key researchers were identified, work began in 2016. With early funding, STAR is exploring using the same gene therapy approach for 4C that was shown to be successful in CMT1X.

CMT1B ...

One Person Can Start a Movement

In 2013, a donor interested in the state of CMT1B research approached the CMTA. At the time, there was no coordinated effort to identify novel treatments for CMT1B. Knowing that this donor had the capacity to make a significant investment in STAR, the CMTA assembled its Advisory Board to map out a strategy for drug delivery for CMT1B. The donor generously donated \$500,000 of the \$1.5 million needed for the project, then another family learned about the strategy and donated \$500,000 to the initiative. The CMTA community met the first donor's challenge, raising the final \$500,000 needed for the research. Since 2013, STAR has:

- ★ Conducted an assessment of the range of mutations within 1B.
- ★ Identified many different mutations within 1B, developing a better understanding of the unfolded protein response (UPR) and how CMT1B works.
- ★ Developed a mouse model of CMT1B to represent the variations of CMT1B patients (early to late onset).

Our vision of a world without CMT is taking shape. With your financial help, the CMTA can continue to leverage the breakthroughs made by STAR, targeting the more than 90 genes known to cause CMT and systematically working to eliminate them. We look forward to the day when all CMTers can stand straight and tall, casting aside their braces, walkers and wheelchairs to move easily through life.

Please help us continue to deliver breakthroughs for all people living with CMT.

Superheroes Emerge at Camp Footprint

Campers find friendship, fun at summer camp for those living with CMT.

BY CHELSEA L. WALLING

At Camp Footprint, Kegan Steckel climbs the rock wall, which is just one of many activities campers are encouraged to try while at camp.

What is CMT?

I could give you a long medical description of exactly how nerves are destroyed and the muscles compromised. I could list the symptoms and the treatments associated with CMT. I could try to paint a picture of what it physically looks like to have CMT.

But that is not what CMT is, at least not to me, and not to the almost 100 individuals, campers and counselors alike, who participated in this year's CMTA Camp Footprint in Pennsylvania.

I was born with CMT. I never really needed a formal diagnosis because CMT is very prevalent through my family. Also, the signs and symptoms of CMT were very much present in me, even at a young age. So, I grew up with it but never really acknowledged it. Most of the members in my family have an awkward gait. We are skinny, clumsy and have the "Walling Walk." It is something we can't explain and that we silently carry with us. Although my family members have it, I had never met anyone else with CMT outside of my family. No one at my school had this not-always-obvious disorder. So, like most teenagers, I tried to ignore what made me unique so I could blend in with my peers.

More than 10 years later, I learned about Camp Footprint through the CMTA website. It happened by chance that I saw the camp being offered and the call for volunteers to be counselors. Without a moment's pause, I entered my information and became excited about something that I had given no thought or preparation to, something that I instinctively signed up for because I knew I just had to do it.

When I arrived at Camp Footprint, I was weighed down with anxiety—anxiety over being in a new place, anxiety over being

away from home (and my dog), and anxiety about meeting people—people who, if I understood the intentions of camp correctly, were going to be just like me. Whether that anxiety was just general anxiety or if it was over finally coming to terms with my disorder, I could not tell. But I could feel it in full force.

Counselors arrived before the campers so they could prepare to make camp the most fun as humanly possible for the kids. The anxiety was almost suffocating at first. I wanted to go home. I was mad at myself that I didn't even think about the stress this would cause me, but I took comfort and found power in my father's encouraging text. It said, "I am VERY proud of you for doing this."

The campers arrived and the anxiety that had been weighing so heavily on me quickly dissipated. The campers were from all over the world. Kids from Texas, Washington, Ohio, Kansas, Missouri, Florida, West Virginia—even the U.K. Some of these kids also had never met another person with CMT. Some grew up with CMT, while others were diagnosed only within the past year or two. Some wore braces while others wore scars of surgeries they had endured. The apprehension I could see on their faces replaced my own anxiety with

The CMTA's Camp Footprint is the only camp in the United States just for kids with CMT! It is a free, five-day sleepaway camp in Western Pennsylvania for kids ages 10–18.

Learn more at cmtacamp.org



empathy as I watched them all processing and predicting what the week would hold for them.

That week was possibly the best week of my life. To be honest, at first, I thought something was wrong with me, maybe something in the Pennsylvania air, because I was on the verge of tears the entire time—not from anxiety, not from sadness, and not from stress. The tears hovered because of the challenges I witnessed these kids overcome, the perseverance they demonstrated, the strengths they learned about themselves and the bonds they formed with other people who were made just like them.

The tears came from seeing kids who were usually bound by braces and wheelchairs soar through the air while zip lining, use every bit of their strength and coordination to climb walls, demonstrate their poise while riding horses and throw caution to the wind while giving their all at water volleyball. But most of all, to see them overcome what they had been told they could not physically do, to tear down the walls that have been put up to protect them

and to take risks and live their life on their own terms—to harness a power that clearly only a true superhero could.

We started as a community—64 campers and 32 counselors—but we ended as family. Fear was conquered, strength was found, memories were formed and bonds were created that will last a lifetime. Camp Footprint was a monumental milestone for all of us and has helped so many of us with CMT feel right at home. Because with CMT, what appears as a curse is actually a very beautiful blessing in disguise. It gives us the opportunity to appreciate what others might not see, to feel strength for things that seem minor and unimportant and to hold ourselves with a sense of pride and confidence that the weight we carry does not hold us back from being the amazing, unique individuals we are.

So, cheers to all my fellow superheroes from Camp Footprint 2017—and here's to doing it again in 2018! ★

Chelsea L. Walling, 28, is from Dayton, OH and has a MA in Forensic Psychology.



Camp Footprint allows campers, like Kristyn Finelli, to have a true outdoor experience with activities like fishing and horseback riding.



Counselors and campers form a unique bond at Camp Footprint. Here, counselor Hannah Roberts and camper Hannah Miles show their strength before tackling the climbing wall.

Camp Footprint is the first camp of its kind for children and teens with CMT. Here, Savannah Evan tries her hand at archery.



C E L E B R A T I N G A W A R E N E S S M O N T H

INAUGURAL WALK IN PITTSBURGH A SUCCESS

Pittsburgh's first ever Walk 4 CMT was held on Sunday, September 17 at Green Tree Park, in Pittsburgh, Pennsylvania. It was an absolutely amazing day in many ways, as well as a huge success!

Jeana Sweeney, CMTA Director of Community Engagement, was on hand to lend her support and helped kick things off with a few words about the STAR initiative, CMTA membership, CMTA research and what it is like living with CMT. Jeana's video can be seen on the CMTA's "The Time Is Now" Facebook page (www.facebook.com/CMTAsso ciation), under videos.

The walk began with a balloon release led by Rick Clemente and his family in honor and memory of his late wife, Cecilia—a Pittsburgh CMTA Branch friend and member.

As walker Flavia Naccarato was participating in the Pittsburgh Walk 4 CMT, her family in Rio De Janeiro had planned their own Walk 4 CMT to coincide with the Pittsburgh walk. They showed their support for the CMTA and raised awareness of CMT in Rio, thus beginning the Pittsburgh/Rio De Janeiro Walk 4 CMT Connection!

The weather was beautiful, and we had a great turnout of over 100 people. As well as raising awareness of CMT in the community, the walk has raised \$10,901 to date.



DALLAS WALK 4 CMT CELEBRATES 3RD YEAR

A big thank-you to everyone who came out for our third annual Dallas Walk 4 CMT on September 30. There was an amazing turnout—115 participants came out to raise awareness and funds for the CMTA. A special thanks to Adam Housley for being this year's DJ and to all of our wonderful volunteers. Thanks to everyone's efforts we were able to raise more than \$9,600! Team Molly won this year's team spirit award along with the Top Dog award—they raised more than \$3,000. Thanks again to everyone for participating, donating and providing awesome baskets for the raffle. The branch looks forward to seeing y'all next year!

THE CAPTAIN'S CALL FOR A CURE EXCEEDS GOAL

The Captain's Call for a Cure, held on September 30 at the Edison Club in Fort Myers, Florida, was a huge success. The nautical-themed event offered excellent food, camaraderie and a silent auction.

Jim and Maralisa Addis of

JAMA Food Services, Inc., hosted the event. Their fundraising goal was \$20,000. The pre-event call for donations set the stage for success. The goal this year was twofold—to raise research dollars and to educate people about CMT and how it affects them on a personal level.

Guests at the Captain's event enthusiastically participated in a silent auction with attendees winning treasures from trips to Paris, Italy



FORT MYERS

and Mexico to cabin vacations in Tennessee. The auction also included charter fishing trips on both the Atlantic and Gulf of Mexico, concert tickets, sporting equipment, golf and tennis outings and jewelry. One lucky winner of the Chocolate Chance went home with a \$500 gift certificate to Diamond District in Fort Myers.

All told, the Captain's Call raised more than \$22,500! Jim and Maralisa agree that this could not have been done without the outstanding CMTA support and guidance.

SPRINGFIELD, MISSOURI CMTA BRANCH HOLDS ITS FIRST WALK 4 CMT

The Springfield, Missouri CMTA Branch held its first ever CMTA Walk 4 CMT this year! There were more than 30 people at the walk, and everyone had a great time. The families enjoyed a kids' craft table where they painted rock and canvases for CMT, played ring toss and shopped at the amazing raffle table and kid's candy treasure box. Springfield branch leader, Jessica Brantner also held a CMTA Reach for the STARS campaign in honor of her son, Mike, who has CMT. Jessica held multiple campaigns, including at her son's school, two hair salons, a mechanic's shop, and his dad's workplace. She raised almost \$900 from just the STARS alone. Jessica says the branch was so honored to be a part of such a bigger plan. The branch will continue to do everything they can to help find the cure!

RIBBONS FOR A CAUSE HELD IN ZANESVILLE, OHIO

Red Rose Tattoo in Zanesville, Ohio held Ribbons for a Cause on September 24 to raise money and awareness for the CMTA.

Ribbon tattoos of any color were \$40, and all proceeds benefited the CMTA. Between



the four tattoo artists—Billy White, Jenn Siegfried, Mat Helton and Brian McCort—the shop made \$1,200 in donations. In addition to the fundraiser, Jerzei Blackketter and Owen White, the children of Billy White, sold CMTA bracelets and handed out brochures at school to educate classmates about CMT. The fundraiser was a huge success in educating the city about CMT. Everyone looks forward to holding an even larger event for awareness month next September!

NASHVILLE, TENNESSEE WALK 4 CMT CONTINUES TO GROW

The third annual Nashville Walk 4 CMT on September 16 was the best walk the branch has had so far. The weather was absolutely beautiful! Not only did the number of teams grow from two to six, but there were also more people walking for CMT. Many new people came to the walk who did not know about the Tennessee branch. There was a special appearance from CMTA's National Manager of Branch and Community Relations, Michelle Hayes, which made the day even more special. The group came very close to the fundraising goal of \$10,000. There are still several donations to come



PITTSBURGH, PA

2017

in, which will get us closer our goal. The group is excited for next year, and they hope you will join them!

PORTLAND, MAINE HOSTS A TRIPLE HEADER OF AWARENESS EVENTS

This year, the Portland, Maine Branch had a Charcot-Marie-Tooth triple header to celebrate awareness month. Jeana Sweeney from the CMTA joined the group for the beautiful fall weather in Maine and the perfect lobster roll.

Gail Fitzmaurice, CO, from Maine Orthotic & Prosthetic in Portland as the speaker. Gail has more than 20 years of experience fitting people with braces and gave an interactive and informative presentation.

ONTARIO, CANADA WALK 4 CMT RAISES \$8,500

The seventh annual Walk 4 CMT in Fergus, Ontario was a huge success. There were 75 participants out on this scorching hot day, and a total of \$8,500 was raised!



ONTARIO, CANADA



PORTLAND, ME

The branch kicked the triple header off on Sunday September 10, with the fifth annual Peaks Island Walk 4 CMT. The beautiful Inn on Peaks hosted again this year, and the walk was a huge success—126 walkers joined us on a picturesque walk around Peaks Island. With everyone's hard work and dedication, the walk raised more than \$6,000 for the CMTA.

On Monday September 11, the first Charcot-Marie-Tooth branch meeting was held in Bangor, Maine. Jeana Sweeney and Mary Louie spoke about what the CMTA is doing in Maine as well as nationally. The meeting was attended by 11 very enthusiastic people, and the group hopes to get back to northern Maine soon.

The final event of the triple header was on Tuesday, September 12. The Portland, Maine Branch held its awareness month meeting and had



CINCINNATI, OH

CINCINNATI, OHIO WALK GROWS IN ITS 2ND YEAR

The second annual Walk 4 CMT was held in Cincinnati on Saturday, September 9 at Parky's Farm in Winton Woods. This year, there were 82 online registrants, a few more than last year's 27! Another 25 people signed up to walk that morning, so there were many new faces!

There was a raffle of 25 items that had been donated by local retailers. The raffle

alone collected more than \$500. The combined fundraising total topped out at a little more than \$10,000—wow! The branch members are amazed at the continued support from Cincinnati friends and families.

This shows that the Cincinnati, OH CMTA Branch has been growing. Watch our Facebook page (www.facebook.com/groups/1033282786746275/) for details about next year's Walk 4 CMT.

WINE AND CHOCOLATES EVENT OFFERS A SWEET NIGHT OUT FOR CMTA

No whining here! A good time was had by all at Elevation Cellars in Woodinville, Washington on September 29. Friends, family, and many other folks dropped by the winery, where they learned more about CMT. There was a fabulous turnout with unbelievably generous donations for the

(continued on page 10)



RUSS MITCHELL TAKES THE MIC FOR CMT

Each week, listeners around the country hear College Football News columnist Russ Mitchell as a guest on more than two dozen regional and local radio stations, as well as national outlets like ESPN, CBS and FOX. While he's usually talking about touchdowns and great plays, this past September Russ took on a more serious topic: CMT. Just this past year, Russ and several of his family members were diagnosed with CMT, including his young daughter Claire.

Before his diagnosis, Russ, like many others, had never heard of the disease. For CMT Awareness Month, he aimed to change that by using his platform as a sportscaster to spread the word. Throughout September, Russ shared messages about CMT on more than 20 state, regional and national radio shows each week. He talked about the signs and symptoms of CMT, as well as how to advocate for yourself or a family member who has CMT. These messages reached more than 1 million people weekly.

"Because I didn't know about CMT or its symptoms, I was well into adulthood before I was diagnosed. As a result, there is damage that might have been reduced or postponed had I known earlier," Russ explains. "Like many, mine is a 'grit your teeth and ignore it' family. But for my daughter, Claire, and her generation, I'll continue to share the message of early diagnosis and support for research. We're so close to some amazing treatments that will help my daughter and her generation fight—and beat—this debilitating disease."

CELEBRATING AWARENESS MONTH (CONTINUED)

CMTA. The group looks forward to celebrating at the same time next year! Cheers!

SOUTHERN CONNECTICUT BRANCH CYCLES, RUNS AND WALKS 4 CMT

The Southern Connecticut branch had nearly 40 participants for their third Cycle/Walk/Run 4 CMT on Sunday, September 10. Branch members, their families and friends, as well as some newcomers, enjoyed a beautiful sunny morning on Hamden's Farmington Linear Canal trail. So far, donations totaling \$8,304 have been raised from the event for STAR.

SOUTHEAST WISCONSIN WALK 4 CMT RAISES \$11.5K

Eighty people walked the Pettit National Ice Center indoor oval on July 29. The group walked, shared awareness and had loads of fun meeting friends, families and Southeast Wisconsin branch members, old and new. Together, the group raised over \$11,500 for CMTA STAR research. The volunteers were amazing, the baskets were awesome and the generous giving was overwhelming.

CHESTER COUNTY, PENNSYLVANIA WALK 4 CMT OFFERS SUPPORT, ENTHUSIASM

The third annual Chester County Walk for CMT was a huge success! It was a beautiful day on October 1, and more than 50 participants enjoyed a walk through West Goshen Community Park, meeting others with CMT, and

playing a game called "What do you know about CMT?" The supportive and energizing atmosphere at the event was inspiring, and everyone is already planning for next year's event!

BUCKS COUNTY BRANCH BUFFET DINNER AND BASKET RAFFLE RAISES FUNDS, AWARENESS

On September 23, the Bucks County branch of the CMTA held its fifth annual Buffet Dinner and Basket Raffle to promote CMT Awareness Month and to raise funds for research to find treatments and



BUCKS COUNTY, PA

a cure for CMT! There were 47 guests at the dinner, which was held at The Buck Hotel in Feasterville, Pennsylvania. The group enjoyed listening to jazz standards by a live musician, Giacomo DeAnnuntis, who played his soprano saxophone during dinner and dessert. There were goodie bags for the children who attended and tables of gift baskets, overflowing with specialty items and gift certificates, which were raffled off at the end of the night! Once again, Tara Cave, co-leader of the Bucks County branch, showed off her talent in designing creative and enticing gift baskets.

The evening was filled with lively conversation over a delicious meal. Julie Schell, co-leader of the branch, welcomed the guests and gave a short presentation about CMT and shared some of the exciting things happening in the research realm, as well as the tremendous success of Camp Footprint. Between dinner ticket sales, generous donations and raffles, this event raised \$1,450 in a single night. Thanks to everyone who donated and attended the dinner. The branch looks forward to continuing the tradition next year!

BOSTON WALK 4 CMT RAISES AWARENESS

Forty people attended the Boston Walk 4 CMT on September 24 to help raise awareness for CMT. A woman sitting in the park with her husband noticed the entourage of orange Walk 4 CMT shirts and caught up to the group to share that her 50-year-old son has CMT. She never knew there were so many others with CMT. The group explained how CMTA helps people living with CMT, as well as the ongoing research taking place and the support available from the many branches across the country. Everyone was happy to answer her questions.

Special thanks to Kelly Yurka, Acceleron Pharma and Craig and Heidi Zeltsar for campaigning and raising \$4,420 of our grand total.

Thanks to all for showing up, supporting the WALK 4 CMT and for being a part of the Boston CMTA Branch! The Boston branch is making a difference!

CHICAGO, ILLINOIS WALK 4 CMT HOSTS LARGEST CROWD YET

Around 150 people gathered on October 7—a beautiful Chicago fall day—to raise awareness and funds for the CMTA. This was the largest crowd yet to gather for this walk. The group walked a mile along a gorgeous path full of fall colors and wildlife at the Wolfe Wildlife Refuge. After the walk, participants gathered under the pavilion for food, drinks and an

amazing raffle with more than 20 baskets! Special thanks go to Erin Sheldon and her family for making more than 11 of the baskets. The walk committee did an outstanding job gathering baskets and goodies for the day. Thanks to all who participated, donated and volunteered. This year's walk was a huge success because of each and every participant and volunteer. The event raised more than \$13,000 with more donations coming in!



SAM HOUSTON STATE UNIVERSITY HOSTS SECOND CMT AWARENESS NIGHT

On September 28, Sam Houston State University hosted its second CMT Awareness Night during the women's volleyball team's home game against the University of New Orleans Privateers. The event was organized by CMTA National Manager of Branch and Community Relations Michelle Hayes, Houston CMTA branch member Devon Gray and Sam Houston women's volleyball coach Brenda Gray.

CMTA STARs were sold for \$10 apiece, or \$100 for a corporate STAR, with all proceeds going toward CMT2A research. Donors wrote their names on the cardboard STARs with encouraging words for eight-year-old old Boston Gray, who was diagnosed with CMT2A in 2015. Devon and her amazing family sold STARs all across town to local businesses, family and friends. The event was advertised on the radio, in local newspapers and on Facebook. Devon's sister, Taylor Gray, sold tickets for the game all across town, and Sam Houston State University generously donated \$3.00 from every ticket sold to the CMTA!

On the day of the event, Michelle, Devon and many volunteers were hard at work adorning the coliseum with the blue and orange CMTA STARs and CMTA balloons. The Sam Houston volleyball players warmed up in CMTA t-shirts. At halftime, a special CMT awareness video made by the volleyball players was played on the coliseum's big screen. Boston's dad, Tim Gray, and Michelle spoke to the crowd. The response amazing and the event raised nearly \$20,000 for CMT research.

The CMTA and everyone living with CMT wish to give a big Texas thank-you to Devon Gray, Brenda Gray, the entire Gray family, Sam Houston State University and the city of Huntsville, Texas! Go Bearcats!

CHESTER COUNTY, PA



THANKS TO ALL FEDERAL EMPLOYEES!

It's time once again for the CMTA to express its gratitude to all federal employees who contributed to the CMTA through the Combined Federal Campaign in 2017. These contributions have helped the CMTA to meet its mission of improving the quality of life for those with CMT by providing community members with resources and information, increasing awareness about CMT and funding research for the development of treatments for all types of CMT. Our progress includes:



- Creating more than 70 Branches throughout North America, providing local resources for those with CMT.
- Building our social media presence and interacting with more than 25,000 people through Facebook, Twitter, LinkedIn and Pinterest.
- Spreading the word about CMT to physicians and clinicians through trade magazines and partnerships.
- Gathering a robust STAR Advisory Board, identifying experts in the industry, and forging partnerships to develop protocols and pathways for 90 percent of all types of CMT—1A, 1B, 2A, 2E, X and 4.

Your generosity has helped us achieve these major milestones.

In the coming weeks, the CFC will open for the 2018 giving year, and the CMTA is once again approved as a national charity. The CMTA has earned a three-star rating from Charity Navigator and has consistently been awarded the Independent Charities Seal of Excellence. Our CFC number is 10597. We ask that you please give generously once again. Thank you!



Leave a Lasting Legacy & Maximize Your Philanthropic Goals

Make a difference in people's lives and always be remembered for your contribution. Benefit yourself, your family and the Charcot-Marie-Tooth Association with your planned gift. Help us fulfill our mission for many years and generations to come.

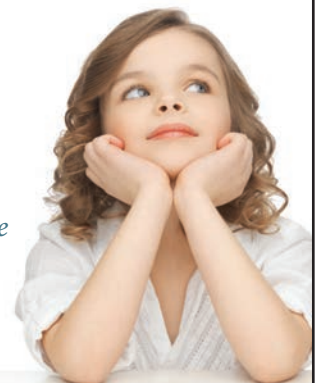
One of the easiest and most meaningful ways to leave a lasting legacy is by making a bequest to the CMTA.

With the help of an advisor, you can include language in your will or trust specifying a gift be made to family, friends or the CMTA as part of your estate plan.

What are your options?

1. You can gift a specific dollar amount or asset.
2. You can gift a percentage of your estate.
3. You can gift from the balance or residue of your estate.
4. You can make a beneficiary designation of certain assets.

*With Your Kindness,
the Promise of a Brighter Future
for So Many is Close at Hand*



To learn more or have a confidential conversation about making a bequest, please call Susan Ruediger, Director of Development, at 800.606.2682 x108.

PIONEERING RESEARCH SHOWS PROMISE FOR CMT1A TREATMENT

A new paper published online in the *Journal of Clinical Investigation* in December revealed an exciting potential treatment for Charcot-Marie-Tooth (CMT), the progressive neuromuscular disease that affects more than 2.8 million people worldwide.

Scientists at Ionis Pharmaceuticals, in collaboration with the Charcot-Marie-Tooth Association (CMTA), have identified a promising early-stage therapeutic approach with antisense technology for CMT1A, the most common form of the disease, accounting for half of all cases of CMT. Because there is currently no treatment or cure for CMT, this CMT1A research is a significant and hopeful breakthrough for medical researchers, healthcare professionals, patients and families.

CMT1A is caused by the duplication of the Peripheral Myelin Protein 22 gene (*PMP22*) which affects the myelin sheath of the nerves, causing neuropathy and muscle atrophy. Reducing the

level of *PMP22* has long been considered the most promising treatment approach for CMT1A. For the study, Ionis researchers used their expertise as a world leader in developing antisense oligonucleotides, which precisely target the genes that cause diseases. The antisense drugs they developed reduced the amount of the *PMP22* gene product (*PMP22* messenger RNA). The researchers then tested the most potent antisense compounds in two different animal models of CMT1A. In both models, weekly injections of the *PMP22*-targeting antisense drug inhibited the progression of neuropathy, and they even improved some aspects of neuropathy during the treatment.

“Our researchers have successfully developed antisense drugs for other neurologic diseases, such as spinal muscular atrophy and TTR polyneuropathy,” says C. Frank

Bennett, PhD, senior vice president of research and leader of the neurological disease franchise at Ionis. “The results we have seen thus far for CMT1A are very promising, but more work is needed to determine if these studies in rodents can be translated to a therapy for CMT1A patients. Our scientists are working diligently with the CMTA and academic collaborators to translate these exciting preclinical studies to the identification of a potential drug.”

Motivated by the exciting findings, Ionis has been optimizing antisense drugs against human *PMP22* to identify those that have the most promise for future clinical trials in people with CMT1A.

“We are committed to delivering therapies for a disease that, until today, has had no hope of a viable treatment option,” says Amy Gray, CEO of the Charcot-Marie-Tooth Association. “Thanks to our donors and our partnership with Ionis, we have made an important stride in advancing a potential drug toward the clinic for patients living with CMT1A. We hope to see a future where the CMT community will be able to walk, run, dance and enjoy life to the fullest.”

CMT1A research is part of CMTA’s Strategy to Accelerate Research (STAR) program that puts top researchers together with pharmaceutical partners—and donors willing to fund their research—so that scientific breakthroughs are possible. ★



For more information on the research paper, please go to www.cmtausa.org

be the breakthrough in their lives

Thanks to your support, Charcot-Marie-Tooth Association's STAR research program is where it is today – on the verge of delivering treatments for CMT, the progressive neuromuscular disease that affects more than 2.8 million people worldwide.

BUT OUR WORK IS FAR FROM DONE.

In the next three years, the CMTA will need \$10 million in funding from people like you to maintain the quickened pace of its research. With these funds, the CMTA will be able to:

- Conduct clinical trials on drugs already identified to treat CMT, poisoning them for Food and Drug Administration approval.
- Continue the search for other treatments for 1A, 1B, 2A, 2E, 1X, 4C, and other types of CMT.
- Continue to pursue every promising avenue toward a cure until we reach our goal of ending CMT.

More than most people, you know what a drug treatment for CMT will mean. You undoubtedly have your own living example. Give today, because there are 2.8 million reasons to end CMT.

ALL DONATIONS DESIGNATED FOR CMT1A BETWEEN NOW AND DECEMBER 31, 2017, WILL BE MATCHED DOLLAR FOR DOLLAR!



Your gift is welcomed and appreciated and is tax-deductible as allowed by law.

Please donate online at www.cmtausa.org/breakthroughs or complete the form below and mail to:

CHARCOT- MARIE-TOOTH ASSOCIATION
PO Box 105 • Glenolden, PA 19036

Yes, the CMTA can count on my contribution to be the breakthrough in their lives and accelerate research for a treatment for CMT!

- \$75 \$150 \$300 Other: \$ _____
- I would like my gift designated to CMT1A research and doubled!
- I am interested in learning about leaving a legacy gift to the CMTA.
- Check enclosed, payable to the Charcot-Marie-Tooth Association, or
- Please charge my: Visa MasterCard American Express

Name _____

Card # _____ Exp. Date _____

Signature _____

Address _____

City _____ State _____ Zip _____

Phone _____



CMTA Branches

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

ALASKA

Anchorage Area
Megan Rodgers
907-244-2100

ARKANSAS

Little Rock
Lisa Jones
501-776-5364
Candice Cargile
501-516-5588

ARIZONA

Phoenix Area
Pamela Palmer
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480-236-2445
Christina Fisher
623-742-8921

CALIFORNIA

Los Angeles Area
Alani Price
310-710-2376
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Sacramento
Holly Stevens
408-203-8804
Rashid Thomas
916-947-5377
Ernie Hinds
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San Diego Area
Annette Van Veen
760-473-5014
Kendall Trout
760-632-5654
South Bay Area
Ori Bash
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Tau O'Sullivan
916-806-2173

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Denver Area
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CONNECTICUT

Hartford
Roy Behlke
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North Haven
Lynne Krupa
203-288-6673

DISTRICT OF COLUMBIA

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Kimberly Hughes
301-962-8885

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Tampa Bay Area
Vicki Pollyea
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Edward Linde
813-712-4101
West Palm Beach
Phil Lewis
561-307-0100
Eileen Martinez
561-901-5566

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Atlanta Area
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678-595-2817

HAWAII

Honolulu Area
Bobbie Gomez
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James Cuizon
808-450-1236

IOWA

Iowa City Area
Jeffrey Megown
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ILLINOIS

Chicago Area
Jay Pate
630-888-4673

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Fort Wayne Area
Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488
Indianapolis Area
Nancy Allen
317-459-8773
Patricia Wood
317-345-2254

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Kansas City Area
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Aron Taylor
913-744-5674
Wichita Area
Karen Smith
316-200-0453

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Jill Ricci
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Easton
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410-350-4812

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Jessica Hardy
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Rick Nelson
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Cleveland Area
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Columbus Area
Jessica Diamond
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Debbie Mchugh
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503-310-7229 (M)

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Nashville Area
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Teresa Shoaf
615-772-8810

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Harrisonburg Area
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Suffolk Area
Jordan Harness
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WISCONSIN

Madison Area
Debi Weber
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Milwaukee Area
Susan Moore
414-604-8736
Frank Gess
414-475-1515

CANADA

Southern Ontario
Kelly Hall
519-843-6119
Toronto Area
Linda Scott Barber
416-997-5084

Interested in starting a branch
in your area?

Contact CMTA Director of Community Engagement
Jeana Sweeney at Jeana@cmtausa.org.

BRANCH LEADER SPOTLIGHT: MISSY WARFIELD, EASTON, MD

For some, retirement is a time to take a break, relax and consider their work done. But, not Missy Warfield. As the leader of the Easton, Maryland branch of the CMTA, Missy saw work to do.

Now 73, Missy was diagnosed with CMT as a young teenager. Missy and her husband, Seth, have a son, Peter, and a daughter, Heather—both diagnosed with CMT. Of their six grandchildren, two are known to have CMT as well.

“When our grandchildren were diagnosed, we knew it was time to do something,” Missy says.

And do something, they did.

Missy, a career writer and editor, got involved when they heard about CMTI in Canada. As the CMTA emerged and became stronger, the Warfields ramped up their involvement. Missy leveraged her experience in public relations and event planning to help raise much-needed funds for CMTA. Missy also launched a letter-writing campaign to friends, family and colleagues, in which she included CMTA publications to help spread the awareness of this rare disease.

“We wanted to raise awareness of CMT because no one seemed to know about the disease,” Missy says. “We started with a big fundraiser with a matching grant that raised \$375,000.”

Their involvement took another huge leap when they started a CMTA branch in Easton, on Maryland’s Eastern Shore, where they retired after living in Washington, D.C. for most of their lives.

“Supposedly, there are 250 people with CMT within 50 miles of Easton,” Missy says. “We

wanted to reach them all because we know it helps to know you’re not alone.”

Since then, the Easton branch has met quarterly on Saturdays from 10 a.m. to noon at the Talbot County Free Library. Missy planned a program for each meeting that often included a speaker knowledgeable about CMT, time for the attendees to share personal stories and tips and tools for living with CMT.

“We typically have had 15 to 25 people at each meeting, and I heard from many more on the phone,” Missy explains. “People have come from throughout the Eastern Shore, Delaware and Baltimore. This just indicates that

“When our grandchildren were diagnosed, we knew it was time to do something.”

people are eager to connect with others who have CMT. Nobody else knows or understands what it’s like to live with CMT.”

While educating others about CMT has long been a passion for Missy, she is clear that she has benefited from her involvement with the CMTA, too.

“I have learned an awful lot about CMT over the years,” Missy says. “And the friendships made and encouragement we have given one another has been a real gift.”

Missy was recently recognized by the local county council for spreading news of CMT in her community and for her work in starting the CMTA branch.

“It was very humbling experience because I did what anyone would do when you have passion for a cause,” Missy says. “Knowing



other people were in the same boat with nowhere to turn, I decided to take it upon myself.” And none of this could have been done over the past six years without Seth at her side—“Team Warfield”!

Even though the quieter life of sailing and retirement calls more often, Missy and Seth have some pretty powerful reasons for continuing their involvement with CMTA.

“First, CMTA formed a consortium of scientists and convinced them that by working together, it will benefit everybody,” Missy says.

“We’re closer to a cure, and what Seth and I want is for our grandchildren to benefit before CMT permanently weakens their arms, legs, hands and feet. Our hope is for our grandchildren to not have the falls I have had or the surgeries. I’d be a guinea pig for anything to make it better for them. That’s just a mother’s and a grandmother’s love.”

Jeana Sweeney, the CMTA Director of Community Engagement, says Missy has been an inspiration.

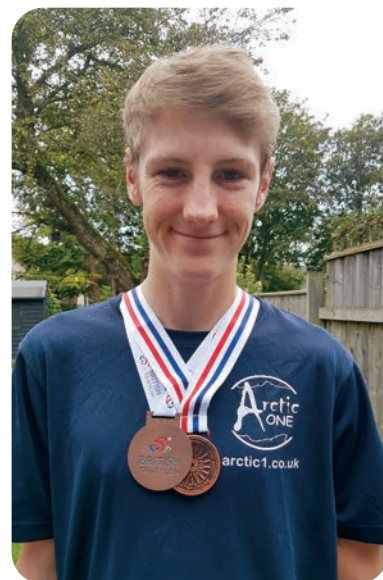
“We deeply appreciate Missy’s hard work and spirit, which brought people together to learn more about a disease that affects three million people worldwide, including three generations of her own family,” Jeana says. “But CMT never stopped Missy, and it never will.” ★

Editor’s Note: Missy and Seth have just stepped aside and turned the leadership of the Easton CMTA Branch over to Clark Semmes, who also leads the Baltimore CMTA Branch.

CELEBRATING CMTAthletes

Paratriathlete & Cyclist Charlie Stanton-Stock: The Road to Toyko in 2020 & Beyond

Editor's Note: Paratriathlon—which combines swimming, cycling and running—made its debut at the Paralympic Games in Rio de Janeiro this summer. The next Paralympic Games are in Tokyo in 2020.



I was diagnosed with CMT in May 2014, when I was 13. I had always been active playing rugby and cricket, running and riding horses, but after my diagnosis, I decided to give up rugby because I just couldn't keep up. To keep fit and strong, I decided to try a triathlon. I found

a children's paratriathlon event to try in September 2014. It went well, and I met some of our paratriathletes from Great Britain. Inspired, I began training with my local tri club.

At the start of 2015, I planned my first youth triathlon. I realized I would have to compete against

able-bodied athletes as para events are few and far between. I planned my first youth triathlon at my club (WaldenJNR). I also decided to fundraise for CMT UK. I had a really good first triathlon. Everyone was so supportive that I decided to continue with my fundraising for the rest of the



Though Charlie Stanton-Stock had to give up playing rugby, he has since found new favorite activity with the paratriathlon.

season. By September 2015, I had completed my first open-water tri, completed two triathlons in a weekend and completed two triathlons in a day. My last event of the season was my first sea-swim triathlon (in a very choppy grey sea)! In 2014/15, I raised almost £3,000 (\$4,300) for CMT UK.

In October 2015, I was invited to attend a para-talent weekend with British Triathlon, I am now classified as a PT5, the classification for ambulant athletes with a lower level of physical impairment. British Triathlon then asked me to train with one of their triathlon academies. I now train once a month elite academy and other paras in my region. I also received my wonderful personalized GB Tri-Suit, which I am so proud to wear.

My mum had been posting my progress on CMTAthletes on Facebook and came across James Cuizon. James was running marathons and Ironman competitions, which are long-distance triathlons. James really

liked his Turbomed braces for running, so in November I fundraised via a Go Fund Me campaign to buy the same kind. They have been amazing! They have aided my deteriorating foot drop, stopped me from falling and really helped my running. James followed my triathlon progress and suggested I apply for Challenged Athletes Foundation (CAF) grant. I filled in the forms and told them my story. I was truly speechless when I received a grant for \$1,000 from CAF! Someone having the faith to invest this much money in me truly amazed me!

This year while at tri camp, I realized that I am really enjoying my cycling, so I decided to have a go at some cycling events in addition to triathlon and duathlon (run, bike, run). I was classified as an MC3 and went on to compete in the Para National Circuit and Time Trial series—I won it! I also attended the Para Cycling National Champs where I also gained a medal for my third place finish. Also this year, I came in third in the National Para Duathlon Champs, so that's two big medals for me this year. They were well worth the effort!

What motivates me? Well, lots of things. The people, for one. I receive so much amazing support within my



The events Charlie competes in include running, biking and swimming.

local club, town and even the other competitors. I'm also motivated by the fact that I really am getting stronger. After my diagnosis, I could stand on one leg for six seconds. A month ago, I managed the same exercise for 48 seconds. Although I won't ever walk a tightrope, falling less and keeping stronger for longer is my ultimate goal—as well as winning an Olympic medal, which would look good in my trophy cabinet! My immediate plan is to work on my track cycling, still all a bit new to me but I have been told that I can compete in the Manchester Paracycling International on November 24, which is a bit scary, but it will be sooo much fun!! ★

Charlie, age 16, lives in Saffron Walden (near Cambridge), UK, and he is the only one in his family with CMT.

IF YOU'D LIKE TO SPONSOR CHARLIE,
all the money goes towards CMT research.
You can make donations at
www.cmtausa.org/donate/charlie-stantonstock/.



Vermont's 4th Annual Cycle (And Walk!) 4 CMT Raises \$215,000

BY ELIZABETH OUELLETTE

The Cycle (And Walk!) 4 CMT event took place on Sunday, August 27 in Charlotte, Vermont at the Old Lantern Inn and Barn. We have some great news—we met and surpassed all expectations by bringing in more than \$215,000 for CMT research! This year, we had 150 attendees, 400-plus donors and 60 dedicated event sponsors! Funds raised will be directed toward CMT research, including upcoming clinical trials. We are in awe of our supporters!

Organizer and CMTA board member Chris Ouellette is determined to make a tangible difference in the life of his nephew Yohan Bouchard and all those with CMT. With little to no fundraising experience and touched by his nephew Yohan's courage and positive attitude, Chris launched the Cycle 4 CMT four years ago in the summer of 2013. Over the past four years, the Ouellette/Bouchard family, along with the generous support of family, friends and



CMT community members, have raised a total of \$640,000!

After one full year on crutches, unable to bear weight on his left foot, Yohan's goal was to walk a mile—a decidedly challenging feat. Calling in from Claremont, California, where Yohan is attending graduate school, he publically announced his success of his one-mile walk and bestowed the title of "Best Uncle Ever" onto to Chris with an honorary t-shirt. We used a lot of

Kleenex that day to dab the tears shed from such an emotional display of love and compassion.

"Due to multiple foot surgeries, this past year has been extremely difficult, but your unwavering encouragement and friendship have truly helped me to keep my spirits up—the idea of giving up was never, ever an option," Yohan writes in a letter of thank you to generous donors. "I am eternally grateful for your generous gifts and steadfast belief in my capacities."

This event has brought not only the local community, families and friends together to fight for a common goal, but it has also forged long-lasting relationships, especially between an uncle and his nephew. We all feel fortunate to have the genuine support and caring of so many individuals.

The fifth annual Cycle (and Walk!) 4 CMT is scheduled for Sunday, August 26, 2018. We'd love to have you join us. It truly will be an unforgettable day!

www.cycle4cmt.com ★

FIFTH ANNUAL FUNDING THE FIGHT TO END CMT

On July 22, my family and I hosted our fifth annual CMTA Fundraiser in Gloucester, Massachusetts. We had 135 friends, family and Boston CMTA Branch members join us to raise \$30,000 for CMT research. We also had the help and support of CMTA Ambassador Maddie Jarrett, who my 10-year-old cousin Ella became immediate best friends with for the night. Each year, we say this may be the last BBQ, but then something happens in the winter months—like my sister Emma painting a shark—and my family decides we have to use it at our next fundraiser. There may be a few hiccups along the way, like no air conditioning in the car, cupcakes melting or my mom stealing my dad's new coffeemaker to use as an auction item, but in the end, it works. There is always something new to share. To quote our thank you cards, "Doing Nothing Is Not an Option." So ... we'll see you next year! —Vittorio Ricci

THE CMTA GRATEFULLY ACKNOWLEDGES GIFTS...

IN MEMORY OF:

DOROTHY AKIN

Mr. and Mrs. Les Henry
Mrs. Theresa Vann

DIANA BEHLKE

Mr. Daniel Ambruso
Mr. and Mrs. James Balcome
Mr. and Mrs. Dave Behlke
Mr. and Mrs. Don Behlke
Mr. Roy Behlke
Mr. and Mrs. Richard Claar
Ms. Suzanne Donais
Mr. and Mrs. Lenny Lavalette
Mr. Edward Linde
Mr. and Mrs. David Lyons
Ms. Marsha Memery
Mr. and Mrs. Vic Vincze
Mr. Robert White

WILLIAM CLEMENT

Mr. and Mrs. Robert
Williams, Jr.

CECILIA CLEMENTE

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WANDA LOVELACE

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DOROTHY MULHALL

Mr. Bradley Bell
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Ms. Eva Demirjian
Ms. Mary Jane Dorr
Mr. Robert Melaragno
Ms. Linda Serra
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MIKE ROSS

Ms. Tricia Ross

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Mr. and Mrs. Jimmy Mayo
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Mr. and Mrs. Mack Mayo
Mr. and Mrs. Whit Mayo
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Mr. Leonard Lozoskie and
Family
Mr. Alex Mansell
Mr. and Mrs. Tom Mansell
and Family
Mr. and Mrs. Ted Marchetti

ROBERT WOOLAVER

Mr. Peter Santucci

BARBARA ANN YOUNG

Ms. Sherry Deckert
Ms. Ruthelyn Hinners
Ms. Gail Rock

IN HONOR OF:

MELVIN BERRY—

Happy 93rd Birthday!
Ms. Rachel Berry

ANDREW BREWER

Ms. Amy K. Morvay

EARL BROOKS

Mr. and Mrs. William Kriner

BARBARA AND GREG BROWN

Mr. Carl Rathmann

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Ms. Megan Fogg

BERNICE KESSLER

Ms. Rita Lidsky

ALAN AND RUTH KOROWITZ

Mrs. Carole Korowitz

ZACHARY KOROWITZ

Mrs. Carole Korowitz
Ms. Elayne Korowitz

WITH HEAVY HEARTS, we announce the passing of Katerina Marks, a beloved volunteer and member of our CMTA family. Many of you knew Katerina, who was an avid volunteer for the CMTA and an advocate for everyone with CMT. Katerina was the leader of the Atlanta, Georgia CMTA Branch, and the organizer of the Atlanta Walk 4 CMT. Her contributions were numerous and we are eternally grateful for her.

Katerina, we will miss your joy, your smile and your passion. You've been a blessing to all of us at the CMTA.



BETH LABONTE

Ms. Chevelle Bazo

ILANA LEVENBERG

Dr. and Mrs. David Dudovitz

DR. MARTIN MARKOWITZ— HAPPY BIRTHDAY!

Mr. and Mrs. Thomas Mann
Mr. and Mrs. Stan Rubin

STACI MAUGHON

Meadowcrest Homemakers
Club

DOROTHY GRACE GEMMA-MULHALL

Ms. Stephanie Sloane

NATASHA AND ROSS NADER—To the beginning of your long and happy marriage!

Ms. Pamela Gray

GEORGIA POMPHREY

Ms. Jean Alexander

CAROLYN ROBERTS

Ms. Lisa Harris

SUSAN RUEDIGER— Happy Birthday!

Mr. Ted Freeman

SADOWSKI FAMILY

Ms. Linda Weaver

KELLY SORRELLS— Happy Birthday!

Mr. James Sorrells

SOUTHEASTERN WI BRANCH—

Happy Awareness Month!
Ms. Polly Maziasz

JENN STENANDER

Mr. Christopher Stenander

CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
 Thank You Anniversary Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

Name: _____

Address: _____

Amount Enclosed: _____ Check Enclosed

VISA MasterCard American Express

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____





CMTA BRANCH NEWS

INDIANAPOLIS, IN

Four CMTA members came out to hear physical therapist assistant Tony Brown at the branch's August 11 meeting.

He said the feet are the foundation for the body. He works on pain, range of motion and strength. Patients are sent home with exercises and that are important to do. He said aquatic therapy helps range of motion and strength without strain on the muscles and body overall. Brown recommended dynamic AFOs, over-the-counter inserts or Powerstep insoles, a line of high quality insoles with high arch support and heel cradles. He also shared information about assistive devices such as single and quad canes, walkers with and without wheels, and walkers with chairs.

★

BALTIMORE, MD

The Baltimore branch of the CMTA had a great meeting on September 10. Guest speakers were Brett McCray, MD, from



Johns Hopkins and Laurie Lasky from Allard. Dr. McCray discussed the recent Peripheral Neuropathy Society Conference in Barcelona, Spain and answered questions from the group. Laurie gave a presentation on the life-changing potential of braces and brought samples for group members to try.

★

GREATER MINNEAPOLIS

Fifteen people turned out for the July meeting, including six first timers and one special guest. After welcoming the newcomers, people shared their feelings about the difficulties of adjusting to life with CMT and talked about compression stockings and weight struggles. Branch Leader Marilyn Menser made an informative and educational presentation on traveling with CMT.

★

ANN ARBOR, MI

The Ann Arbor CMTA Branch had another great meeting on August 5. The 65 people in attendance heard from Advisory Board member Dr. Greg Stilwell, who talked about



David Tannenbaum met with the Charlotte, NC branch in September.

the care and treatment of feet, diet, and the benefits of pole walking and how to do it! Many members had their own one-on-one foot exams with him after the meeting.

★

CENTRAL NEW JERSEY

Branch Leader Jacky Donahue reported on STAR Research at the branch's July 29 meeting. Following introductions, the group had an open discussion about bracing, providers and services and challenges and solutions. Advisory Board member David Tannenbaum donated several copies of 101 Practical Tips to members.

★

WESTCHESTER, NY

Jeana Sweeney was the guest speaker at the September 9 meeting. There were 22 people in attendance, and Jeana gave a PowerPoint presentation, covering everything from where the CMTA was 15 years ago to where things stand today. There was reflection, laughter and even some tears. It was both emotional, nostalgic and uplifting. Jeana explained the exiting advances in STAR, and she spoke about how everyone can make a difference. Kim Magee, the CMTA Director of Finance and Administration, joined Jeana and spoke about the many changes in the CMTA over the past few years. There also was a potluck brunch for all to enjoy.

★

CHARLOTTE, NC

The Charlotte, North Carolina branch of CMTA had a great meeting September 9, hosted for the third time this year by friends at The Hanger Clinic in Charlotte. There a very special guest, David Tannenbaum, LCSW, who has been a practicing psychotherapist in New York City for the past 30 years and is on the CMTA Advisory Board. He shared his personal struggles with CMT, which allowed the group to open up to him and the rest of the members throughout the meeting. The group shared great stories and solutions for living with CMT on a daily basis. Many members left with big smiles on their faces, a renewed sense of worth and joy in their hearts.

As part of the group's fundraising efforts for the year, they also collected the Change for CMTA jars the Charlotte branch kids decorated at the first meeting. Members filled these jars with change throughout the year to turn in at this meeting to further research for a cure of CMT. There were 14 jars filled for the CMTA.

There will be a holiday get-together for the Charlotte branch before the end of the

year. To get details, sign up for branch emails at www.cmtausa.org/branch/cr or visit the Charlotte CMTA Branch on Facebook at www.facebook.com/groups/CharlotteCMTA/.

★

PORTLAND, OR

On August 6, in the heat of the Northwest summer, two groups met together for the first time, enjoying an old-fashioned ice cream social in the comfort of an air-condi-



tioned meeting room near the banks of the mighty Columbia River.

While enjoying sundaes topped with everything from gummy bears to Oreo cookies, to Reese's Peanut Butter cups (with cherries on top), branch members discussed ways to raise awareness of CMT, as well as raise funds for research for the CMTA. Getting acquainted was a large part of the time together and a good time was had by all!

★

NASHVILLE, TN

The Nashville branch hosted a meeting on Saturday, October 14 with guest speaker Jonah Berger. He shared his story and challenged people at the meeting to find what they love about CMT as well as to always take one step outside their comfort zone. Occupational therapist Penny Powers talked about the exciting developments in occupational therapy that are improving the lives of people with CMT.

★

SUFFOLK, VA

The Suffolk, Virginia branch held its first branch meeting on October 7. The group discussed the welcome packet and the great resources the CMTA website (www.cmtausa.org) has to offer. These include webinars, ask-the-expert questions, a neurotoxic drug list, Facebook groups, orthotic guides, CMTA Centers of Excellence and tools for finding a CMT physician. There is a Facebook group for the branch (www.facebook.com/groups/842171385957015/) that allows for access to branch and

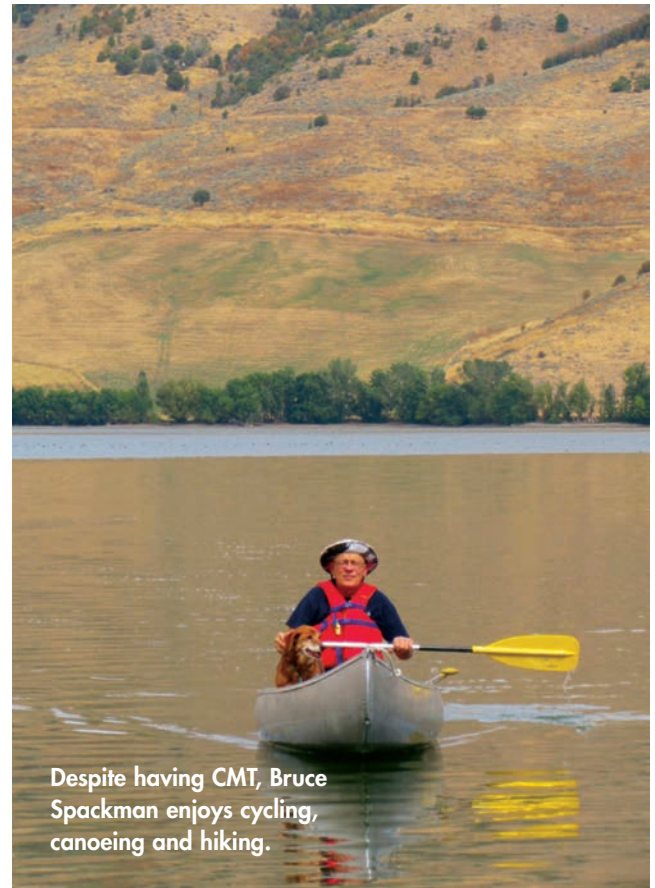
PERSONAL PROFILE: Bruce Spackman

I am 63 years old. I grew up on a dairy farm in northern Utah. I have a brother and a sister, both with CMT. We inherited CMT from our mother. There is always plenty of work on a dairy farm, and our parents never cut us any slack. They were kind and patient, but they expected us to do our share of the family responsibilities. I learned to drive a tractor, milk cows and move sprinkler pipe at a very young age. I believe these expectations have helped us succeed in spite of our limitations.

For years, we never knew that our condition had a name. We assumed we were just unfortunate to have inherited some strange foot abnormality. Back then, kids would gather at a pasture and play tag, baseball or football. I was always chosen last and performed poorly. PE was required in school, and I hated it. The teachers weren't always understanding.

My career has been in agricultural crop production. I am not as strong as others, and I don't walk as fast. But in all of my career, only a few have arrived on the job earlier in the morning and stayed later into the night than I have. Crop production is seasonal, and the spring, summer and fall hours are intense.

I was about 30 years old when my nephew was given an official diagnosis of CMT. It was a relief to learn there were others in the world with my same condition and that it had a name. I have six children, three of who have CMT. I enjoy cycling, canoeing and, to a limited degree, hiking. One of my favorite motivating quotes is by Henry Wadsworth Longfellow: "The heights by great men reached and kept were not attained by sudden flight, but they, while their companions slept, were toiling upward in the night." ★



Despite having CMT, Bruce Spackman enjoys cycling, canoeing and hiking.

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

Cedars-Sinai Medical Center (Los Angeles)	Drs. Robert Baloh and Richard Lewis
Children's Hospital of Philadelphia (Philadelphia)	Dr. Sabrina Yum
Connecticut Children's Medical Center (Farmington)	Dr. Gyula Acsadi
Massachusetts General Hospital (Boston).....	Dr. Reza Seyedadjadi
Johns Hopkins University (Baltimore).....	Dr. Thomas Lloyd
Lucile Packard Children's Hospital at Stanford (Palo Alto).....	Drs. John Day and Ana Tesi Rocha
Nemours Children's Hospital (Orlando).....	Dr. Richard Finkel
Stanford Neuroscience Health Center (Palo Alto)	Dr. John Day
University of Iowa (Iowa City)	Dr. Michael Shy
University of Miami (Miami).....	Dr. Mario Saporta
University of Michigan (Ann Arbor).....	Dr. Sindhu Ramchandren
University of Minnesota (Maple Grove)	Dr. David Walk
University of Pennsylvania (Philadelphia)	Dr. Steven Scherer
University of Rochester (Rochester, NY)	Dr. David Herrmann
University of Texas Southwestern (Dallas)*	Drs. Susan Iannaccone and Diana Castro
University of Utah (Salt Lake City)	Dr. Russell Butterfield
University of Washington (Seattle).....	Dr. Michael Weiss
Vanderbilt University (Nashville)	Dr. Jun Li

*UT Southwestern is not part of INC.

INTERNATIONAL

The Children's Hospital (Westmead, Australia)	Dr. Manoj Menezes
The National Hospital for Neurology & Neurosurgery (London, England)	Dr. Mary Reilly
C. Besta Neurological Institute (Milan, Italy)	Dr. Davide Pareyson
University of Antwerp (Edegem, Belgium)	Dr. Jonathan Baets

CLINICAL DIRECTOR

? WHAT'S ON YOUR MIND? *Ask David.*

Dear David,

I am a 57-year-old woman with CMT. I am not severely affected, but I do get fatigued easily and like many others, I need to choose where I expend my energy. The problem is with my siblings. They think I am faking it to get out of certain responsibilities like helping to clear out my 90-year-old mom's home after she recently moved into an assisted living facility. I am the only one in my family with CMT, and I find myself continually apologizing for not being able to keep up. I am not a confrontational type, but I am tired of defending myself for what feels to me like insensitivity to me and my limitations.



Write to David at info@cmtausa.org.

David replies:

First, there is no need to feel defensive. Absolutely stop apologizing for having CMT. It is unfortunate, but true that until someone has walked in our shoes, or perhaps I should say sneakers, they cannot fully understand what we experience on a daily basis. I think it is particularly difficult when many of us look okay. Some of us apologize automatically for all sorts of things, which is completely unnecessary and places us in a victim mentality. Psychologist Carl Jung once said, "I would rather be whole than good."

Keep in mind, there is always some anger beneath our defensiveness. I remember many years ago when I asked my then six-year-old

niece to sit next to me at the table, she said, "no." When I asked her again, she reasserted her answer, put her hands on her hips and said "No is no." I was shocked at the time, but years later, I give her credit for expressing herself in a strong and guilt-free manner. Like all of humanity, we have limitations. This is just a fact, not a weakness. We make it a weakness with our apologies. Your siblings' limitations are their insensitivity to your CMT. Tell them you will help in the ways you can but that you will not compromise your health. ★

David Tannenbaum 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.

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- | | |
|---|---|
| <p>Subscription Membership Benefits:</p> <ul style="list-style-type: none"> • Online access to valuable information about living with CMT • An information kit and a 10% discount at the CMTA store • Quarterly delivery of <i>The CMTA Report</i>, (electronic and/or hard copy) | <p>STAR Membership Benefits:</p> <ul style="list-style-type: none"> • All of the benefits of Subscription Membership <p>PLUS</p> <ul style="list-style-type: none"> • One free pair of Aetrex Shoes in the style of their choice (new STAR members only) • 50% off all Aetrex shoes (new and renewing STAR members) • An expanded and updated copy of the CMT Survivor's Guide • A 20% discount at the CMTA Store • One <i>You're a STAR</i> auto decal |
|---|---|

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My Child Has CMT		\$5	\$5	
CMTA T-Shirts <input type="checkbox"/> Navy Blue with white logo) <input type="checkbox"/> White with blue logo) Quantity and Size: S__ M__ L__ XL__ 2XL__ 3XL__		\$15	\$12	
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BRANCH NEWS

(continued from page 20)

meeting information and makes it easy to connect with other branch members.

Guest speaker JT Clay is a coach who is certified to work with adaptive athletes. He has worked with people from amputees to people in wheelchairs. He has learned to modify a workout for literally any challenge that someone may have. In November, there was an awareness event called CROSSFIT 4 CMT, and JT created a special workout to raise awareness for CMT. The group tried to get as many gyms as possible on board to do the workout during the month of November. There is even a gym in California with people who have CMT, and they did the workout.

★ SOUTHEAST WISCONSIN

Twenty-two people gathered on a Saturday morning at the Pettit National Ice Center. There were eight new CMT friends present. The group shared conversation and kringle, while enjoying laughter, chocolate and fun. Attendees also learned a lot about what's happening in the CMTA world from Michelle Hayes, CMTA Manager of Branch and Community Relations, who gave the group so much hope as she shared highlights of research advancements made because of the efforts of the CMTA, the STAR project and the 20 CMTA Centers of Excellence.

The group also learned about Camp Footprint, the CMTA's camp for kids that will be held for the third time next summer, and CMTeen, an online magazine for teens and young adults. Michelle also encouraged the group to subscribe to *The CMTA Report* and to check out all the resources available at www.cmtausa.org.

Thanks to Michelle for sharing her expertise and enthusiasm with everyone. Come back soon to the land of brats, cheese and football!

★ TORONTO, ON

The Toronto branch meeting was held in the library at St. Lawrence on the Park. The group welcomed four new members. The group gathered the money, the stubs and unsold from the sale of the 50-50 raffle tickets. The winner, Morgan Roy, will receive \$310 CDN. The CMTA will receive a check for approximately \$250 US for research. Thanks very much to all members who sold tickets, bought tickets, returned tickets and educated people about CMT while doing so!

The guest speaker was Jim Amesbury, who is a certified orthotist with Custom Orthotics Design Group in Mississauga. His presentation was excellent and very educational. Jim brought many different types of brace for the group to look at and explained how they benefit patients with CMT.

The group also talked about genetic testing for CMT. Some people have had it, and some have not. If a member wants to have the testing, the first step is to get a referral to a neurologist, who can then order the test.

The next meeting will discuss the topic of medical marijuana. The speaker will be from Apollo Cannabis and Research Clinic.



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)
Ethinbutol
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 CMTA Report

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WHAT IS CMT?

- ▶ CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- ▶ CMT may become worse if certain neurotoxic drugs are taken.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT can, in rare instances, cause severe disability.
- ▶ CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ▶ CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ▶ CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ▶ CMT does not affect life expectancy.
- ▶ CMT is sometimes surgically treated.
- ▶ CMT causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- ▶ Although there is no drug treatment for CMT, physical therapy, occupational therapy, and moderate physical activity are beneficial.
- ▶ CMT is usually inherited in an autosomal dominant pattern, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- ▶ CMT Types that can now be diagnosed by a blood test include 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN.
- ▶ CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.