FALL 2020

THE CMTA Report

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CAMP FOOTPRINT GOES VIRTUAL

7 > 1A, 1B, 4B Projects Approved
11 > Pharnext Collaboration Announced
18 > Awareness Month Celebrates Champions

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

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Riding 4 CMT page 12

INSIDE THIS ISSUE:

RESEARCH
Board Approves $360,000 in Grants 7
1A Research Roundup 8
CMTA Partners with Pharnext..................11

CMT COMMUNITY
Why I Give 14
RIP Anthony Zahn...............................17

FUN AND FUNDRAISERS
Virtual Vermont Cycle 4 CMT 12
Awareness Month................................18
Team Julia Swims Again 19

LIVING WITH CMT
Foot Surgery Consensus........................10
"Never Say Never" 13
Ebikes for Fun and Mobility...................16
"Sole-Searching" for Shoes 20
City Living Aids Exercise 22
Ask David 23

CMTA YOUTH
Camp Footprint Goes Virtual 4

THE CMTA Report

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A MESSAGE FROM THE CEO

DEAR FRIENDS,

To quote Freddie Mercury of the band Queen, “We are the champions.” During Awareness Month in September, we came together as a community to champion our cause—an end to CMT. We also recognized and celebrated our “champions with CMT”—the people in our lives who inspire us with their courage, strength and heart in facing the daily challenges of living with the disease. From spreading CMT education to health care professionals to decorating AFOs, community members took every opportunity to engage in fun and empowering Awareness Month activities to help make CMT known and understood around the world.

Our crack researchers are also champions and they have been hard at work on a wide array of studies, screens, trials and tests. In addition to a CMT1A research roundup in this issue, you’ll read about a new partnership with Pharnext and $360,000 in new research recently funded by the CMTA Board of Directors.

We’d also like to make sure you’re “aware” of the efforts of our dedicated Board of Directors, who have stepped up this year as never before. Some board members swam for CMT. **Herb Beron** and Team Julia held a virtual swim this year, raising $71,000 for a total of more than $1 million in the last 14 years. **Steve O’Donnell** also went virtual for his Sixth Annual Funathlon in June, swimming with his son across the Tred Avon River, then biking 20 miles to raise more than $80,000, for a lifetime total of more than $1 million. Steve also held a golf tournament to benefit the CMTA in September, raising an estimated $120,000. Some board members biked and walked for CMT. **Chris and Elizabeth Ouellette** organized the virtual Seventh Annual Vermont Cycle (and Walk!) 4 CMT, which raised over $200,000, for a seven-year total of more than $1.2 million. Event founder Chris also rode 300 miles in three days for the 3 million people worldwide who have CMT. Board Chair **Gilles Bouchard** and **Thomas Dubensky** biked across the Golden Gate Bridge in support of the virtual event.

Some board members held virtual fundraisers: New board member **Dave Coldiron** and his family held a first-year fundraiser that brought in $32,151 and in New York, **Alan Korowitz and Phyllis Sanders** pivoted from their usual New York City gala to raise money through a friends and family fundraising campaign. Other board members pledged their own funds. New board member **Dan Chamby** and his family pledged $1 million, including a $200,000 match for Awareness Month. **Kevin Sami, Tom Dubensky, Gary Gasper, Laura Fava** and **David Norcom** all made personal commitments to support our mission through their generous donations this year.

Last but not least, the trio of doctors on our board—**Drs. Michael Shy, John Svaren and Steven Scherer**—spearheaded our STAR research strategy to ensure we are investing our funds in the most promising efforts for our community. As CMTActive moderator Benjy Hershorn put it in a Facebook post, “[T]he ongoing and consistent commitment (year after year) of people like Steve … and including so many others doing the ‘BIG STUFF’ inspires and motivates me to do my small part.” Thanks to all for doing their parts, big and small.

All my best,

Amy Gray

AMY GRAY, Chief Executive Officer

VIRTUAL

KIDS WITH CMT Join Tribe of the Funky Feet Online

BY MARCIA SEMMES

For kids with Charcot-Marie-Tooth (CMT) disease, Camp Footprint is the one week a year they can connect with their peers, an irreplaceable opportunity to share the hopes and fears of living with a rare neuromuscular disorder. When COVID-19 made real-life camp impossible, the CMTA decided to recreate the camp experience online. It worked better than anyone dreamed possible.

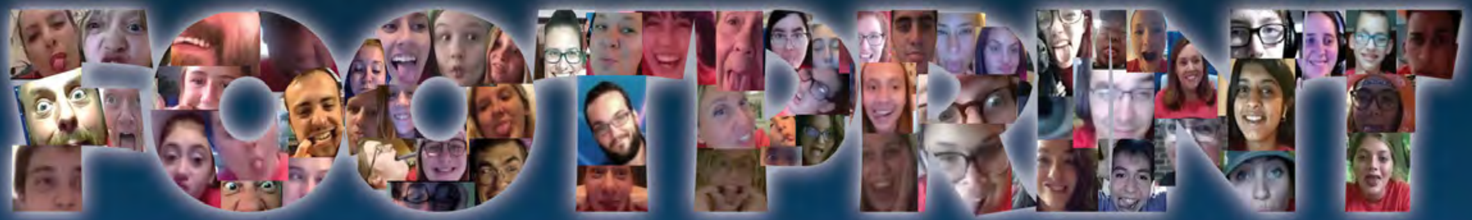
Former camper/now counselor Erin Black, 19, explained her virtual camp week this way: "Imagine walking around with a backpack full of bricks for 360 days, but then one day someone tells you that you can take it off for five days and feel free, joyful and empowered. For one week CMT isn't an ugly, painful neurological disease—it's a superpower."

The CMTA started the only U.S. sleepaway camp solely for kids with CMT in a beautiful wooded setting outside of Pittsburgh in 2016. For four years, it was a place where kids who had never met another kid with CMT found each other in what they soon came to call The Tribe of the Funky Feet. Camp Footprint (motto: One Step at a Time) gave campers the chance to master their environment, participate in activities planned just for them and celebrate their abilities.

One hundred campers experienced all the same benefits when the fifth year of Camp Footprint, funded in part by the Pennsylvania Department of Education, migrated onto Zoom in August 2020. To an amazing extent, planners were able to replicate or find workarounds for all the campers' favorite activities.

Take the traditional first-night campfire, for example. The "Camp in a Box" kit mailed to each camper contained everything necessary for a virtual bonfire: portable lanterns with a campfire setting that created a flickering light in their own personal "forts," a camp T-shirt, shaker eggs for the drum circle and a campfire mug. While planners wanted to include graham crackers, Hershey bars and marshmallows for the traditional campfire treat of s'mores, they were concerned about the items melting during shipment. Their solution? S'more Pop-Tarts.

Each of camp's five nights had a theme: The Monday night campfire was followed by a



Tuesday night scavenger hunt, an "adventure room" on Wednesday, a movie night on Thursday and the traditional dance party on the last night. Props from the Camp in a Box enlivened each activity: There were free pizza gift cards for campers to use on Movie Night and ribbon wands and glow bracelets for the Camp Dance.

Camp days started with announcements, stretching or chair yoga and the CMTA Youth Council's broadcast-quality News Report, including a weather forecast that was always sunny and beautiful—everywhere. Campers then moved on to a full day of programs, one every hour from 10 a.m. until 5 p.m. Day-time sessions also included a number of typical camp activities—everything from arts and crafts to beatboxing to baking and decorating cakes and cookies—ingredients all included.

Pranks are always a big part of Camp Footprint and this year was no different—campers enlisted the families of their counselors to deliver pies in the face and ice-water dunkings. The planners even managed to pull off Camp Footprint's traditional powder battle, including packets of powdered chalk in the camp boxes and instructing campers to go outside on the final day and film themselves, their friends and families dowsing each other in the colorful dust.

> "Day after day, the screen lit up with over 100 beautiful faces …"

After the general session ended at 9 pm, campers split into their cabins for "Foot-time." Because CMT destroys the long nerves to feet, foot care is critical, and the camp goody boxes included a variety of tools for taking care of them, including foot lotion, portable foot baths, hot and cold packs, pedicure boards and stretch bands.

Camp director Jonah Berger, a 30-year veteran of the camp business, cited several unexpected benefits to conducting camp online. The Zoom platform

(continued on page 6)

Left: **Counselor Cassidy Miller, 20, worked online from Ohio.**
Right: **CMTer Elsa Groenink, 15, and her sister Molly, 13, camped out in Michigan.**

CAMP FOOTPRINT

(continued from page 5)

allowed campers to see into each other's homes, which were set up with specially decorated "forts" around their computers. This enabled them to show and tell each other about their families, pets and musical instruments. Being in their own homes also made campers more comfortable and more willing to open up, he said. On a logistical level, transitioning between activities only took 20 seconds online, Jonah said, compared to the 20 minutes it takes IRL.

Parents also played a greater role this year, Berger said, hurling chalk in the powder battle, slow dancing with their kids at the dance and even pranking their unsuspecting campers. Two parents went above and beyond: One, a NASA employee, had a star named for Camp Footprint, then arranged for the Hubble Telescope to focus on it and show the kids online. And the father of an Egyptian camper whose Camp in a Box was returned to sender recreated the entire kit for his son, complete with giant foam foot.

Campers and counselors—both first-timers and old hands—praised the online iteration of Camp Footprint. First-time camper Emmily Stufflet, 16, says she went into the week feeling nervous and anxious, but after her first full day she "couldn't help but cry tears of pure joy." In the first day, she "met new friends, heard new stories, and knew INSTANTLY what the Tribe of the Funky Feet is all about ... love."

2020 marked Camp Footprint's 5th Anniversary

Returning camper Elisheva Landau-Pope, 18, said that she was devastated when she first heard that Camp Footprint was going online: "The week I spent in Pittsburgh last summer was the best of my entire life. I met the most incredible people and was empowered beyond words." But virtual camp didn't disappoint, she said: "The magic was still there."

Checking in with the entire camp each morning "felt like breakfast in the dining room in Kon-O-Kwee, with Jonah greeting everyone individually" she said, and the daily broadcast from the Youth Council always brought laughter and instantly set the day up to be filled with positivity and smiles.

"Talking to other people my age with CMT is an opportunity I never had before camp, and it's helped me accept having CMT and be much more open about it with others," she said, adding, "Although we weren't together in person, seeing everyone's smiling faces on the screen reminded me how grateful I am to have such a wonderful, supportive community."

First-time counselor Cara Leith, 26, the only person in her

CAMP SPIRIT

COLOR BATTLE!

Left: Liam Perry, 12, unpacked his camp shirt in New York. *Right:* Counselors Cassidy Miller, Hannah Roberts and Erin Black held a powder battle together in Ohio.

family with CMT, thrilled to the feeling of finally getting to be around people who understood what life with CMT is like. Prior to Camp Footprint, she said, her six-year CMT journey was something she had to navigate alone: "In some ways, it was like everyone's angsty teenage belief was true—quite literally, no one around me understands." At virtual Camp Footprint, by contrast, "Day after day, the screen lit up with over 100 beautiful faces who know exactly what it's like and can understand those pieces of me that I've carried alone without having to say a word. The joy in that togetherness, and the sense of peace that came with seeing other happy, thriving people with CMT across all age groups, was such a gift. I cannot wait to experience it in person one day!"

Returning counselor Erin Weierbach, 34, said the moments that made the strongest impression on her came when the 52 counselors least expected it: "In between organized activities and planned engagement, campers connected through opportunities to ask questions, getting to know each other and share stories. Bonds formed in front of us as young people celebrated each other's differences, similarities and shared experiences and our tribe grew by many."

Berger found it unsurprising that a group of campers and staff used to fighting through CMT's daily challenges refused to let COVID-19 get in the way of their week in the Tribe of the Funky Feet. And, while he hopes that campers and counselors will be able meet in person next year, he says that whatever happens, "Camp Footprint will keep moving forward—one footstep at a time." ★

CMT1A, CMT1B, CMT4B PROJECTS APPROVED

THE CMTA BOARD OF DIRECTORS approved $360,000 in new grants to top CMT scientists at its September meeting. Covering work on types 1A, 1B and 4B, the grants represent the CMTA's commitment to finding treatments for the community.

The projects are aimed at improving understanding of disease mechanisms, discovering new therapeutic targets and preparing for and moving into clinical trials.

For more than three decades, the CMTA has funded basic, clinical and translational research, investing more than $16 million through STAR in the last decade alone to develop therapies for the community. The new projects include:

CMT1A Project: The board awarded Dr. John Svaren, University of Wisconsin Madison, $60,000 to explore approaches for lowering the expression of the gene *PMP22* in animal models. If successful, this approach—using an FDA approved drug and similar compounds—could lead to an accelerated treatment for patients.

CMT1A Project: The board awarded Dr. Luigi Puglielli, University of Wisconsin Madison, $89,889 to explore a potential new target for treating CMT1A. He will conduct genetic, cellular and pharmacologic tests to validate this target.

CMT1B Project: As part of that $89,889 grant, Dr. Puglielli will also explore a potential new target for treating CMT1B, conducting genetic and pharmacologic tests to validate this target.

CMT4B1/B2 Project: The board awarded $201,000 to Dr. Alessandra Bolino, Ospedale San Raffaele in Milan, Italy, to explore treating CMT4B1 and CMT4B2 with an FDA-approved drug. In addition, Dr. Bolino's team will conduct studies with CMT4B1 and 4B2 patients to better understand the natural progression of the disease and help prepare for clinical trials in the future.

CMT1A Research Agenda Fuller than Ever

Back at the dawn of the Strategy to Accelerate Research (STAR), the CMTA decided to focus its initial research efforts on CMT1A because it affects more people than any other type. While the CMTA's focus has expanded in the decade since, it is not neglecting Type1A. In fact, the 1A agenda is fuller than ever before.

In addition to the recently funded projects outlined on p. 7, the CMTA has formed research alliance relationships with companies specializing in small molecule, biological and genetic therapies and is now actively engaged in therapeutic testing alliances with organizations interested in creating new therapies for CMT disorders or in re-positioning therapies developed for other diseases.

The CMTA is actively engaged in therapeutic testing alliances with organizations interested in creating new therapies or repositioning ones developed for other diseases.

Apart from enabling company-sponsored efforts, we are also actively identifying novel approaches and opportunities to develop therapies for CMT1A. There are a number of new initiatives and opportunities in the works.

Studies of peripheral nerve and CMT neuropathy have revealed the central role of metabolism in maintaining the energy of axons that conduct nerve impulses. The energy source for nerves comes from mitochondria and mitochondrial defects cause neuropathy. There are two approaches for addressing the metabolic issues of neuropathy affecting myelin in CMT1A. First, the critical factor driving CMT progression is axon degeneration, which has been shown to involve a critical metabolite, NAD, that must be maintained at a specific level to initiate the degeneration program. Several approaches have emerged to try to prevent axon degeneration and preserve nerve function.

Second, the maintenance of myelin around the long axons in the peripheral nervous system depends on a number of metabolic pathways. For example, the formation and maintenance of the myelin sheath are tightly coupled to lipid synthesis pathways. Moreover, as documented in several studies (including a recent lecithin study from Dr. Michael W. Sereda's laboratory at the Max Planck Institute for Experimental Medicine in Göttingen, Germany), one of the metabolic aspects of CMT1A neuropathy is the downregulation of lipid production that is required for maintenance of axons and myelin. Therefore, the maintenance of Schwann cell metabolism and support of axon health is likely central to CMT1A and other types of CMT. Some studies have employed cholesterol or lecithin as ways to restore myelination, but these involve agents that likely do not completely rescue metabolic defects in CMT1A Schwann cells.

On another front, while the CMTA has initiated several studies to advance anti-sense oligonucleotide (ASO) and adeno-associated virus (AAV) genetic therapies for CMT1A, delivering them to Schwann cells remains a fundamental issue. Depending on the results of ongoing pilot studies and emerging ideas, the CMTA will likely need to increase investments to make these types of therapies safer and more efficient.

OVERALL NEXT STEPS INCLUDE:

- The progression of all types of CMT occurs as the longest axons are compromised in a process called axon degeneration. We are working with partners to develop chemical inhibitors of the triggers of axon degeneration. We are currently testing the applicability of this approach to multiple models of CMT1A and collaborating with several companies on candidate drugs to promote axon survival and preserve nerve function. Additional studies to validate this as a legitimate target for CMT1A are needed.
- Target screens for CMT1A have identified some pathways that regulate PMP22 levels, and candidate compounds from these screens are being tested using cell-based assays in preparation for animal model testing.
- Recent studies have shown that lipid metabolic pathways are affected in CMT1A, and strategies to stimulate the necessary production of lipids to maintain myelin and axons are ready for testing once we secure the needed funds for animal model testing.
- Finally, new therapeutic approaches are being developed to manipulate the levels of overexpressed proteins. These are being tested in CMT1B with possible application to CMT1A.

The CMTA has established a unique capability to develop new therapies directly with companies and to expertly test those potential

STAR
Strategy To Accelerate Research
1A TIMELINE
CMTA Roadmap to Success

2008
Strategy to Accelerate Research (STAR) project launched

2009
Inherited Neuropathy Consortium (INC) launched

2010
Development of first drug screening assays in partnership with the NIH

2011
First NIH funding for small molecule screening project

2012
First drug screen published; first stem cell project initiated; CMT Pediatric Scale published

2013
First clinical trial in USA published (Lewis et al JAMA Neurology); partnership with Sanofi initiated

2014
First use of genome editing to create drug screen; rodent models incorporated into testing platform; Ionis alliance initiated

2015
InFlectis and CMTA Board Member Dr. Lawrence Wrabetz publish successful CMT1B studies, later developed for CMT1A clinical trials; over 2.3 million compounds screened in partnership with the NIH and Sanofi; human stem cells made in NYSCF alliance

2016
Biomarker studies with Sanofi initiated

2018
Ionis-CMTA partnership leads to breakthrough proof-of-principle of PMP22 effect on disease phenotype; the INC develops patient-centric clinical scales

2019
Stem cell studies published, first gene modifier and skin biopsy assay (treatment-responsive for CMT1A); CMT Health Index (CMT-HI) and CMT Functional Outcome Scale (CMT FOM) published

2020
Sanofi partnership identifies novel blood biomarker; natural history study published (>1000 patients); gene therapy project with three major institutions launched; CMTA engaged in pre-clinical testing or clinical planning with a record 10 biotech partners

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Charcot-Marie-Tooth Association

therapy candidates. This allows a company interested in positioning a therapy for CMT to access the infrastructure needed to evaluate the therapy without committing significant time and money upfront. A number of companies are engaged in testing for CMT1A with us. Of the four CMT types currently in preclinical testing, CMT1A has attracted the highest interest due to its prominence in the CMT patient population.

Current CMT1A alliance activity includes the following partners:

- **Sanofi** was our first alliance partner for CMT1A and we are currently evaluating small molecules that came from this joint program as potential new alliance partners have expressed interest in acquiring them. In addition, Sanofi has entered discussions with the CMTA to lead evaluation of small-molecule approaches already advancing for different but related disease areas.

- **Ionis Pharmaceuticals** was the first partner to demonstrate that a genetic modifier of the *PMP22* gene (anti-sense oligonucleotide or ASO) could effectively repair CMT1A defects in animal models of the disease. Since then, Ionis has been working to solve a generally understood limitation of its technology—delivery of an ASO to the target cells. Recently, they have acquired from us the CMT1A stem cell lines in the New York Stem Cell Foundation repository for use in support of continuing CMT effort.

- **Regenacy** owns a drug candidate that has been in human testing for a different disease but may have value in treating CMT. Regenacy accessed our testing resource to evaluate the candidate in several CMTs, including CMT1A. Regenacy is currently evaluating which efforts merit further study.

- **Acceleron** is a Boston-based company working to develop a biological therapy aimed at maintaining muscle. Our testing resource was accessed for clinical trials to evaluate whether the therapy prolonged patient mobility in CMT1A animals as the disease progresses. This clinical effort was discontinued after it was shown that while the ACE-083 increase muscle size, it did not improve muscle strength. The CMTA had a strong patient advocacy presence during these clinical trials.

(continued on page 10)

CMTA1A RESEARCH

(continued from page 9)

- **Confidential Partner A** owns a drug candidate derived from a program at a major pharmaceutical company. Based on known evidence of the drug target's possible role in CMT disorders, the company pursued evaluation in both Type 1 (CMT1A) and Type 2 CMT animal models. We have some evidence of effect in CMT1A and very detailed data on which nerves are affected was recently passed to the company for further discussion.

- **Confidential Partner B** is a mid-sized international pharmaceutical company seeking to establish if a drug candidate has possible activity in CMT1A. Their small molecule did not work in CMT1A, which may reflect a likely site of action at a different cell type.

- **Confidential Partner C:** The testing resource described in the previous section is "therapy agnostic" and can be used to evaluate gene therapy approaches. Our first partner in this area is currently evaluating delivery of its gene modifying system, packaged inside an AAV virus, to nerves in CMT1A animals. If delivery is sufficiently effective, this will be followed by a complete series of preclinical efficacy studies this year to determine if the approach can correct the CMT1A defect and restore normal function in the animals.

- **Confidential Partner D** is developing a novel biological approach to treat CMT and asked for our help in evaluating their candidate in both Type 1 (CMT1A) and Type 2 models. These studies are currently in progress.

- **InFlectis**, a French startup company, is working to develop a new approach to CMT1B and CMT1A. Sponsored research studies have been performed in the CMTA STAR consortium to assess drug effects in both animal models, and InFlectis is currently raising funds for clinical trial testing of the molecule in patients.

- **Pharnext**, a French company, is developing a combination of several exciting drugs for the treatment of CMT1A. The small molecule combination showed benefit in early clinical trials, and regulatory authorities

CONSENSUS STATEMENT ON SURGICAL TREATMENT OF CMT PUBLISHED

An orthopedic foot and ankle surgeon should be part of the care team early in the course of CMT, according to "A Consensus Statement on The Surgical Treatment of Charcot-Marie-Tooth Disease," published in *Foot & Ankle International* in June. The prestigious journal is a publication of the American Orthopaedic Foot & Ankle Society.

Funded by the CMTA, 13 experienced, board-certified orthopedic foot and ankle surgeons and a neurologist specializing in CMT convened at a one-day meeting to discuss clinical and surgical considerations based on existing literature and individual experience. Led by orthopedic surgeon Dr. Glenn Pfeffer, a member of the CMTA Advisory Board, the group defined consensus terminology, agreed upon standardized templates for history and physical examination and recommended a comprehensive approach to CMT foot surgery.

The article concluded that "Patients with CMT present with a wide range of foot and ankle deformities that often worsen as the disease progresses. These are complex deformities that require highly specialized care. Early surgical intervention should reduce deformity progression and help preserve a plantigrade foot [in which the surface of the whole foot touches the ground during locomotion]."

The authors recommended a multidisciplinary approach involving neurology, physical therapy and orthopedic surgery, with an orthotist as needed. Shared decision-making with the patient, family and multidisciplinary team will provide the highest quality of care, the group concluded.

***Download a PDF of the study at* www.cmtausa.org/download/14564/**

have asked the company for an additional, expanded trial using the highest proposed dose combination. The CMTA has supported Pharnext with patient advocacy efforts and is providing biomarkers in preparation for Phase III clinical trials (See related story this page.)

OVERALL NEXT STEPS INCLUDE:

- Development of an in vitro test model for CMT1A: Our alliance partners are constantly asking for a "CMT in a dish" model for initial evaluation of potential therapies. Properly done, this could predict likely activity in an animal model where additional issues of drug delivery and metabolism have to be managed. The current best available model is a co-culture in a dish, in which nerve cells and Schwann cells isolated from the CMT1A animal model are put together, thus allowing myelin to be formed and used as an outcome measure in the test.
- Sanofi has asked for our help in preclinical testing for a new program opportunity. If we take this on, there is potential to launch a new and advanced effort that they will take forward and finance.
- Ensuring the scalability of the testing resource: The testing resource has attracted strong, continued interest and engagement by pharmaceutical alliance partners. As the demand increases, the CMTA commitment needs to scale up accordingly. ★

Due to space constraints, genetic therapy projects for CMT1A will be covered in an upcoming issue.

CMTA Announces
Collaboration with Pharnext On Key Biomarkers for CMT1A

The Charcot-Marie-Tooth Association and Pharnext SA announced a research collaboration September 3 aimed at identifying and validating potential treatment responsive CMT1A biomarkers that could be further explored in future clinical studies.

Pharnext is an advanced clinical-stage biopharmaceutical company pioneering new approaches to developing innovative drug combinations based on big genomics data and artificial intelligence. It's preparing for the upcoming Phase III study of its lead drug candidate, PXT3003.

The Paris-based company intends to investigate blood samples collected from CMT1A patients with mild to moderate cases enrolled in the first Phase III study of PXT3003. Notably, this collaboration will evaluate the potential of TMPRSS5, a recently identified Schwann cell-specific biomarker in CMT1A patients, to confirm if it can be used to assess treatment response in future clinical trials.

The collaboration between Pharnext and the CMTA "underscores the importance of involving patient advocacy organizations…"

TMPRSS5 is part of a broader neurology panel that tests many additional potential biomarkers and the collaboration between Pharnext and the CMTA could lead to the identification of additional, as yet undescribed biomarkers for CMT1A. The development of TMPRSS5 evolved from a STAR (Strategy to Accelerate Research) collaboration involving CMTA Board members Michael Shy and John Svaren and the Inherited Neuropathy Consortium.

CMTA Board Chair Gilles Bouchard said, "[W]e are thrilled Pharnext is focusing its clinical development effort on CMT1A. Our collaboration with Pharnext aims to identify potential biomarkers for CMT1A, which are crucial to understanding the pathophysiology of the disease better, and to evaluate new therapeutic agents in future clinical trials."

Pharnext CEO Dr. David Horn Solomon said, "This exciting collaboration between Pharnext and the Charcot-Marie-Tooth Association underscores the importance of involving patient advocacy organizations in better understanding the disease and working to bring new therapies to CMT1A patients.

"Through this collaboration, we aim to further assess blood samples collected during our first Phase III trial of PXT3003 for novel biomarkers and notably confirm the potential of TMPRSS5 in CMT1A. Results of this research collaboration might inform the addition of new exploratory endpoints in our next Phase III trial of PXT3003 to be initiated in Q1 2021. We believe this alliance will enable us to accelerate our efforts in bringing a safe and effective therapeutic for this disease that currently has no viable treatment options." ★

Vermont Cycle (and Walk!) 4 CMT Goes International

Vermont Cycle (and Walk) 4 CMT founder Chris Ouellette *(second from right)* and members of Team Vermont

> **"Thanks to the power of social media, the hard-working team at the CMTA and the relentless commitment of our supporters, the VIRTUAL Cycle (and Walk!) 4 CMT was supremely successful."**

Twenty teams and 132 participants from all over the United States and Canada took part in the Seventh Annual Vermont Cycle (and Walk!) 4 CMT, which migrated online due to the pandemic. The virtual event raised more than $200,000 for CMT research.

In past years, the Cycle (and Walk!) 4 CMT was, as the name indicates, primarily a cycling and walking event. The pandemic forced the event to go virtual, which meant participants could do their events wherever they wanted, whenever they wanted. Each chose their own activity—rowing, swimming, wheelchair rolling and horseback riding—then friends, family and donors tracked their progress online.

Event founder Chris Ouellette, who biked 300 miles over three days for the 3 million people with CMT, said, "Thanks to the power of social media, the hard-working team at the CMTA and the relentless commitment of our supporters, the VIRTUAL Cycle (and Walk!) 4 CMT was supremely successful."

"We are profoundly grateful to all our participants near and far for their unwavering dedication to funding treatment-driven CMT research," he added, noting that matching gifts from CMTA board members super-charged the entire CMTA community to make this year's virtual event a triumph.

Over the past seven years, the Cycle (and Walk!) 4 CMT has raised more than $1.2 million for CMT research.

Thanks to the virtual nature of the event, there were lots of highlights this year. Team Chunky Monkey Torpedoes (CMT), led by Mary Cate Zipprich, drove to Vermont with her teammates to ride the traditional Vermont course. Paul Kang, who created the Love is a Superpower Team, joined Chris Ouellette and friends in a 40-mile ride to honor Julianna Yuri Snow, who died at the age of 5 from complications of CMT. From Ontario, Canada, Toronto Branch Co-leader Michael Driedger challenged himself to ride 1,000 kilometers, while his Co-leader Linda Scott Barber walked 4 CMT. Suzi Moore hopped on her trusty Terra Trike and rode more than 200 miles with her children and grandchild.

The energy, enthusiasm and commitment to this year's event were palpable throughout August and September.

The Cycle (and Walk!) 4 CMT event fundraising pages will be open until December 31. Please visit www.cycle4cmt.com to learn more or to sponsor a participant. Plans are in the works for both virtual and in-person events next year: Stay tuned for more details! ★

Editor's Note: There was one unexpected rider in this year's Vermont Cycle 4 CMT: Yohan Bouchard, whose uncle started the race, actually biked this year for the first time, riding his e-bike across the Golden Gate Bridge, up the Marin Headlands and back for a 20-mile ride with 2,200 feet of climbing. Proud mother and CMTA Board Member Elizabeth Ouellette describes her son's path to victory.

Never Say Never

BY ELIZABETH OUELLETTE

The training wheels came off my bike long ago. I've forgotten the emotions, challenges and vulnerable feelings of trying to balance on two wheels for a few pedal strokes without crashing to the ground. In fact, I had always taken riding a bike for granted until my then 5-year-old son, Yohan, attempted to ride his bike without training wheels. The experience was stressful, defeating and frustrating.

"This is not fun. Not fun at all. I'm done," he said as he walked slowly back in the house, head down. "I keep tipping over. I can't get my feet on the pedals. I'm going to die out there. Biking is too dangerous!" When Yohan sets his mind to something, there is no going back. He gave up biking on the spot—forever.

Fast forward 15 years to the excitement of leaving home for university. Yohan was thrilled to have been accepted to Pitzer, a small college in southern California spread out over 35 acres of relatively flat land. At 20 years old, Yohan's arches had become extremely high, his toes curled and his ankles were unstable. Chronic burning pain and fatigue were also issues. Pitzer did not offer transportation between classes, so we discussed alternative solutions.

We suggested that Yohan try a moped, a scooter, a golf cart or a Segway. Every single idea was shot down in the blink of an eye until Yohan's dad mentioned a bike. There was a pause before Yohan said, "I'll think about it."

The following week, we went looking for a bike with a low crossbar. "Oh, you are looking for a girl's bike?" joked the salesperson. No one laughed. "Idiotic comment," I muttered under my breath. "No, we are looking for a low top tube for people who have a hard time swinging their leg over that bar."


Team Yohan


Yohan Bouchard training on his e-bike

At about the same time we purchased Yohan's bike, my brother, Anthony, happened to be in town. He spent an hour with Yohan in our long driveway, providing the guidance, confidence and tips Yohan needed to succeed. With a little practice, Yohan overcame his fears, stayed upright and felt comfortable enough to take the bike to campus, where he used it a few times to get back and forth to class.

Riding a bike on campus comes with its own challenges, though, including other student bikers doing wheelies, skateboarders weaving in and out and inattentive students on their cellphones. At graduation, we packed up all of Yohan's belongings, minus the bike, which was in a state of complete disrepair, still attached to a bike rack and with a kryptonite lock whose combination had been long forgotten.

Just when we thought biking wasn't in Yohan's future, I happened to rent a Scott e-bike during a trip to Tahoe and our lives changed forever. Yohan tried it out and his entire perspective on biking changed overnight. He could go further, faster, and for the first time in his life he could accompany his friends and his dad on some longer rides. It has a low step-through design (not called a girl's bike) and in pedal-assist mode, you still get a great workout with backup power when needed.

We never thought that the child who could not ride a bike due to lack of balance, sensation and confidence would one day ride over the Golden Gate Bridge, maneuvering around pedestrians, cyclists, kids and dogs. There were setbacks, spills, road rash and fatigue, but with the support of friends, family and our CMT community, he conquered. And that's the reason I never say never. ★

WHY I GIVE:

New CMTA Board Member Dan Chamby is jumping in with both feet, issuing a challenge to the CMT community to match his $200,000 donation for 2020 by year's end. A former portfolio manager for BlackRock, Dan explains why he made the commitment—and what his due diligence revealed about the CMTA.

"Energy," "enthusiasm" and "expertise" are the three words new Board Member Dan Chamby uses to describe the CMTA. Dan already has the first two—in spades. With his business background and an attitude of "Hey, Coach, put me in the game I want to help out," there's no doubt that he'll soon develop the CMT expertise needed to help steer the CMTA ship toward a cure.

Dan retired in March after a 27-year career as a portfolio manager with BlackRock. Determined not to sit around watching sports in retirement, he asked his neurologist, Dr. Steven Scherer, what he could do to help the CMTA. Scherer put him in touch with CMTA Board Chair Gilles Bouchard, who put him in touch with other board members and staffers, culminating in his joining the board in May.

Before coming on board, Dan did his due diligence, just as he would before making any investment. He looked carefully at the CMTA's mission, management and finances. He was impressed with the engagement and energy of everyone he spoke with. "In my career, I've worked with some great organizations and some mediocre organizations," Dan says. "They were populated by really smart people for the most part. The difference between the two is that the great ones have energy and enthusiasm and a strong sense of mission and collaboration."

Dan sees that sense of mission and collaboration in the CMTA, which he compared to BlackRock for its ability to "swarm" a problem, with everyone putting everything they have into solving it. He also sees strength in the CMTA's diversity, noting that the organization comprises scientists, business people, educators and patients all working toward the same goal. "This is a serious organization full of people with serious backgrounds," he says, and on top of their diplomas, there's also a strong sense of dedication. Dan praised Gilles for "harnessing a core group of people and focusing their energy to transcend the elements that create dysfunction."

Dan says he hadn't thought much about the CMTA's community outreach efforts before joining the board but has come to understand that "one benefits the other." The community provides the

The Chamby Family, left to right: Etsuko, Anna, Aïko and Dan

DAN CHAMBY

energy and excitement for the research, he pointed out, quoting Ralph Waldo Emerson's words: "Nothing great was ever achieved without enthusiasm."

In deciding to join the CMTA's quest, Dan was also influenced by its four-star, or exceptional, rating from Charity Navigator, indicating that the CMTA exceeds industry standards and outperforms most charities in its cause. The CMTA pays close attention to costs, he observed, and really knows how "to make a little bit of money scream."

Above all, it was the organization's Strategy to Accelerate Research (STAR) that appealed to his sense of business strategy. The global partnerships it has fostered with leading academic, pharmaceutical, biotech and service companies using the latest genetic and neurological technologies strikes him as a remarkably disciplined approach to solving CMT.

> "This is a serious organization full of people with serious backgrounds."

All in all, Dan says he has a strong sense that he is joining an organization just hitting its sweet spot of momentum and impact. While some organizations develop a sense of complacency after success, he believes the CMTA has the excitement and enthusiasm to sustain the existing momentum. "The extremely heavy lifting has been done," he notes, though there is still a long way to go.

Dan called the task of learning about CMT both a "daunting challenge" and an interesting opportunity. His two daughters—Anna, 26, a second-year medical student and Aïko, 24, a clinical researcher in cancers—have both been instructing him on basic biological science.

Dan's CMT journey started fairly recently. Now 60, he played rugby in his early 30s until he blew out one knee and had to have it reconstructed. He blew out his other knee while skiing at the age of 50, requiring a second reconstruction. Afterward, he developed foot drop and noticed he wasn't running quite as well and his balance wasn't great, but his sports injuries masked the neuropathy. He began to suspect CMT after his French father was diagnosed at the age of 80, by chance at La Pitié-Salpêtrière in Paris, where Drs. Jean-Martin Charcot and Pierre Marie worked in the late 19th century. That led him to the CMTA Center of Excellence at the University of Pennsylvania, where Dr. Scherer confirmed his diagnosis of an unidentified Type 2.

Dan was no stranger to the University of Pennsylvania, where he earned his MBA in 1988. Afterward, wanting to learn an Asian language, he moved to Japan, where he taught English in a rural public school, and he met his wife Etsuko. Today, they live in Princeton, New Jersey.

While Dan won't be watching a lot of sports in retirement, he says that the CMTA's match against CMT "has all the excitement of a good sporting event." He's sure it's a contest the CMTA will win. ★

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HONOR ROLL

ACCORDING TO THE DICTIONARY,

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

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> "Monthly giving is the easiest way to stand up and fight, without fail, for STAR and the mission of the CMTA."
>
> —Joyce Steinkamp

ELECTRIC BICYCLES:
Transportation, Mobility and Laughs

BY DR. GREG STILWELL, DPM

"I never thought I'd ride a bike again." This phrase is uttered over and over again by people who try e-bikes, as I recently did. All I can say is: You gotta love a bicycle with a throttle. The cruiser bike I tried had seven gears, but twisting the throttle handle kicked on an electric motor that magically boosted me forward. Freedom! Fresh air! The fragrances of the outdoors! No mask required, but a helmet is probably prudent.

Various types of e-bikes are available. My favorite provides just a throttle boost, with pedals that still propel the bike by adjusting through the various gears. There is also a "pedal-assisted" type, which has the twist grip throttle, but the bike senses and propels you forward even faster. I don't like the pedal assist, mostly because the "boost" can also be activated while turning a corner, which can be scary and probably dangerous if you have decreased balance or lack of experience with the bike accelerating through a turn.


Greg Stilwell with his e-bike

What a gratifying feeling it is to be able to pedal up a super steep hill and keep the bike going around 11 miles per hour. The throttle boost can lug that heavy bike up the hill while you are still getting some workout in your legs by doing "supplemental pedaling."

I decided to rent before buying and had a Pedago cruiser delivered to my doorstep before setting off on a hard surface river trail on a Saturday afternoon. There were quite a few walkers, bikers, strollers and even a few recumbent bikes out on the trail, and it was really fun to pass them quickly and effortlessly. The speed limit for e-bikes on the trail was 10 miles per hour, but it was easy to exceed that speed while passing or even going up a hill.

Imagine if your leg strength is compromised, you've had surgery or have a heart or lung condition—and still being able to bike 15 miles in an hour and a half, and get off feeling refreshed. You control how much effort you exert via the gears, but more importantly, by how much "juice" you give the electric motor with your twist-grip throttle. Hand strength isn't important for the throttle, but changing the gears can be challenging while negotiating a busy bike path. The button to lower the gear is easy to tap, but to go faster in a higher gear requires significant thumb strength. I used the heel of my hand to push the high gear lever, with mostly good success.

I have CMT1A and lumbar scoliosis and the rental bike allowed me to keep my back straight and long, while still being able to breathe freely. The legs get some workout just pedaling, and it's soothing to be able to keep a regular pedal cadence going while using the throttle to even out the effort required during uphill slopes or acceleration.

I also rented a mountain bike type e-bike but didn't like it nearly as well as the "cruiser" with the step-through top tube. These used to be called "girls bikes." The more open frame makes it much easier to take off from a stop and to get on and off. The extra weight of most e-bikes can be offset by having a well-balanced and easy step-through configuration so that there's a sense of ease and grace while mounting and dismounting.

Try several different e-bikes before deciding if one is right for you. They range in price from several thousand dollars to $20,000, but riding one could be your primary source of motorized transportation, depending on your locality's bike paths and overall friendliness to bicycles. There are trailers, extra bags (panniers), baskets and other utility devices to carry home groceries, take a pet along or store gear for extended outings.

So get on a bike again! Have fun out there! Laugh and be merry, and forget for a little while you have CMT or mobility issues. ★

Dr. Stilwell is a member of the CMTA Advisory Board.

Anthony Zahn:
A REMEMBRANCE

Paralympic cyclist and CMT activist Anthony Zahn passed away from pancreatic cancer on August 7 at the age of 45. A longtime member of the CMTA, Anthony served as an ambassador for the association while coaching cyclists at all ability levels.

Anthony's wife, Liz Bernstein, set up an “In Memory” page on the Cycle 4 CMT website (cycle4cmt.com/#) in his honor. She also organized a memorial ride on his favorite route in Mill Valley, California, to mark the 12-year anniversary of his medal-winning performance at the Beijing Paralympics.

Anthony’s grit and determination inspired many people, no matter what their athletic ability.

As a teenager, Anthony dreamed of riding in the Tour de France despite the pain in his knees. After a neurologist diagnosed CMT, he decided that he could be even more famous as the first person to ride in the event with a degenerative neuromuscular condition.

Anthony won the first race he ever entered, a relay triathlon in which he rode the bicycling portion of the race. He went on to compete in road races until a fellow racer with multiple sclerosis suggested that he race as a Para-athlete.


Anthony competed in the 2008 and 2012 Paralympic Games and won a bronze medal in 2008.

Anthony’s disability was officially classified in July 2005 and he soon began competing as a disabled athlete. It took him two years to rise through the ranks to the very highest level of competition, the USA National “A” Team. In 2008, he won a bronze medal at the Beijing Paralympics.

Four years later, Anthony was hit by a car at a World Cup race, causing a concussion, two cracked ribs and a separated shoulder. Despite his injuries, Anthony traveled to London just six weeks later, putting together two eighth-place finishes in the 2012 Paralympics.

Anthony retired from bicycle racing in 2014 because he no longer had the energy for the training required to compete at a world-class level. After his retirement, he coached other cyclists at all levels, from weekend athletes to Paralympic hopefuls. He was guest of honor at the 2019 Vermont Cycle (and Walk!) 4 CMT.

Anthony’s grit and determination inspired many people, no matter what their athletic ability. He used his sports fame to shine a light on CMT and he will be sorely missed by everyone in the community. ★

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Awareness Month Celebrates CMT Champions

The CMTA family once again came together during Awareness Month 2020 to tell the world about the rare disease. We also recognized and celebrated our "champions with CMT"—the people who inspire us and lift us up with the courage, strength and heart they show in facing the daily challenges of living with the disease. Completing fun and engaging activities and challenges, the CMTA community gained greater knowledge of CMT, educated peers and health care professionals and championed our cause: a cure for CMT.

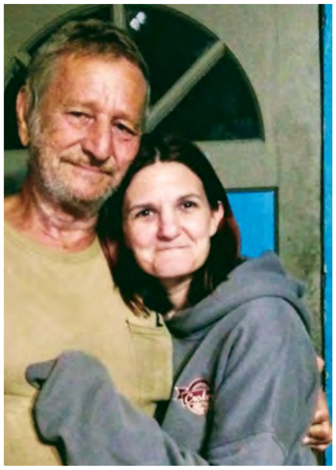
As CMT patients know all too well, meeting someone who knows about CMT is rare. Although CMT affects 3 million people worldwide, relatively few people have heard of it, even within the health care community. CMT's extensive and deep impact on daily life—socially, professionally, emotionally and physically—is an experience that patients are uniquely qualified to voice.

The CMTA Youth Council kicked off the month with energy and enthusiasm, creating and broadcasting a "Breaking News Report" that was viewed 3,654 times online. Challenging themselves and their social networks with a "What is CMT?" Quiz and gathering on Zoom for an educational "CMT Mythbusting" event, community members seized the opportunity to deepen their knowledge of CMT and leverage it to make an impact. The CMTA family shared our "What is CMT?" informational graphic on social media 2,372 times, reaching 215,092 unique individuals online. We rallied together to make the patient voice heard, helping educate health care workers locally and nationally by disseminating CMT educational and advocacy communicational pieces.

The CMTA family contains many champions. From veteran branch leaders and board members to young walk participants and new donors, every one of our members deserves to be celebrated for their determination and passion in raising awareness and the funds that make our shared mission possible. With the help of these champions, the CMTA is accelerating the field of CMT research toward treatments and a cure. ★

My Champion

By Vanessa Pope



My daddy, Rayford Redding, is my CMT champion! He is 66 years old and when he was 17 they told him he would be in a wheelchair by 21. This strong-willed, hard-headed man walks to this day and will run circles around any "young" man when it comes to working. He has beaten all odds and shows me every day that I can do anything I want, even with CMT. He has shown me that some things are difficult to do when you have CMT, but there are other ways to do them. He is brave and amazing and I love him so much! He inspires me to believe in myself and do my best at all times, never give up and never sit down, go the extra mile and achieve all my goals.

TEAM JULIA SWIMS AGAIN

While there were only three people in the pool for the 14th Annual Team Julia swim on August 9, the ripples from the virtual event spread far and wide.

CMTA Board Member Herb Beron, his wife Rachael and daughter Julia were joined by family members and friends who did their own virtual swims and walks in their communities, raising more than $71,000 for the CMTA's STAR research program. Over the past 14 years, the Beron event has raised over $1 million for research.

"We are incredibly thankful for donors' continued commitment to the CMTA and to the youth living with CMT," Herb said, noting that it is not too late for others to join the Beron family by holding their own virtual events or by donating to the dollar-for-dollar match for 2E research at www.cmtausa.org/julia.


Rachael, Julia and Herb Beron

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.

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Sole-Searching: Finding Shoes to Fit Your Feet and Personality

BY BETH DELORIA

Did you know that shoes can reveal someone's traits or characteristics? A 2012 study showed that 90 percent of a person's personality is reflected in his or her choice of footwear. For those of us who need shoes that accommodate ankle-foot-orthoses (AFOs), what do our shoes say about our personalities? Are our personalities altered by our diagnoses? Is this reflected in our shoes?

Of course not! We are not defined by our injuries or conditions even though we may feel confined by them at times. This is why one of the most common complaints from AFO-wearers is not being able to wear the shoes of our choice; we want the same style options as everyone else.

The good news is that more stylish, orthotic-friendly shoes and boots are available today than ever before. The key to finding your perfect shoe is to first understand how footwear fits into a four-part puzzle:

Each of the above components is totally interdependent. The first piece represents your foot and its unique characteristics. For CMTers, these may include high arches, toe curl, ankle instability and foot drop.

To address these issues and restore proper alignment and gait, the next two pieces of the puzzle—the orthotic insert and the AFO—are critical. When properly designed and paired, customized inserts and AFOs can offer many long-term benefits: pain alleviation, fall-prevention, better ankle stability, improved proprioception and balance, higher energy levels, decreased rates of muscle atrophy, increased confidence and better overall quality of life.

However, even a perfect insert-AFO combination is incomplete without the fourth and final piece—the shoe. The characteristics and design of the shoe will determine what benefits the orthotic devices provide, and the same care should be taken when selecting and customizing your footwear as when choosing your orthotic devices. Only when this four-part integrated system is fully optimized will you achieve the maximum benefit from your orthotics.

For AFO-wearers, orthotic needs come first, but this does not have to mean sacrificing style. Orthotic-friendly shoes can also reflect your individual flair and panache if you know what to look for and where. While you may not be able to wear stiletto heels or flip flops with your AFO, countless fashionable styles are AFO-friendly, and many companies now offer large selections of “adaptive and attractive” footwear. Below are some key features to look for in choosing your favorite style:

- A removable insole allows for proper AFO positioning and the use of custom inserts.
- A roomy toe-box allows room for AFOs and toe crest pads or spacers for those with toe curl.
- A firm heel of adequate height allows for optimal AFO function and increases stability.
- Extra depth allows room for AFOs and arch supports or metatarsal pads to alleviate pain.
- Fully extended zippers, especially in boots, allow for easy insertion/removal of AFOs.
- Laces or buckles provide more secure closures than Velcro to keep AFOs in place.
- Stable rocker-bottoms—with a slightly elevated heel and a mostly flat sole that curves up near the toe—facilitate forward motion and proper gait mechanics.

Today, it’s easy to find high-end retailers offering selections of adaptive shoes and boots, but the odds of finding the perfect pair for you are increased by searching:

- Online retailers like Zappos and ShoeStores.com that offer free return shipping if a shoe doesn’t work with AFOs
- Adaptive footwear sellers that specialize in corrective footwear like Orthotic Shop, Flow Feet and The Healthy Feet Store
- Mainstream retailers like Nordstrom, Birkenstock, L.L. Bean and many more that offer odd-sized pairing for little or no extra cost and easy-return policies
- Certified pedorthist facilities, or “footwear pharmacies,” that offer custom-crafting services along with specialty shoe selections

Some retailers offer odd-sized pairing for little or no extra coust

In addition to searching online and retail outlets, it can be helpful to look for brands that are known for their stylish, adaptive lines of shoes and boots, such as Aetrex, BeautiFeel, Drew, Ecco, TheNorthFace, Propet, Rockport, Waldlaufer and Wolky.

The bottom line is that needing to wear AFOs should not limit how we present ourselves to the world. Our choice of shoes should speak more about our personalities than our disabilities. ★

Beth has been an AFO-wearer since 2004 and currently leads AllardUSA’s TeamUP movement. She gathered the vendors and brands mentioned here via input from hundreds of actual brace-wearers, none of whom were compensated for their opinions.

Tubin’ down the Stonycreek River

TUBAPALOOZA 2020 RAISES $5,500 FOR CMTA

More than 400 people—socially distanced and in pods—drifted down the Stonycreek River in Johnstown, Pennsylvania, September 6, raising $5,500 for the CMTA in the process.

Jill and Chad Gontkovic, the owners of Coal Tubin’ Adventures, dedicate a day on the river to a different charity every year and this year the CMTA was the lucky recipient.

Jill and Chad play in Development Director Jeana Sweeney’s annual softball tournament, which was canceled this year because of the pandemic. Knowing of Jeana’s passion for creating CMT awareness and raising funds for CMT research, they chose to champion the CMTA.

It’s yet another example of the amazing way that events and fundraisers have morphed during the pandemic, but continue to help the CMTA. Many thanks to Coal Tubin’for being a CMTA champion.

City Living Helps CMTer Stay Active

BY MIKE DRIEDGER

As someone with CMT, I've found that living in a city—in my case, Toronto—has made maintaining a healthy and active lifestyle easy. Of course, urban living might not work for you. But I'd like to share with you how I owe much of my health, mobility and happiness to living in a walkable and bikeable community.

Author Mike Driedger with his trusty bike

To start, let me introduce myself. My name's Mike. I'm a 39-year-old male living in Toronto with my wife, and I have CMTX. While I haven't begun using AFOs yet, my CMT has progressed to the point that I do regularly walk with a cane for stability—like many of you, I'm a wobbly guy who's prone to falling.

I live just outside of Toronto's downtown core in a 25-story apartment building. I originally moved in because it had both a swimming pool and a gym, which has made daily exercise, especially in our harsh Canadian winter, much easier—all I have to do is go downstairs! Even at the end of a long day, having the pool and gym only a few floors away makes it hard to be lazy. On average, I swim about two km (1.2 miles) each week. And now, after 12 years of living with these amenities, I can't imagine living without them.

Toronto is a dense metropolis with many walkable neighborhoods. Most of central Toronto has a high walk score, which means most amenities—grocery stores, pharmacies, community centers, restaurants and bars—are within walking distance of residential areas. So, I walk a lot. I walk for groceries with a wheeled "drag bag." I walk to run errands, go out to restaurants and meet up with friends and family.

For distances a little farther away, I walk to public transit stops, take a bus, subway, or streetcar, and then walk the rest of the trip. As I already mentioned, I walk with a cane most of the time, but I occasionally switch to walking poles in the winter.

When I'm not walking, I'm biking. I bicycle to work most of the year, except during the iciest and snowiest months of winter. During those months I drive my car—yes, I have a car but only drive about 6,500 km (4,000 miles) a year.

My office is about 8 km (or 5 miles) from home, so it's a reasonable bike ride both ways. I'm also lucky that my employer values active transportation and has shower facilities for employees. This seems to be something that more and more urban-based employers are providing, and it's definitely appreciated.

Urban living has allowed me to stay physically active on a regular basis. In fact, many urban centers like Toronto actually make it harder and more expensive to drive than to walk, cycle or take public transit. I'm active and getting physical exercise just going about my daily life. Whether heading to work, shopping for groceries, running errands, visiting friends or heading out on the town, I'm using my own body to get there. Plus, having a gym and pool in my building means I don't have any excuses, even when I'm home.

Luckily for me, my wife loves being active and exercising too, maybe even more than I do, and she often pushes me to keep going. We joke that our hobby is exercise.

As someone with CMT, I find that this works really well to ensure I'm fit and staying active. Not only do my daily routines and life keep me mobile, but I actually enjoy swimming, cycling and going on long walks in my spare time. Urban living has made all of this easy.

I've found that the best path for physical health is about making exercise a part of my daily routine—and making it as easy as possible. Even if big-city living won't work for you, maybe it would benefit someone you know. If you're young and still trying to figure out where you want to live for school or work, at least consider the simple health benefits of living in a more accessible and walkable city or town. As a person with CMT, you won't need to "find time" to be active—it'll just happen! ★

Mike is the co-leader of the Toronto CMTA Branch. He recently completed a 1,000-kilometer ride for the Vermont Cycle (and Walk!) for CMT.

WHAT’S ON YOUR MIND? *Ask David.*

Dear David:
I am the mother of a 10-year-old boy who was diagnosed with CMT one year ago and fitted for his first pair of braces a few months ago. He is my heart and is the best thing that has ever happened to me. He seems well-adjusted, but he is so quiet that I honestly don’t know what is going on with him much of the time. Although I have not been tested for CMT, I am sure I have it as well. My mom is in her seventies and has CMT, but thankfully she is only mildly affected. She never speaks about it and has always been the "grin and bear it" type, though she often seems angry. I was clumsy growing up, but whenever I expressed frustration my mom would tell me to "stop complaining and feeling sorry for yourself." I was not allowed to express any negative feelings, so I just basically shut down emotionally. Fortunately, at 50 years old and with the help of a good therapist, I am finally learning not to be ashamed of any of my feelings. I want my child to be able to express himself and not be self-conscious about his CMT or hold himself back from doing whatever he wants.

David replies:
You are already doing both of you an invaluable service by getting help from a therapist who teaches you that there is no shame in expressing feelings and that feeling vulnerable is about feeling alive. Showing others who we are is an act of courage. Sometimes the best way we can help our kids be okay with their emotions is to be a parent who models a healthy expression of feelings for her child. Anxiety and depression often come from an unhealthy suppression of emotion. Our kids notice everything, so if your son senses that you are comfortable with yourself—including your CMT—that will give him a great start in knowing that one doesn't have to be perfect to succeed in life. He will undoubtedly have challenges in school, but creating a safe home environment where he knows he can tell you anything is invaluable. Asking him what’s going on without being judgmental is the key. True attentive listening is golden. Put down your phone, look him in the eyes and gently listen. Listening is a powerful form of love. Knowing that it is okay for him to express feelings of fear or sadness or anger will help him develop healthy coping skills. Knowing that he can share these feelings without being reprimanded will help him feel safe. Your child may not want to talk and that is okay, but simply knowing that you are there for him when he is ready will be very comforting.

Whenever possible, point out the things your son excels in so he begins to develop a healthy sense of self-esteem. He might resist your warm and fuzzy compliments, but pour it on because he is taking it in. By the way, there is nothing wrong with your child being quiet or a bit shy. I was a quiet kid and somewhat of a loner growing up, but that helped me develop a rich internal life. Check in with your son so he knows that you care about what he is going through, even if he is not ready to speak about it. Being accepting and compassionate with yourself despite your own imperfections as a parent will teach your son to do the same. Modeling self-love—CMT and all—will go a long way toward helping him become his best self. ★

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.*

CMTA WELCOMES NEW ADVISORY BOARD MEMBER

The CMTA is happy to welcome Kenneth Raymond to the Advisory Board. Kenneth, who was diagnosed with CMT1 in 2002 at the age of 29, is a writer, a CMT blogger and a CMT patient community advocate. He is passionate about learning as much as he can about CMT and translating the disease’s complexities into easily relatable narratives presented from the patient perspective.

Born and raised in the metro Detroit area, Kenny earned an associate’s degree from Northwest Michigan College. He was a machine operator in a metal stamping plant in Traverse City, Michigan for 10 years and was elected recording secretary of his local union. He was also elected to the bargaining committee, where he helped negotiate labor agreements and administered the health and safety program. He retired on disability in 2008.

Kenny stays busy in retirement: In addition to helping moderate the CMTA discussion group on Facebook and writing a blog on CMT (www.thecryptidsloth.com/), he is a photographer and photo editor, video editor, 3D CGI creator, motion graphics creator/editor and a woodworker. He still lives in metro Detroit with his wife and five children, who range in age from 15 to 27. They also have two young grandsons.

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CMTA BRANCH NEWS

CHICAGO, IL

The Chicago branch held virtual meetings on July 8 and July 23. Branch member Paul Fowler, a health coach and registered Thai therapist, spoke at the first meeting. He gave a wonderful and timely presentation entitled Breath Work, Meditation, and Movement—stress Reduction Techniques for a Stressful Time. He led some great breathing exercises, a body awareness meditation and a joint-loosening exercise. Dr. Ryan Jacobson, director of the CMTA Center of Excellence at Rush University, spoke to the second meeting about the various forms of CMT, research news and ideas for living with CMT. He also outlined what a typical visit to his clinic entails.

BALTIMORE, MD

The Baltimore Branch held three virtual branch meetings via Zoom last summer. The first meeting was held on July 19 with guest speaker Jonah Berger, National Youth Programs Manager for the CMTA, who spoke about Camp Footprint and his own CMT journey. Camp Footprint was held virtually this year but did not lack in enthusiasm or good times. The second meeting was held on August 15 with guest speaker David Tannenbaum, psychotherapist and CMTA Advisory Board member. He discussed methods for dealing with the blues while coping with both CMT and a pandemic. The third meeting was held on September 19 with guest speaker Dr. Steven Scherer, a neurologist at the University of Pennsylvania and one of the country's leading experts on CMT. Dr. Scherer discussed the latest advancements in the search for a cure and answered questions from participants.

NEWBURY, NH

The Newbury, NH CMTA Branch met online July 11 with seven people in attendance. They welcomed two guest speakers: CMTA Board Member Elizabeth Ouellette, co-chair of the annual Cycle (and Walk!) 4 CMT, which raises funds for STAR research, and Laurel Richardson, CMTA director of community outreach. Laurel talked about the CMTA's Patients as Partners in Research initiative, clinical trials, Camp Footprint, CMTA Centers of Excellence and much more.

CENTRAL NEW JERSEY

Twenty people from the Central New Jersey and Buck's County Branches gathered on Zoom July 12 for a presentation by genetic counselor Shawna Feeley, MS, LGC, from the University of Iowa CMTA Center of Excellence. Shawna, a member of the CMTA's Advisory Board, is one of only a few geneticists who specialize in neurogenetics and an expert in the genetics of CMT. She started with a slide presentation that was packed with info on inheritance patterns and followed that with an extended question-and-answer period.

NEW MEXICO

The New Mexico Branch met on Zoom for the first time on August 1 with nine members in attendance. CMTA Board Member Elizabeth Ouellette spoke on staying active with CMT and using "activity as a treatment." She pointed out that there is a lot of exercise information on the CMTA website (www.cmtausa.org) including things such as Pilates and chair yoga. The next New Mexico Branch meeting will be on Saturday, November 7, most likely on Zoom, and the topic will be CMT and pain.

CLEVELAND, OH

Thirteen people attended the Cleveland Branch's July 16 meeting. The topic was "Enhancing Overall Wellness through Exercise & the Benefits for CMT" presented by Lisa Augustine, PhD. Dr. Augustine reviewed key points of healthy self-care, including stress management, adequate sleep, healthy eating and exercise. She then reviewed stretching exercises and exercises that could aid in balance. She closed by asking each attendee to set a small goal of something they wanted to do to help with a healthier lifestyle.

COLUMBUS, OH

The Columbus Branch welcomed special guest speaker neurologist Dr. Zarife Sahenk to its virtual branch meeting July 15. Dr. Sahenk leads the CMTA Center of Excellence at Nationwide Children's Hospital in Columbus. In addition to seeing many CMT patients in her clinic, she works extensively on CMT research. Dr. Sahenk gave an in-depth presentation on CMT and shared information about her upcoming gene therapy trial at Nationwide.

CHESTER COUNTY, PA

The Chester County Branch met on August 31 to discuss their plans for participating in the Virtual Walk 4 CMTA and CMT Awareness Month. Branch co-leader Ashley Trout shared her screen with the group and explained how to register for the walk. Individual walks took place throughout the month of September. A few of the members planned to walk together, socially distanced, at a local park. In addition to the virtual walk, the branch held a virtual Bingo Night on September 24 as a way for members to get together and also raise money for the CMTA.

SEATTLE, WA

The Seattle Branch met virtually on July 11 with 12 people in attendance. Participants talked about the ups and downs of the pandemic, braces and foot surgery. They also discussed the idea of a virtual wine tasting and having Camp Director Jonah Berger as a guest speaker.

THERE'S STILL TIME TO WALK 4 CMT

Because this year's Walks 4 CMT are virtual, participants aren't limited by either time or location. Sign up today to hold a walk or mini-walk—anyone, anywhere can participate!

Walk 4 CMT is a volunteer-led national fundraising campaign for the CMTA. Funds raised fuel the CMTA's quest to find treatments and a cure for CMT. The walks have already started, but participants have until year's end to hold one.

The walks look a little different this year—and sometimes stretch the definition of "walk" to its breaking point, but the momentum continues. Walk leaders have come up with a number of creative ways to be together using Zoom and social media. Many are kicking things off with a fun activity like a Bingo or trivia game night, then walking for an entire month, some in smaller groups, all with proper social distancing. Mike Casey from the Syracuse Walk even had a face mask fashion show on Zoom to kick things off.

Look for a walk near you or check out our OWN Walk page www.walk4cmt.org and don't forget to join our new Walk 4 CMT Facebook page www.facebook.com/Walk4CMT.

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For more information on how to donate stock or mutual funds to the CMTA, please contact Jeana Sweeney, Director of Development, at jeana@cmtausa.org.

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Jessica Barton
541-218-5350 (cell)
541-846-8525
Portland Area
Laurel Richardson
800-606-2682,
Ext. 112

PENNSYLVANIA
Bucks County Area
Julie FitzGerald Schell
315-573-3919
Chester County
Carol Aruffo
610-405-9291
Ashley Trout
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Harrisburg
Erin Weierbach
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Johnstown Area
J.D. Griffith
814-539-2341
Jeana Sweeney
814-269-1319
Northwestern Area
Joyce Steinkamp
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Pittsburgh
Debra Czarnecki
412-331-6744

SOUTH CAROLINA
Columbia Area
Zack Boyd
803-622-6565
Kyle Bryant
803-378-6202
Greenville Area
Rebecca Lauriault
864-918-2437

TENNESSEE
Nashville Area
Teresa Shoaf
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TEXAS
Austin Area
Nate Halk
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Dallas/Fort Worth
Thomas Roderiguz
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El Paso Area
Jo Ann Longoria
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Olivia Longoria
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Houston Area
Miranda Burge
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UTAH
Orem Area
Melissa Arakaki
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VIRGINIA
Blacksburg/ Roanoke Area
Karen Brown
540-252-9453
Fredericksburg
Leigh Van Doren
540-370-1968
Harrisonburg Area
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Ext. 112
Suffolk Area
Holly Hall
757-477-6122

WASHINGTON
Seattle Area
Denise Snow
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Emily Osborne
425-220-4225

WEST VIRGINIA
Charleston Area
Karen McClure
304-548-4413

WISCONSIN
Madison Area
Debi Weber
608-712-8709
Milwaukee Area
Lois Hawkins
414-249-0390

CANADA
Southern Ontario
Kelly Hall
519-843-6119
Toronto Area
Linda Scott Barber
416-997-5084
Michael Driedger
647-680-7601

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 (Erbitux)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Eribulin (Halaven)
Fluoroquinolones
Gold salts
Ipilimumab (Yervoy)
Ixabepilone (Ixempra)
Lefluonamide (Arava)
Lenalidomide (Revlimid)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Nivolumab (Opdivo)
Pembrolizumab (Keytruda)
Perhexiline (not used in US)
Pomalidomide (Pomalyst)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:

5-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in US)
a-Interferon

Negligible or doubtful risk:

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

CMTA
Charcot-Marie-Tooth Association

The Charcot-Marie-Tooth Association
P.O. Box 105
Glenolden, PA 19036
1-800-606-CMTA (2682) FAX (610) 499-9267
www.cmtausa.org

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.