

THE

# CMTA Report

FALL 2019

[www.cmtausa.org](http://www.cmtausa.org)



## THE TYPE 2 ISSUE

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THE **CMTA** Report

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# WE ARE FAMILY...



DEAR FRIENDS,

**“Family means no one gets left behind or forgotten,”** actor David Ogden Stiers once said. Those are words the CMTA lives by as we push hard every day to make sure no one in our CMT family gets left behind or forgotten. The goal of our Strategy to Accelerate Research (STAR) is to develop treatments for all types of CMT and the entire CMT family.

We will have many exciting research developments to share with you in the coming months, but this issue of *The CMTA Report* is focused on the Type 2 branch of our family. Because of the crossover involved, we think many of these developments will also apply to Types 1 and 4 (which we’ll be updating later this year). Thanks to STAR and the support of two committed Type 2 families who are challenging the community to match \$1.5 million in donations, we have set the stage for a number of Type 2 breakthroughs on our way to treatments for CMT. Our CMT2 strategy covers virtually all Type 2s, including those with unknown genetic causes.

Despite the diversity of genetic causes of CMT2, there are encouraging signs that a few types of therapy may have broad application. We have identified three major therapeutic approaches—gene therapy, inhibition of axon degeneration and small molecule therapies—that can be used to bring CMT2 therapies to clinical trials (and that may also apply to the unknown and/or undiagnosed Type 2s).

The opportunities to take our research efforts to the next phase are due in large part to the momentum we generated in 2011 with our work in 2A and 2E, developing the animal models and other tools that attracted half a dozen pharmaceutical companies as partners. These three strategies will require a host of ancillary efforts to reach clinical trials. In total, the CMTA will need \$5 million in the next four years to implement our Type 2 strategy. If you or a loved one has Type 2, we are asking you to help us as we keep reaching for our goals.

Donations will be matched on a dollar-for-dollar basis, thanks to challenge gifts made by Bob and Gail Buuck, who have been supporting the CMTA since 1997 because of the successes they’ve seen over the years, and the Chizen family, whom you’ll read more about on page 7.

Type 2’s time in the STAR spotlight is here. With your support and our relentless hard work and determination to bring treatments to you, we can force a breakthrough.

Sincerely,

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

AMY GRAY, Chief Executive Officer

# STAGE SET FOR TYPE 2 BREAKTHROUGHS

**WHILE BREAKTHROUGHS ARE TYPICALLY VIEWED AS SUDDEN, DRAMATIC DISCOVERIES, they are in fact the result of relentless hard work and determination. That's what has been going on with Type 2.**

To recap, CMT2A is caused by dominant mutations in Mitofusin 2 (*MFN2*). The STAR team has developed two excellent rat models for CMT2A that are being made available to the research community and represent an important tool to test potential new modulators of mitofusin activity. Stem cell models of CMT2A have also been developed for CMTA-sponsored research in the laboratory of Dr. Robert Baloh at Cedars-Sinai Medical Center. In partnership with several companies, therapeutic approaches under study include inhibition of axon degeneration and gene therapy. Other candidate molecules have emerged from academic research, with planning underway to test these as well.

CMT2E is caused by dominant mutations in the Neurofilament Light Protein (*NEFL*) gene. With support from the CMTA, one of the best mouse models of CMT2E, made by Dr. Ronald Liem at Columbia University, has been extensively characterized in collaboration with Dr. Steven Scherer at the University of Pennsylvania. Both human and mouse stem cells containing CMT2E mutations have been differentiated into motor neurons and are being used in drug screens to identify therapies that prevent aggregations of neurofilaments seen in CMT2E. Candidate compounds have been identified and are being

further tested, and human stem cell cultures are being developed for larger chemical screens.

Despite the diversity of genetic causes of CMT2, there are encouraging signs that a few types of therapy may have broad application. The three major therapeutic approaches that can be used to bring CMT2 therapies to clinical trials (and that may also apply to undiagnosed Type 2s) are:

## GENE THERAPY

**Progress:** One of the most exciting clinical developments has been the development of gene therapy for Spinal Muscular Atrophy (SMA), which affects the same motor neurons that are affected in CMT2. The CMTA has supported pilot studies of gene therapy in CMT mouse models and convened a meeting of gene therapy experts to outline the next steps in bringing this therapeutic strategy to CMT2. We have recruited leaders in the gene therapy field to our scientific advisory board, who are guiding our efforts in this area. We are also partnering with an eminent expert in the new technology of genome editing to explore the application of this therapeutic approach to CMT2A and CMT2E.

**Next Phase:** Support the first single-patient clinical trial of gene therapy for CMT2 in 2020, and extend this therapy to more common forms of CMT2 by the end of 2021.

## INHIBITION OF AXON DEGENERATION

**Progress:** The progression of all types of CMT occurs as the

longest axons are lost in a process called axon degeneration. CMTA partners are working on developing chemical inhibitors of recently identified biochemical triggers of axon degeneration. The CMTA plans to explore the applicability of this recent technology to the multiple forms of CMT2 using the many models of CMT that have been generated within our network.

**Next Phase:** Test the applicability to CMT2A and CMT2E by the end of 2019, leading to phase 1 clinical trials by 2021.

## SMALL MOLECULE THERAPIES

**Progress:** The most common cause of CMT2A is mutation of the Mitofusin 2 gene. Researchers have recently identified custom-designed molecules that can stimulate the activity of mitofusin proteins. We are seeking to promote development of this therapy by testing for efficacy in our recently developed rat models of CMT2A.

**Next Phase:** Complete the first evaluations of these compounds in our CMT2A rats by 2020, leading to phase 1 clinical trial as early as 2021.

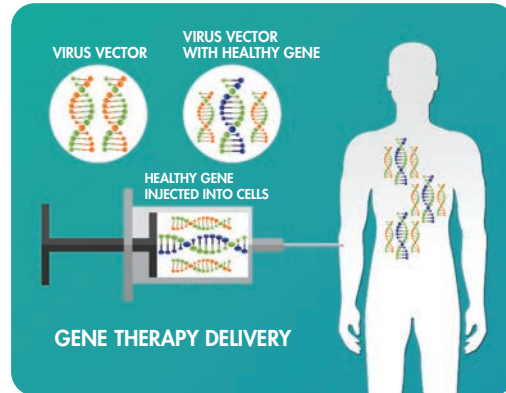
These three strategies require a host of ancillary efforts—stem cell studies to make human neurons based on cells obtained from CMT2A and CMT2E patients, definitive genetic diagnoses for the 50 percent of CMT2 patients who don't yet have them and the development of effective biomarkers and outcome measures for clinical trials that will make CMT an ideal target for therapeutic development. ★

# NEW GENE THERAPY DEVELOPMENT PROGRAM FOR CMT2A ANNOUNCED

The CMTA and Passage Bio announced September 9 the licensing of a gene therapy development program for CMT2A under the company's research, collaboration and license agreement with the University of Pennsylvania.

Passage Bio is a privately held, fully integrated genetic medicines company with a mission to develop a portfolio of life-transforming AAV (Adeno-associated virus)-delivered therapeutics for the treatment of rare monogenic central nervous system diseases. The company is based in Philadelphia and has a research, collaboration and license agreement with the University of Pennsylvania and its Gene Therapy Program (GTP), as well as the Orphan Disease Center at Penn.

"CMT2A affects almost all of the severe dominant CMT2 cases and patients suffering from this rare disease experience progressive muscle atrophy of legs and arms, with no FDA-approved curative or symptomatic medications available," said Dr. Stephen Squinto, co-founder and interim chief executive officer at Passage Bio. "The Gene Therapy Program at Penn has developed AAV vectors and delivery methods to target the nerve cells that are affected in CMT2A, raising the possibility of slowing or preventing progression of the disease



by tackling the underlying genetic cause. Passage Bio will develop this experimental therapy, designed to restore the normal function of the MFN2 gene, which is mutated in patients with CMT2A, and we look forward to initiating a clinical trial in the near future."

CMTA Board Chair Gilles Bouchard said, "Just one year after we formally launched our gene therapy program, we are witnessing two major players in the field working col-

laboratively to develop potential treatments for one of the more common types of CMT. We are delighted to partner with Passage Bio and Penn in this effort and to contribute key elements of the Strategy to Accelerate Research (STAR) program, such as pre-clinical and clinical assets, access to top CMT experts and engaging the CMT community."

The clinical trial is anticipated to be a global, open label, multicenter, dose escalation study to evaluate the safety, tolerability and exploratory efficacy endpoints in subjects with CMT2A. ★



## CMTA Board Approves Extension of CMT2E Project



Ronald Liem

The CMTA Board of Directors voted June 18 to award \$96,803 in second-phase funding to Ron Liem, PhD, for continued testing of an FDA library of compounds aimed at reducing the neurofilament aggregation of CMT2E. The money will be used to screen the remaining 35 percent of an FDA-approved library (360 compounds) and to test four HDAC6 inhibitors. Screening a library of compounds pre-approved for other purposes can expedite the drug discovery process.

Researchers at Liem's Columbia University lab are looking for compounds that reduce the neurofilamentous swellings observed in a mouse model of CMT2E. Their strategy is twofold: to identify potential drug targets for treatment of CMT2E, and perhaps other CMTs, and to identify FDA-approved drugs that can be repurposed for treatment of CMT.

The CMTA's reviewers said the proposed experiments are a natural progression of Liem's initial work and are necessary to move leads further in the development pipeline.

CMTA CEO Amy Gray said the newly approved project "aligns nicely with the CMTA's Strategy to Accelerate Research (STAR)."

# THE ST. LOUIS PATIENT/FAMILY CONFERENCE: *A Patient's Perspective*

BY KATHIE KERR

I attended the CMTA Patient/Family Conference in St. Louis on September 7 and I'm glad I did! The speakers and displays were very informative and provided me with answers to questions like "What's next?" for me in terms of treatment options and orthotics.

Dr. Raghav Govindarajan, director of the CMTA Center of Excellence at the University of Missouri, advised taking a holistic care approach to CMT, including healthful eating habits, exercise and mindful meditation. He recognized that there are times when pain has to be managed with medication but encouraged listeners to seek alternative paths as well.



Asked how medical marijuana and CBD oil work to control CMT symptoms, Dr. Govindarajan said that while there is no research on the subject yet, some of his patients have reported a lessening of pain.

Dr. Vovanti Jones from University of Missouri Health Care introduced me to a specialty

title I had not heard before: "physiatrist." A physiatrist is a doctor who specializes in the rehabilitation and physiological treatment of patients with an illness or injury that affects movement. These specialists have extensive knowledge of the nerves, muscles, bone, and brain.

(continued on page 8)

## THE NATIONAL CMTA PATIENT/FAMILY CONFERENCE IS COMING TO ATLANTA ON NOVEMBER 2



### Please join us and learn about the many advances in CMT research

The Charcot-Marie-Tooth Association is pleased to announce its Atlanta CMTA Patient/Family Conference. The conference will be held at the Le Meridien Atlanta Perimeter Hotel – 111 Perimeter Center West, Atlanta, GA 30346.

Conference topics include neurology, genetics, breathing, surgery, physical therapy, gene therapy, STAR Research Update and much more!

To learn more go to:

[cmtausa.org/get-involved/patient-family-conferences](http://cmtausa.org/get-involved/patient-family-conferences)

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# WHY I GIVE: Bruce Chizen

**THE CMTA is pleased to announce a second challenge grant to support the organization's exciting new Type 2 CMT research strategy, which you can read more about on p. 4. Bruce Chizen, a special advisor to the Board of Directors, will match donations to CMT2 research on a one-to-one basis, up to \$500,000. The former Adobe Systems CEO tells us why he thinks STAR research is such a good investment.**

**W**hen Bruce Chizen was diagnosed with CMT2 in 2016, the CMTA was the first place he turned to for help and information. His internist put a name to the symptoms that had bothered Bruce for most of his life, but discouraged him from having genetic testing because he couldn't do anything about the results.

Unwilling to accept that answer, Bruce went to the CMTA website for a better understanding of the disease. Today he says that the help the CMTA provided him and the potential of finding a cure for the next generation made him want to assist the organization in any way possible.

In the past three years, he's done just that. His first donation to the CMTA led to a breakfast meeting with CMTA Board Chair Gilles Bouchard, his Silicon Valley neighbor. That quickly led to a role as special advisor to the Board of Directors, where he brought his extensive business and nonprofit experience to the organization's search for a new CEO.

That business experience began in Brooklyn, where he was

born and raised "before it was cool." His mother was a homemaker and his father owned a store specializing in radios and TVs—"the tech of its time." Bruce thought he would be a teacher after studying health sciences at Brooklyn College, but early on discovered a knack for business. He started off as a salesman at Mattel Toys, selling the first wave

**Bruce Chizen calls the CMTA "an extremely focused and effective organization."**

of video games, then joined pre-IPO Microsoft in the mid-eighties as its East Coast sales manager. He moved to California to work for Claris, a software subsidiary of Apple, then joined

Adobe for 14 years, seven as CEO.

Starting out with nothing left Bruce "very sensitive" to how nonprofits use his donations. "I've seen a lot of waste," he says. Happily, he hasn't seen it at the CMTA, which he calls "an extremely focused and effective organization." Bruce praised the board's entrepreneurship, and likens the business-focused STAR model to "what a venture capitalist would do with a startup," engaging partners to provide needed services and capital.

"The path to a cure is possible and probable," Bruce believes, "so



**Bruce Chizen,**  
special advisor to  
the CMTA Board

the more money that can be raised to help with the research, the faster a cure can be had." He's encouraged by STAR's progress in the past several years as he sees "success breeding success."

Bruce also considers education and community services a "critical" part of the CMTA's mission. It's what drew him to the CMTA in the first place, and he sees the need for a continued strong presence in this space.

Bruce says he is "semi-retired" now, though he admits that his wife might dispute that characterization. He serves as a senior advisor to Permira LLC, a private equity fund, and as a venture partner for Voyager Capital, an early stage VC firm. In addition he sits on a number of for-profit boards, including publicly listed Oracle Corp. and Synopsys Inc. He also continues to advise nonprofit institutions including KQED, a PBS affiliate, and the Silicon Valley Education Foundation. ★

**To have your donation in support of CMT research matched, please visit [www.cmtausa.org/wearefamily](http://www.cmtausa.org/wearefamily) or mail in the form on p. 23 with your check.**

## ST. LOUIS CONFERENCE

(continued from page 6)



Sisters Meredyth and Elyzabeth Waymam

## YOUTH OUTING IN ST. LOUIS

While conference attendees networked and listened to presentations, the kids in the room piled into a van and headed out for a day on the town. They got to know each other on the ride to the first stop, finding connecting easy because everyone understood what it's like to deal with CMT.

The first stop was the famous St. Louis Gateway Arch. The group rode one of the tiny transport pods up to the top, some 630 feet in the air. After the Arch, the group lunched at Fitz's, a restaurant and soda factory with windows where diners can eat while watching production. Group members indulged in ice cream sodas bigger than their heads while talking about the ups and downs of life with CMT. The day ended with a tram tour through the animal preserve at Grant's Farm.

Throughout the day, the kids connected with and took care of each other, leaving their self-consciousness behind. CMTA Youth Director Jonah Berger, who led the trip, said that any child who deals with a daily challenge like CMT earns a certain wisdom and "magic occurs whenever you get those children together in the same place. You get to watch them relax and be their truest selves."

Jonah encourages everyone to attend CMTA Patient/Family Conferences when they come to a nearby venue and to sign their kids up for the youth outing. "It is a day they will not soon forget," he said.



Physiatrists are also experts in pain medication. There aren't that many listed in Kansas City, Missouri, but I think it would be very helpful for me as I seek physical therapy to find a facility with one on board to coordinate treatment. Dr. Jones talked about the importance of exercising and strength building and improvements in adaptive equipment that help people function better in their homes.

Kyle Fiala, DPM, from University of Missouri Health Care, reviewed surgical options for treating the CMT foot. While always the last thing to try, if surgery goes exactly as expected and is a total success, it can get people out of braces, he said.

The five-hour conference concluded with information from orthotics and physical therapy specialists. Fortunately, the conference leaders allocated plenty of time for Q&A. For \$40, and a reasonably priced hotel room, the conference was so worth it. I'm looking forward to others.

To stay current with CMT research, scroll to the bottom of any of the CMTA website pages, and click on "Subscribe to the latest news from CMTA." In the "Our Research" section, you can also submit a CMT "Patients as Partners in Research" profile and subscribe to receive research updates about a specific type of CMT.

As far as I know, I am the first one in my family to have CMT, and I have no friends or anyone outside the medical community I speak to about it. So, for me, the best part of this conference was meeting some wonderful people, young and old, who reminded me I was not alone. And, after seeing a 3-year-old with braces, it made me count my blessings that my CMT didn't worsen until my 60s. ★

*Kathie Kerr, 66, lives in Kansas City, MO.*



# Challenged Athletes Foundation Offers Grants To Support CMTers' Fitness Goals

The annual application period for grants from the Challenged Athletes Foundation (CAF) opened September 3 and runs through November

1. Anyone with CMT can apply for a CAF grant, which provides financial assistance to support the recipient's physical goals for fitness, health and recreation.

The Challenged Athletes Foundation (CAF) was founded 25 years ago to help triathlete Jim McLaren buy a wheelchair accessible van after he was injured while competing in a race. The foundation's first efforts were met with enthusiasm and a developing sense of need as they found a community of people who wanted to be active but lacked the opportunity or financial means. Since 1984, the CAF has awarded more than 26,000 individual grants to individuals with physical challenges across 103 sports.

As the CAF website notes, millions of individuals with physical disabilities do not have access to the critical adaptive sports equipment and programming they need to be active. As a result, 50 percent of adults with disabilities get no aerobic exercise and children with disabilities have a 38 percent higher obesity rate than children without those challenges.

The foundation's mission is to provide opportunities and support to people with physical challenges, so they can pursue active lifestyles through physical fitness and competitive athletics. It believes that involvement in sports at any level increases self-esteem, encourages independence and enhances quality of life.

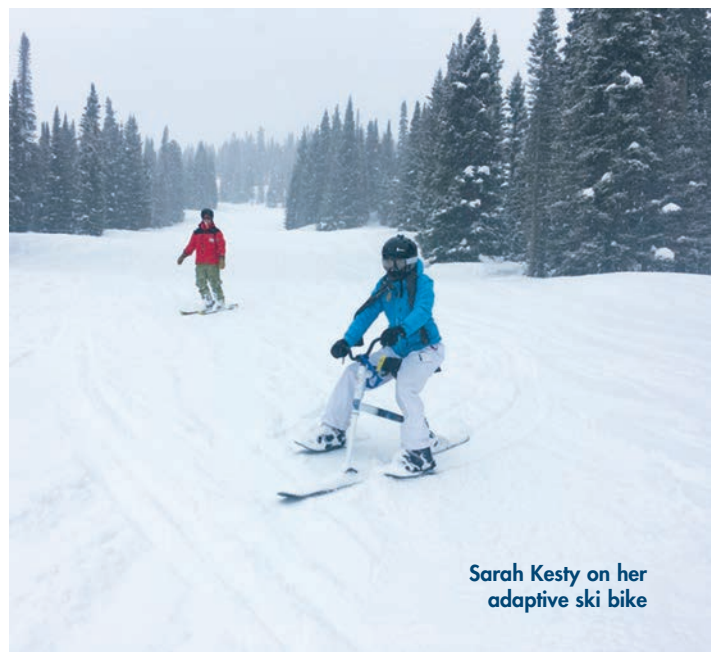
## Applicants can request assistance for:

- **Purchasing sports equipment**, adaptive or not. Examples include bikes, hand bikes and adaptive ski equipment.
- **Travel and competition expenses** for people who want to participate in a local, national, or international sports event.
- **Training or gym expenses** for people who want to develop strength and balance.
- **Prosthetics** for amputees.

## To apply for funding, applicants must submit:

- **A medical verification of disability**, such as a doctor's note that documents a permanent physical disability, no matter what year the note was written.
- **A personal letter of reference** that describes both the applicant's journey in sports and athletics as well as how the CAF grant would help in that journey. This can come from a coach, trainer, peer or parent (in the case of a minor).
- **Two photos**, preferably doing the chosen activity or sport.
- **Financial documentation** of income. Examples include 1040, W2, SSI or SSDI forms. CAF gives preference to those showing greatest financial need.

CMTer Diane Easter said "The CAF grant allows me to belong to an adaptive gym. My workouts have made me stronger, improved my balance and decreased my falls. The best part is the hope I have again. I can positively impact my strength and how I feel. I'm so thankful for the CAF grant!"



Sarah Kesty on her adaptive ski bike

**APPLY FOR A GRANT AT:**  
[www.challengedathletes.org/programs/grants/](http://www.challengedathletes.org/programs/grants/)

CMTA Advisory Board Member Sarah Kesty, who was awarded a grant to purchase an adaptive ski bike last winter, said the CAF grants provide the "opportunity to fight back against our CMT—its pain, sometimes hopelessness—and have fun in the process."

According to Sarah, "You don't have to be the embodiment of an 'athlete' to enjoy sports and activities, and CAF helps remove the financial barrier you may face in accessing an adaptive activity." Sarah encourages others "to transform the pain of CMT into motivation." ★

A poster for the CMTA 10th Annual New York Star Cocktail Reception. The poster features a diamond-shaped logo with the CMTA logo and the text "A Night of Celebration". The event is scheduled for October 29, 2019, at 6:30 PM. The event is hosted by Phyllis Sanders and Ruth and Alan Korowitz at The Essex House, NYC, 160 Central Park S, NY, NY 10019. The poster also includes contact information for RSVP and ticket purchases.

HOSTED BY  
PHYLLIS SANDERS AND  
RUTH AND ALAN KOROWITZ

THE ESSEX HOUSE, NYC  
160 CENTRAL PARK S  
NY, NY 10019

RSVP by October 5  
For any questions, contact:  
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516-741-5252 x2145

To purchase tickets and/or  
make a donation, please visit:  
[cmtausa.org/nygala](http://cmtausa.org/nygala)

CMTA  
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A Night of  
Celebration  
10TH ANNUAL NEW YORK  
STAR COCKTAIL  
RECEPTION  
OCTOBER 29, 2019  
6:30 PM

# CMT and Wrist-Hand Interventions

BY JUSTI APPEL, CO, BOCP, PHD, FAAOP

**T**he goal of a wrist-hand orthosis (WHO) is to help achieve a hand position that is more functional or that prevents deformity or pain. The amount of deformity (if any), weaknesses in the joints of the hand and wrist, and lifestyle goals should all be considered in determining which wrist-hand orthosis best meets the wearer's overall needs—and what modifications may be necessary.

There are several types of WHOs: resting hand splints, restrictive movement splints and custom-designed hand splints.

A **resting hand splint**, which can be used daily or solely at night, provides a prolonged stretch that promotes safe joint positioning and reduces morning stiffness. Resting hand splints are recommended for patients who need help with preventing contractures and with maintaining and increasing the range of motion in the fingers. The resting splint is also helpful in elongating and extending the wrist and fingers and preventing over-lengthening of



**A RESTING HAND SPLINT: Allard "S.O.T." resting WHO**

weak or paralyzed muscles. The resting position can help with improving circulation and can support both the hand and finger joints, reducing the risk of hyperextension of the thumb.



**RESTRICTIVE MOVEMENT SPLINTS: Allard's Vission Laced and Strapped WHOs (above) and Allard's S.O.T. Thumb Splint (below)**



A **restrictive movement splint** is designed to limit movement of the carpal and metacarpal joints and/or to support the hand's arch and thumb position for optimal patient comfort. Restrictive movement splints help prevent overstretched ligaments that may lead to abnormal positioning of the joints. These orthoses are adjustable and can easily be shaped to fit individual anatomy. They can be adjusted as the hand changes. These devices allow for more mobility of the fingers than the resting splint.

**Custom-made splints** are usually designed and fitted by an occupational therapist. The purpose and function can vary—

they are intended to meet each individual's specific needs. A custom splint may be required when pre-made devices cannot be adjusted or fit to address the needed application of the device.

The first steps in getting a wrist-hand orthosis are getting a doctor's prescription, then finding a local certified orthotist. A good starting place is [www.bocusa.org](http://www.bocusa.org) or [www.abcop.org](http://www.abcop.org) for lists of all providers. Anyone considering an Allard WHO/S.O.T. can email [info@allardusa.com](mailto:info@allardusa.com) or call 888-678-6548 and ask for the contact information for an Allard District Manager, who can provide the name(s) of local O&P providers who have experience fitting upper extremity devices.

When scheduling an appointment, it's important to ask what insurance the provider accepts and if they have a practitioner who has worked with patients who have CMT. It's also important to ask what types of devices they have on hand that can be tried on in the office and how long the process will take from measurement to device delivery.

On the initial visit, one should take the physician's prescription, any devices that are in current use or that have been used in the past and a list of goals for the new device. After receiving the new orthosis, any issues like pain or discomfort should be brought to the immediate attention of the provider. ★

*Justi is the Director of Education and Clinical Support for Allard USA Inc.*



**CUSTOM MADE SPLINTS**

# NEWLY FORMED YOUTH COUNCIL HOLDS WEEKEND RETREAT

The newly appointed CMTA Youth Council held its inaugural meeting in Denver June 20-22. Nine teens from across the country spent a weekend connecting, exploring leadership and mapping out plans to empower the youth of the CMT community. They strategized on council membership requirements, issues confronting youth with CMT, ways the CMTA can connect and support the youth more effectively, development of a CMTA Youth Database, social media development for their community and committees to manage future action items.

The social media plans include a youth-specific Facebook page and Instagram account. The team decided to work on ways for youth with CMT to tag and bring in other youth to build the network. The Youth Council will also form a database to collect and organize members of the youth community.

The Youth Council will send a speaker to every Patient/Family Conference, where they will update attendees on youth initiatives and participate in the youth outings that happen at each conference. The next PFC is in Atlanta in November.

CMTA Youth Leader (and Camp Footprint Director) Jonah Berger said members of the Youth Council bring “a fresh perspective, energy, and understanding of modern connectivity to the table,” benefiting everyone in the CMT community.

Youth Council Member Riley Williams called the weekend a dream come true, adding, “It was almost as if something happened that I didn’t even know I wished for.” She continued, “As a council member I have many hopes and dreams. I want to make CMT known. I want to tell people I have CMT and have them know exactly what it is. I want the youth to know just how mighty

their voices are. Lastly, I want people to look at their CMT as a purpose and not a burden. When I started looking at my CMT in a different light is when everything changed.”

Youth Council Member Erin Black said the “weekend was something much larger than any of us could have imagined. The nine of us ... left this retreat weekend reminded of our mission. Three words. Youth empowering youth! I’m hopeful that this is the board that will reach every youth across all corners of the United States affected by Charcot-Marie-Tooth disease.”

In addition to Erin and Riley, the members of the Youth Council are Emily Stufflet, Evan Zeltsar, Sean Tyree, Sam Docker, Meghann McClung, Jaden Ellman, Anthony Herrera and Hannah Roberts. To find out more about the CMTA’s Youth Council, contact Jonah Berger at [jonah@cmtausa.org](mailto:jonah@cmtausa.org). ★



Members of the CMTA Youth Council with CMTA Community Services Director Laurel Richardson at right.

# WHY I FUNDRAISE: *Whitney Wright*

**W**hen Whitney Wright met CMTA goodwill ambassador George Ouellette at the Franklin County Fair in early August, she knew from his Vermont Cycle 4 CMT hat that she had found a kindred soul. She had met people who had family members with CMT before, but George “had support that I never knew about,” she says. George put Whitney in touch with his sister, CMTA Board Member Elizabeth Ouellette, and the 17-year-old quickly enlisted as the CMTA’s newest fundraiser.

Whitney was diagnosed with CMT at 18 months old. She was able to play sports like basketball and softball until she was 11 when she realized that she was different from the other kids. She was upset about it, but she adapted quickly and became the girls’ basketball team manager, a position she’s held ever since. The experience taught her how not to give up and how not to let her CMT affect how she lives her life.

In middle school, it became evident that Whitney’s CMT was getting worse. She recalls: “It was pretty hard because I was starting middle school in a different town with none of my childhood friends, and no one knew how I walked and what my condition was. I grew up with the kids in my elementary school so they thought nothing of it. However, at this new school I was asked questions, which was foreign to me.” She soon learned that “CMT isn’t a terrible thing to be embarrassed about” and that her new classmates were “understanding and welcoming” when she explained it to them.

As Whitney’s condition and pain from hip dysplasia worsened, her family’s search for a doctor became more urgent. With the cartilage in her hips virtually gone, the constant pain was “like gravel rubbing together” as bone scraped bone. The search for relief eventually led to Dr. Ernest L. Sink at the Hospital for Special Surgery in New York City, who performed two surgeries on Whitney when she was 15—a periacetabular osteotomy, a surgical procedure to try and preserve the hips, and a femoral osteotomy to correct deformities in the femur.

Recovery was rough, Whitney says. She couldn’t bear weight on her hips for six to eight weeks and didn’t go to school for a month, which she hated because she loves being around her friends. She also had to do physical therapy for a few months to gain strength back after being immobile for a few



Whitney Wright was diagnosed with CMT when she was 18 months old.

**If you’d like to donate to Whitney’s fundraising campaign, visit [www.cmtausa.org/whitney](http://www.cmtausa.org/whitney). As *The CMTA Report* went to press, she had raised \$3,550.**

weeks. She says that the result was worth the pain, though, and that she “can’t imagine still having hips like that.”

Along with CMT, Whitney also has retinitis pigmentosa, a rare and incurable eye disease that affects the rods and cones in her eyes, leaving her unable to see in the dark or to see fine detail.

Today, Whitney gets around with the help of a walker or a scooter or a friend’s arm. She tries to maintain the muscle she has by swimming in an endless pool. A rising senior, Whitney wants to go to college outside of her native Vermont and become either a speech pathologist or a forensic investigator. “It is tough to have CMT sometimes, but you need to be able to accept it—which I have done—and persevere,” she says. A cure for CMT “would be life-changing,” the new fundraiser adds, both for herself and for others like her. ★

## A SPECIAL THANKS TO ALL FEDERAL EMPLOYEES!

**T**hank you very much for your support of the CMTA through the Combined Federal Campaign. By the end of August 2019, contributions amounted to more than \$11,000, allowing us to continue to meet our mission of improving the quality of life for those with CMT by providing resources and information, increasing awareness about CMT and funding research for the development of treatments for all types of CMT.



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# REPORT FROM CAMP FOOTPRINT

## One Counselor, Two Campers

### A Counselor's Perspective: Maddie Jarrett

**I**walked down the terminal of the Pittsburgh airport alone. I was on the way to my first year of Camp Footprint, and frankly, I was terrified.



Counselor Maddie Jarrett (left) with Paola Martinez

Thankfully, my fears were unfounded. Camp Footprint was a time of abundant celebration, joy and hope. Our days were full of dancing, laughing, swimming, singing, story-telling, prank-pulling and thrilling (but safe!) golf-cart rides. We encouraged one another to slide down the slip-n-slide or try standing on the paddleboard. Joy, acceptance and empowerment were the air we breathed, and for one week, CMT and feelings of celebration were coupled together.

Unfortunately, my experience with CMT during the other 51 weeks of the year is often less than celebratory. Just two days after returning from Camp Footprint, I was walking by a stranger who asked in an inappropriately curious tone, "What's wrong with your leg?" The pain of these less-than-celebratory moments was also shared at camp. One evening, the older girls and counselors shared their stories in a vulnerable, heart-wrenching and incredibly tender discussion of the burdens of CMT. We talked about the stares we feel when moving in public, the physical pain we experience, the inaccessibility of many of our schools, our fear of the disease's progression and the emotional burden all of these have the potential to cause. It was an incredibly powerful moment for me. In all my 27 years, I had

never before connected with other people about these specific elements of my reality.

Amidst all of these celebrations, sorrows, triumphs, tears and blossoming new friendships, I realized that something was changing. I didn't realize the full power of this change until I was at

the airport returning home after camp had ended. After hugging the final camper goodbye, I made my way to my gate. For the first time in a week, I was walking alone. I was immediately re-awakened to the

stares of strangers, which accompany virtually all of my public outings. For most of my life, I have felt those stares. And I have felt them alone. But something was different as I walked down the terminal that afternoon.

We think of our bodies as our own. In fact, it seems a bit ridiculous to argue otherwise. After all,

**"Joy, acceptance and empowerment were the air we breathed, and for one week, CMT and feelings of celebration were coupled together."**

each of us is contained within a very particular space with very clear perimeters: My body ends at the top of my head and at the ends of my fingers and at the tips of my toes. However, my experience with Camp Footprint has challenged this idea.

Before Camp Footprint, I was alone as I walked through the airport. My feet, my legs and my braces were solely mine. After camp ended, though, I carried something more as I walked in the other direction down that same terminal. In each step I took down that ridiculously long hallway, I held my new community. My sore muscles, the bony arch of my feet, the brace on my leg and the awkward jolts of my gait carried in them the stories of each camper, counselor and staff member I met at Camp Footprint. And each step also held their courage, pride and strength.

The change I felt was almost mystical. My body—my story—had expanded. My body is no longer only mine: The stories of all my new friends live in each step I take and my story lives in them. My pain is no longer only mine; it is held by a community of people who have felt it too. And, just as profoundly, my joy is no longer only mine. With each moment of celebration, victory and hope felt by a member of my CMT community, my soul rejoices.

Because of Camp Footprint, my body—a body in which I used to feel so alone—holds in the deepest caverns of its bones some of the most beautiful, powerful, courageous and sacred stories I've ever had the gift of knowing. Each step I take carries in it the hope and strength of the CMT community. Now I never walk anywhere alone. ★

*Maddie, 27, lives in Boston where she teaches theology and psychology at Mount Alvernia High School.*

### Camper #1: Elisheva Landau-Pope, 17, London, England

This summer I had the privilege of attending Camp Footprint. It was the first time I'd met anyone with CMT aside from my family and it was the most empowering, inspiring week of my life. Being surrounded by people with shared experiences and understanding created a safe, welcoming environment. I instantly made friends and felt like I could be my most authentic self.

I took part in activities and water sports like kayaking and paddleboarding that I would have otherwise been reluctant to try out of fear of failing and judgment from peers. My biggest achievement was standing up on the paddleboard. This took lots of encouragement from my counselor and several attempts, but the feeling of pride when I finally did it was well worth falling off the board a few times.

Being at Camp Footprint gave me the opportunity to talk openly about my disability with people who really understood. The smallest achievements were celebrated, and it felt like everyone there was rooting for each other. For the first time in my life, I was in an environment where having CMT was not only normal but celebrated. I met people my age who were proud of their disability, something I had never personally felt, and they inspired me to stop seeing my disability as a limitation and start seeing it as an opportunity to meet new people and educate others. I am so grateful for the opportunity and I can't wait to return to camp for many years to come.



### Camper #2: Paola Martinez, 16, San Diego, California

After my first time at Camp Footprint in 2018, all I wanted to do was to go back. Camp Footprint changed me by helping me open up more and not be ashamed of having CMT. It motivated me to change stuff back at home and to work harder at everything I do.

Attending Camp Footprint boosted my confidence with CMT: It inspired me to start swimming in a Paralympic setting and gave me the courage to speak in front of the whole camp, one of my biggest accomplishments this year. I am also proud of the fact that I was able to take part in filming several videos for CMT Awareness Month in September, a crucial month for the whole community.

The thing I will miss about camp is the people. Everyone was so nice, welcoming, fun and inspiring. The friendships and connections made during camp are truly out of this world!

Being part of this community is overwhelming. All the counselors and campers truly go above and beyond in everything they do. More than anyone, they understand what it's like. Being disconnected from "normal life" and enjoying the time we have together is priceless.

# REMEMBERING VICKI POLLYEA: A Woman of Great Strength, Courage and Conviction

BY ELIZABETH OUELLETTE

*Editor's note: As The CMTA Report went to press, we received word of Vicki's passing from her beloved husband Archie. We wish she'd had a chance to read once more how much we all appreciated her but trust that she knew it.*

When I first met Vicki over 12 years ago, she was the leader for the Tampa CMTA/MDA branch, the largest CMT group in the country. We hit it off immediately: I knew she'd be a forever friend and I was right. Over the years, she has played a variety of different roles at the CMTA, pouring her heart and soul into each of them. Even while recuperating from radiation therapy for recurrent lung cancer, Vicki continued to moderate the CMTA's Facebook Group from her hospital bed, giving fact-based answers to questions about CMT and helping others find resources, comfort and support.

Born into a family with CMT1A, Vicki grew up in Tampa. Her CMT prevented her from riding a bike and running, but she could swim and catch needlefish to sell for bait to tarpon fishermen.

After undergoing a lot of physical therapy in her youth, Vicki decided to get a degree in occupational therapy from the University of Florida. She worked as a pediatric occupational therapist until her CMT forced her to change her life path. Undeterred by this setback, and soon on full



disability, Vicki became a CMTA branch leader and neighborhood activist. She was part of a former Mayor's Neighborhood Task Force and helped draft Tampa Bay's tree-protection code. Vicki was also president and one of the founders of Bayshore Gardens Neighborhood Association, where she and her husband, Archie

*"Love is a steadfast commitment in the well-being of others."*

—Cornel West

Giannella, lived in a 1921 bungalow they restored. She and Archie shared a passion for fishing.

Vicki endured more than two dozen orthopedic operations in the last 34 years. As she became more homebound, she turned to the phone and online CMT chat rooms. Soon thereafter, she stepped up as a CMTA Branch Leader. Her mantra: "I cannot control the things that happen in life, but I can control my attitude about the things that happen."

Vicki valiantly battled lung cancer in the past, but the most recent bout was found to be inoperable. After six weeks of intensive radiation therapy, pneumonia set

in. Yet, whenever she had a chance or a little extra energy, she continued to spread CMT awareness and moderate the CMTA Facebook group, sharing her lifelong experience and knowledge of CMT.

In addition to her sister, Vicki had two cousins who live in New Zealand and also have CMT. She believed with all her heart that the research currently underway will make a difference in their lives. Vicki reflected, "I don't know how much longer I'll live, but Archie will be by my side. It teaches you to live in the moment, to tell the people around you that you love them. You never know what will happen tomorrow."

Vicki's selfless volunteerism made a tremendous difference in the world of CMT and beyond. She touched many people and the CMTA is eternally grateful for her relentless drive and motivation

One of Vicki's favorite quotes was from Cornel West: "Love is a steadfast commitment to the well-being of others." We thank her for the love and steadfast commitment she showed the CMT community. ★



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# RAISING FUNDS

## 6TH ANNUAL CYCLE (AND WALK!) 4 CMT RAISES MORE THAN \$200K

**M**ore than 200 people took part in the 6th Annual Cycle (and Walk!) 4 CMT in Charlotte, Vermont, on August 25. With more than 100 sponsors, including the Manning Personnel Group and Turbomed, the event surpassed its \$200,000 goal, bringing the six-year total to more than \$1 million for CMT research.

Participants came from far and wide and included Paralympic champion Anthony Zahn and his wife Liz Bernstein, from California, and people from many northeastern states, as well as Texas, Florida and Virginia. Whitney Wright, 17, from Franklin County, Vermont, not only connected with other CMTers for the first time in her life, she met another woman who shares the same rare type and they are now friends (see related story p. 12).

Event founder Chris Ouellette noted the record number of participants, sponsors and donations, which included 100 cyclists, 75 walkers, 100 event sponsors and more than 1,000 individual donations. “Many, many thanks to all our volunteers, sponsors, participants and donors who chose to get involved to fund critical research to treat and find a cure for CMT,” Ouellette said, adding, “You are making a mighty impact, changing the course of CMT for the generations of today and tomorrow.”

In addition to local participants, 20 enthusiastic participants did their “OWN” challenges (walks, rides, and a horseback adventure) on their “OWN” terms, in their “OWN” time frames.

There’s still time for anyone who would like to donate or do their “OWN” cycle or walk challenge. Go to: [www.cycle4cmt.com](http://www.cycle4cmt.com) and to set up a challenge or email Elizabeth Ouellette at [elizabetho@outlook.com](mailto:elizabetho@outlook.com) to learn more.

**The 7th Annual Cycle (and Walk!) 4 CMT will be held on Sunday, August 30, 2020. Interested in volunteering for next year’s event? Please email Elizabeth Ouellette at [elizabeth@outlook.com](mailto:elizabeth@outlook.com)**



### WALK THIS WAY: SOUTHERN CONNECTICUT BRANCH

**O**ur Walk 4 CMT on September 22 was our branch’s fifth. We call it the Southern Connecticut Cycle/Walk/Run 4 CMT so participants know they have options. Before we started holding the walks, our branch’s first two fundraisers offered food, music and raffle prizes and were quite successful. They also required a lot of planning and preparation. When the CMTA announced in April 2015 that it planned to hold a coordinated set of nationwide events during September’s Awareness Month, I thought it might be a good time to change our model. I liked the idea of our branch being a part of something bigger that raises awareness and research funds.

The first item on our to-do list is always finding a location that’s accessible to everyone. This year, we settled on the Farmington Canal Heritage Trail, which runs through the nearby town of Hamden, Connecticut. The popular trail is paved, shaded in most parts and even has benches sporadically placed along the route. It’s a popular destination for runners, bicyclists and walkers of all ages.

We meet at nearby Brooksvale Park, which has access to the trail, plenty of parking, a small playground, farm animals, and another necessity—a Porta-Potty. We always receive confirmation from the park ranger that the September date we want is available and approved and then the CMTA takes care of the necessary insurance information. Since the park and trail can be busy at times, we hold our event on a Sunday morning when it isn’t so crowded.

# AND AWARENESS



Southern Connecticut Branch's 2018 Walk 4 CMT

The park has restrictions so we're not able to use balloons or decorate, but it doesn't deter us from making our check-in area noticeable. I set up a portable table, cover it with a blue plastic tablecloth and drape my CMTA towel—a makeshift banner—on the front. On the table are plenty of CMTA brochures and giveaway items such as the bracelets and bandanas we had last year. At a minimal cost, I also provide water bottles, granola bars, cookies and bananas. I always make sure there's a donation container on the table.

The number of participants has varied over the years but we always manage to have an enthusiastic group and usually welcome some first-timers. It's rewarding to meet the newcomers and share information, but most importantly, we are all out there spreading awareness and raising crucial research dollars.

—Lynne Krupa, branch leader

## LEMON-AID RAISES FUNDS FOR STAR

Last year my kids had a lemonade and cupcake stand to collect donations for my son's CMT walk team, "Harrison's Troopers," and they raised \$250. Unfortunately, there was no CMT walk close to us in Avon Lake, Ohio, this year, but Harrison and his sisters Annabelle and Ellie still wanted to

have a lemonade and cupcake stand for CMT. So they did, making more than 90 cupcakes and a ton of lemonade for the August 2 sale.

The Avon Lake Fire Department and Police Department made a surprise visit, sirens and all! When the first police officer came to our driveway, my oldest daughter thought: "Do we have to have a permit to sell lemonade?" That officer promised to tell all her friends about the sale and 10 minutes after she left another police officer showed up and got some lemonade and cupcakes. He said he would tell all of his friends, too. Ten minutes went by and another police officer showed up and got some lemonade and told us that he also would tell all of his friends.

About 10 minutes later we looked down the street and there were about 7 or 8 police cars, a fire truck, and an ambulance coming down our street. I immediately knew where they were headed and got tears in my eyes. My kids all started shouting and clapping and jumping up and down. They were ecstatic to say the least.

The officers and firemen all came up to Harrison and shook his hand and talked to him. They gave him a bag of goodies and a baseball cap from the Police Department. Before they left, one of the police officers said that

some friends of his from the library might be stopping by. Soon after that, a car pulled up and it was one of the librarians who was dropping off a donation. Apparently they heard about what we were doing and took up a collection at the library.

So many people stopped by. Some we knew, and a lot of others who just wanted to support a child in the community. A lot of people were curious as to what CMT was and how Harrison is doing. We ended up raising a total of \$565! It was amazing to see the support of everyone in our community. I am so glad my kids could see the generosity of complete strangers. They will definitely remember this for years to come.

—Renee White





# CMTA Branches

Most CMTA Branches can be accessed  
online at [www.cmtausa.org/branches](http://www.cmtausa.org/branches)

## ALASKA

**Anchorage Area**  
Lisa Hubert  
907-223-4566

## ARKANSAS

**Little Rock**  
Lisa Jones  
501-776-5364

## ARIZONA

**Phoenix Area**  
Christina Fisher  
623-742-8921

## CALIFORNIA

**Antelope Valley Area**  
Donna Murphy  
661-317-6332  
Danielle Metzger  
661-317-6533  
**Los Angeles Area**

Alani Price  
310-710-2376

## Sacramento

Holly Stevens  
408-203-8804  
Rashid Thomas  
916-947-5377

## Ernie Hinds

916-205-5682

## San Diego Area

Annette Van Veen  
760-473-5014  
Kendall Trout  
760-632-5654

## South Bay Area

Ori Bash  
408-829-4562  
Tau O'Sullivan  
916-806-2173

## COLORADO

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

## CONNECTICUT

**Hartford**  
Roy Behlke  
239-682-6785  
**North Haven**  
Lynne Krupa  
203-288-6673

## DISTRICT OF COLUMBIA

**Washington, DC**  
Steven Weiss  
Kimberly Hughes  
301-962-8885

## FLORIDA

**Central Florida**  
Linda Davis  
Mitch Davis  
863-875-4239  
**Jacksonville Area**  
Tim Nightingale  
904-504-1953  
Stephanie Burkhalter  
904-710-3771

## Melbourne Area

Clark Semmes  
410-350-4812

## Naples

Roy Behlke  
239-455-5571  
Bill Millar  
202-309-5685

## Sarasota Area

Rachel Rivlin  
Manuel Goldberg  
941-870-3326

## Tampa Bay Area

Edward Linde  
813-712-4101  
Sarah Gentry  
941-706-5348

## West Palm Beach

Phil Lewis  
561-307-0100  
Eileen Martinez  
561-901-5566

## GEORGIA

**Atlanta Area**  
Jeannie Zibrida  
404-307-6519

## IOWA

**Iowa City Area**  
Jeffrey Megown  
319-981-0171

## ILLINOIS

**Chicago Area**  
Jay Pate  
630-888-4673  
Doreen Pomykala  
815-351-1328

## INDIANA

**Fort Wayne Area**  
Aimee Trammell  
574-304-0968

## KANSAS

**Kansas City Area**  
Tammy Adkins  
314-608-6889  
Aron Taylor  
913-744-5674  
**Wichita Area**  
Karen Smith  
316-200-0453

## LOUISIANA

**Baton Rouge Area**  
Corey Dalfrey  
Danielle Dalfrey  
318-294-1976

## MASSACHUSETTS

**Boston**  
Mimi Works  
617-913-4600  
Jill Ricci  
978-887-1014

## MARYLAND

**Baltimore**  
Clark Semmes  
410-350-4812  
**Easton**  
Clark Semmes  
410-350-4812

## MAINE

**Portland Area**  
Mary Louie  
207-450-5679

## MICHIGAN

**Grand Rapids Area**  
Cabrielle Rudisill  
717-816-4986  
Amy Reynolds  
616-916-6732

## MINNESOTA

**Central Minnesota**  
Jo Smith  
612-807-4729  
**Minneapolis Area**  
Duane Hodges  
612-325-5448

## MISSOURI

**Kansas City Area**  
Tammy Adkins  
314-608-6889  
Aron Taylor  
913-744-5674  
**St. Louis Area**  
Payton Rule  
618-401-4822  
Amanda Rule  
618-698-3039  
**Springfield Area**  
Jessica Brantner  
417-468-8049  
Jessica Hardy  
417-434-1656

## NORTH CAROLINA

**Charlotte Area**  
Carrie Johnsen  
704-904-2828  
**Durham Area**  
Jeanne Boehlecke  
919-942-7909  
Rick Nelson  
919-889-9776  
**Wilmington Area**  
Laurel Richardson  
910-515-8488

## NEBRASKA

**Lincoln Area**  
Brandon Lederer  
402-680-0502

## NEW HAMPSHIRE

**Newbury Area**  
Jacinta Gantz  
978-596-4444

## NEW JERSEY

**Central New Jersey**  
Mark Willis  
732-252-8299  
Jacqueline Donahue  
732-780-0857

## NEW MEXICO

**Albuquerque Area**  
Gary Shepherd  
505-296-1238

## NEVADA

**Las Vegas Area**  
Martha Boadt  
231-852-4251

## NEW YORK

**Buffalo Area**  
Peter Morris  
716-866-3519  
Maryann Ciskal  
716-435-3899  
Kristen Braun  
716-270-3095  
**Syracuse Area**  
Michael Casey  
315-439-9325  
**Upstate New York**  
Elizabeth Misener  
David Misener  
518-527-0895  
**Westchester Area**  
Beverly Wurzel  
Frank Wurzel  
201-224-5795

## OHIO

**Cincinnati Area**  
Jill Stuhlmueller  
513-254-4065  
Jo Koenig  
513-607-2822  
**Cleveland Area**  
Shelly McMahon  
440-781-8329  
**Columbus Area**  
Jessica Diamond  
216-570-6432

## OKLAHOMA

**Tulsa Area**  
Lonna Henry  
918-961-1418

## OREGON

**Grants Pass**  
Jessica Barton  
541-218-5350 (cell)  
541-846-8525

## PENNSYLVANIA

**Bucks County Area**  
Julie FitzGerald Schell  
315-573-3919  
**Chester County**  
Ashley Trout  
484-364-9334  
**Harrisburg**  
Erin Weierbach  
717-379-7504  
**Johnstown Area**  
J.D. Griffith  
814-539-2341  
Jeana Sweeney  
814-269-1319  
**Northwestern Area**  
Joyce Steinkamp  
814-833-8495  
**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  
Amanda Jenkins  
864-313-2872

## TENNESSEE

**Nashville Area**  
Bridget Sarver  
615-390-0699  
Teresa Shoaf  
615-772-8810

## TEXAS

**Austin Area**  
Nate Halk  
512-415-6097  
**Dallas/Fort Worth**  
Thomas Roderiguz  
817-913-8477  
**El Paso Area**  
Jo Ann Longoria  
915-526-0676  
Olivia Longoria  
915-491-0786  
**Houston Area**  
Kristin Leard  
713-516-8630  
Benij Hershorn  
832-731-0121  
Meredith Wells  
832-264-7312

## UTAH

**Orem Area**  
Melissa Arakaki  
801-494-3658

## VIRGINIA

**Blacksburg/ Roanoke Area**  
Karen Brown  
540-252-9453  
**Fredericksburg**  
Leigh Van Doren  
540-370-1968  
**Suffolk Area**  
Holly Hall  
757-477-6122

## WASHINGTON

**Seattle Area**  
Denise Snow  
206-321-1261  
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

Interested in starting a branch in your area?

Contact CMTA Director of Community Outreach  
Laurel Richardson at [laurel@cmtausa.org](mailto:laurel@cmtausa.org).

# LESSONS FROM JULIA

BY RACHAEL BERON

I've been a CMT parent for 19 years and I like to think I've learned a few things along the way. My daughter Julia is my teacher. She is a shining example of the way kids with CMT overcome challenges.

I was thrilled to learn I was having a girl. I already had a 2-year-old son, Josh, who was anxious for a sibling. I imagined my daughter looking just like me—tall with crazy brown curly hair (that's mostly grey with blonde streaks now) and brown eyes. To my surprise, Jules was a petite, beautiful, green-eyed blonde, who looked nothing like I had imagined for those nine months. Unlike her very active brother, she was an easy baby, docile and content to hang out wherever we went. I was so relieved.

The only concern we had initially was that Jules' left eye was crossed. We met with an optometrist who told us that we should wait until she was 2 to have her "lazy eye" corrected. We wouldn't learn until later that she had optic nerve damage in that eye. For 18 months, I enjoyed this happy baby who loved to be carried and was always smiling. I didn't realize anything was wrong—I was always on the go with Josh and she was just a pleasure to be around. My mom told me that I didn't walk until I was 18 months old, so Jules not walking before that age didn't concern me much. But when 18 months went by and still no walking, my husband Herb and I got concerned, and we started taking her for tests.

I first took her to an occupational therapist who came highly

recommended by our pediatrician. She took Jules away from me and tested her for more than an hour. Jules was not happy about that. She didn't like to be away from me and I knew the test wouldn't go well. (**LESSON ONE: You know your child better than anyone else!**) The OT concluded that Jules was not only physically delayed (which I knew) but also cognitively impaired. That's when I lost it. How can someone test an 18-month-old child without her mom present and come up with that conclusion? (**LESSON TWO: Initial diagnoses can be completely wrong; get second opinions!**) I left feeling that although she was right about Jules being physically delayed (anyone could see that), she was completely wrong about her being cognitively impaired. I eventually found another occupational therapist who led me to Julia's physiatrist who eventually diagnosed Jules with CMT2E when she was 4. (**LESSON THREE: Be your child's advocate. No one is better at it than you!**)

We had never heard of CMT: No one in our family had it, and in the beginning it was very scary. We inundated ourselves with information, which led me to CMTA Board Member Steve O'Donnell, who was doing a swim across the Chesapeake Bay to raise funds for research. I called the CMTA and told them that my daughter had just been diagnosed with CMT and I would love to participate in the swim. That was 12 years ago, in 2007. Since then, Herb joined the Board of Directors, serving as chairman for several years, and we formed our own swim under the

**Julia is "a shining example of the way kids with CMT overcome challenges."**

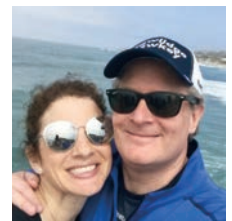


Rachel Beron and her daughter Julia

banner of TeamJulia, raising almost \$1 million to help fund programs and research initiatives for the organization.

Two years ago, Julia was diagnosed with Type 1 diabetes. This came completely out of left field and really threw all of us for a loop. We had just spent 15 years trying to learn all we could about CMT, and then we had to learn how to help her manage her blood sugar levels? This couldn't be happening! But in true Julia fashion, this fork in the road only made her stronger. She joked: "When G-d made Julia, he mixed in a little left optic nerve hypoplasia, figured he'd throw in a little CMT, thought this still isn't right so let me mix in a little diabetes."

As usual, Julia doesn't let anything stop her. (**LESSON FOUR: Kids with CMT are resilient!**) Last summer she interned with Runway of Dreams, a nonprofit that supports initiatives to broaden the reach of adaptive clothing and promote the differently abled community in the fashion industry. She also worked for University Tees, a national apparel company that provides shirts, hats and other apparel to college organizations, and continued her successful art business sketching animals, homes and anything else she comes up with. Her resilience never ceases to amaze me and I look forward to continuing to learn from her for many years to come. ★



Rachael Beron and her husband Herb have supported the CMTA in a multitude of ways for more than a decade. To participate in conversations about the challenges and rewards of raising a child with CMT, visit the CMTA Parents Facebook group at [www.facebook.com/groups/CMTAParents/](http://www.facebook.com/groups/CMTAParents/).



# CMTA BRANCH NEWS

## TAMPA BAY AREA, FL

A dozen members met June 8 to share STAR research updates, talk about patient involvement in the research process, and chat about the many CMTA community events happening around the country, including the branch's September Walk 4 CMT. Members also learned that neurologist Dr. Nivedita Jerath was accepting patients in Winter Park, Florida. The meeting included an open discussion about bracing, medicines including CBD and exercise.



Tampa Bay



Chicago

## CHICAGO, IL

The Chicago Branch welcomed guest speaker David Tannenbaum to its meeting on June 8. David is on the CMTA Advisory Board and is a licensed psychotherapist in New York City. He leads the Emotional Support Group on the CMTA website and writes the Ask David Column in *The CMTA Report*. He reminded the 15 members in attendance to live in the moment, feel and identify feelings, take a deep breath and move on. He also suggested that people with CMT have great compassion for others, learn to plan ahead and become creative problem solvers. Finally, David told members that it's ok to ask for help, that asking is not a sign of weakness and that they should just ask positively and directly for what they need.

## NEWBURY, NH

The Newbury, NH Branch welcomed CMTA Board Member Elizabeth Ouellette to its June 8 meeting. Before Elizabeth began, Jacinta Gantz welcomed members to the newly formed branch and everyone introduced themselves. Elizabeth shared a STAR research update, reviewed key CMT facts and talked about CMTA resources, partnerships and



New Hampshire

events, including the Cycle (and Walk!) 4 CMT fundraiser, which is held every August.

## PITTSBURGH, PA

Eighteen people from the Pittsburgh Branch turned out on May 18 to hear special guest speaker Clark Semmes. Semmes, a CMTA branch leader and Advisory Board member, joined the group via Skype to share information about the CMT clinical trial he's taking part in with Acceleron Pharma. Clark humorously talked about his adventures being a patient participating in the research process. The group had many questions for Clark and wonderful conversation ensued.

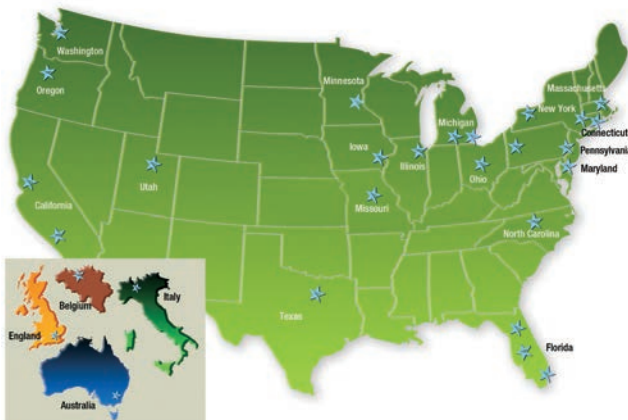
## MADISON, WI

Thirty members of the Madison, WI branch welcomed CMTA Advisory Board Member David Tannenbaum to their meeting on August 17. Members called Tannenbaum's presentation "phenomenal" and agreed that it was one of their best meetings yet. After a two-hour chat about the emotional and intellectual issues that accompany CMT, members socialized over pizza and drinks.

## CMTA CENTERS OF EXCELLENCE

[www.cmtausa.org/coe](http://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
Children's Hospital of Pittsburgh (Pittsburgh)* .....	Dr. Hodas Abdel-Hamid
Connecticut Children's Medical Center (Farmington).....	Dr. Gyula Acsadi
Hospital for Special Care* (New Britain, CT) .....	Dr. Kevin J. Felice
Johns Hopkins University (Baltimore) .....	Dr. Thomas Lloyd
Kane Hall Barry Neurology (Dallas/Fort Worth)* .....	Dr. Sharique Ansari
Lucile Packard Children's Hospital at Stanford (Palo Alto) .....	Drs. John Day and Ana Tesi Rocha
Massachusetts General Hospital (Boston) .....	Dr. Reza Seyedasadjadi
Nationwide Children's Hospital (Columbus)* .....	Dr. Zarife Sahenk
Nemours Children's Hospital (Orlando) .....	Dr. Richard Finkel
Northwestern Memorial Hospital (Chicago)* .....	Dr. Daniela Maria Menichella
Ohio State University (Columbus) .....	Dr. Amro Stino
Oregon Health & Science University (Portland)* .....	Dr. Chafic Karam
Rush University (Chicago)* .....	Dr. Ryan D. Jacobson
Stanford Neuroscience Health Center (Palo Alto) .....	Dr. John Day
University of Florida (Gainesville)* .....	Dr. James Wymer
University of Illinois at Chicago (Chicago)* .....	Dr. Charles K. Abrams
University of Iowa (Iowa City) .....	Dr. Michael Shy
University of Miami (Miami) .....	Dr. Mario Saport
University of Michigan (Ann Arbor)* .....	Dr. Dustin Nowacek
University of Minnesota (Maple Grove) .....	Dr. David Walk
University of Missouri (Columbia) .....	Dr. Raghav Govindarajan
University of North Carolina (Chapel Hill)* .....	Dr. Rebecca Traub
University of Pennsylvania (Philadelphia) .....	Dr. Steven Scherer
University of Pittsburgh Medical Center (Pittsburgh)* .....	Dr. Sasha Zivkovic
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
Wayne State University (Detroit) .....	Dr. Jun Li

\*These Centers of Excellence are not part of the 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

Cedars-Sinai Medical Center (Los Angeles).....	Drs. Robert Baloh and Richard Lewis
Children's Hospital of Philadelphia (Philadelphia).....	Dr. Sabrina Yum
Children's Hospital of Pittsburgh (Pittsburgh)* .....	Dr. Hodas Abdel-Hamid
Connecticut Children's Medical Center (Farmington).....	Dr. Gyula Acsadi
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Ohio State University (Columbus) .....	Dr. Amro Stino
Oregon Health & Science University (Portland)* .....	Dr. Chafic Karam
Rush University (Chicago)* .....	Dr. Ryan D. Jacobson
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University of Missouri (Columbia) .....	Dr. Raghav Govindarajan
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University of Pennsylvania (Philadelphia) .....	Dr. Steven Scherer
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University of Rochester (Rochester, NY) .....	Dr. David Herrmann
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University of Antwerp (Edegem, Belgium) .....	Dr. Jonathan Baets



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

Dear David,

*I recently got my first pair of orthotics and although my braces help me walk better, I can't seem to get over my self-consciousness at work. I often give presentations and I feel everyone is focusing on my legs, which makes me anxious. I feel my anxiety is affecting the quality of my presentations. I often wear pant suits but I would love to wear dresses once in a while. I am a 35-year-old executive and despite getting a lot of positive feedback, I'm concerned my career will be hurt by my disability. How do I get over my insecurity?*

**David replies:**

Thanks for bringing up a topic that affects many of us with CMT. Although anxiety is uncomfortable, it forces us to deal with the fears associated with being self-conscious. This is not about getting over it, rather it is about working through your inability to accept yourself fully and coming

to a place of peace. Your career is very important: It gives your life meaning and nothing should stand in its way. We all have anxieties around our appearance, but this kind of worry can stand in the way of showing off the best part of who we are, which has little to do with our physical appearance. You have obviously achieved success in your field already, so focus on that instead of what you imagine people are thinking. Most of the time we are imagining stuff that's simply not true. If people at your company are uncomfortable with your braces, that is their disability. It is not their job to love and accept you; it is your work to love yourself braces and all. We need to remember that self-love and self-acceptance is important work for most people, whether or not they have a physical disability. Our CMT simply pushes this work to the surface faster and nudges us to deal with this issue more quickly.

Accepting our limitations helps us to go beyond them. If accepted and integrated in our personality, our differences can make us stronger, more powerful and more successful in the long run. True beauty is about having the confidence to be exactly who you are.

Coming out with CMT is a lifelong process. Take small steps even if it's uncomfortable. It gets easier with time, but you need to take little risks whenever possible. Trust that with practice it is possible to be free of self-consciousness. Every time you feel it a little, just note it to yourself and push through it even if it causes discomfort. That's how you build any new muscle. In truth, it is our fears around CMT that hold us back, not our innate intellect or talent. Push yourself out there and buy a great dress that says: "Look at me. I'm a fabulous woman with much to offer. Pay attention people because I'm going places!" ★



Write to David at [info@cmtausa.org](mailto:info@cmtausa.org).

*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. "My CMT has been my greatest challenge and my best teacher in life," says David.*

**Donate to one of the matching challenges online at [www.cmtausa.org/wearefamily](http://www.cmtausa.org/wearefamily) or return the form below.**

**Yes, double my contribution to STAR Research, so we can continue the fight against the progressive and devastating effects of CMT.**



Complete and return to: CMTA • PO Box 105 • Glenolden, PA 19036

Please earmark my match gift for:  Type 2  Type 1  Type 4  STAR Research  
 \$1000  \$500  \$300  \$250  \$100  \$50  Other: \$ \_\_\_\_\_

- Check enclosed, payable to the Charcot-Marie-Tooth Association. Donate online at [cmtausa.org/wearefamily](http://cmtausa.org/wearefamily)
- I am interested in learning more on how to make a major gift or a multi-year pledge to support STAR.
- Please make this amount a  One-time or  Monthly gift and charge to my  Visa  MasterCard  American Express

Name \_\_\_\_\_ Card # \_\_\_\_\_ Exp. Date \_\_\_\_\_  
Signature \_\_\_\_\_ Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Phone \_\_\_\_\_

If you would like to receive more tailored research updates, please go to [cmtausa.org/pap-profile](http://cmtausa.org/pap-profile)



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

### **Uncertain or minor risk:**

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

### **Negligible or doubtful risk:**

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



The Charcot-Marie-Tooth Association

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## WHAT IS CMT?

- ▶ More than 2.8 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](http://www.nsgc.org)) or your physician for more information.
- ▶ Although there are no drug treatments for CMT, a healthy diet, moderate exercise, physical and/or occupational therapy, leg braces or orthopedic surgery may help maintain mobility and function.
- ▶ The CMTA'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.