SPRING 2024

THE CMTA REPORT

www.cmtausa.org

REACHING OUT:
EXPANDING EDUCATION AND ENGAGEMENT

LOOKING FORWARD
TO CAMP FOOTPRINT
2024

CONTENTS

SPRING 2024

COMMUNITY

LIVING WITH CMT

RESEARCH

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Email the CMTA at info@cmtausa.org

A LETTER FROM SUE, OUR CEO

Dear CMT Community,

As we embark on the journey that is 2024, I am filled with an overwhelming sense of gratitude and excitement. The past year has been a testament to the incredible strength and resilience of our community, and I am honored to stand alongside each and every one of you as we continue our mission to support the development of new treatments for CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure.

At the heart of the CMTA lies an unwavering commitment to our community-led, community-driven focus. Your voices, your experiences, and your relentless dedication are the driving force behind everything we do. From our groundbreaking research initiatives to our vibrant community programs, every decision we make is guided by your needs and priorities. Together, we are not just partners in name but partners in action, working hand-in-hand to shape the future of CMT research and advocacy.

Reflecting on the achievements of 2023 fills me with an overwhelming sense of pride. Together, we have made tremendous strides in accelerating research towards bringing treatments and a cure, in expanding access to care and support, and in raising awareness of this often-overlooked disease. From the successes of our Youth, Camp Footprint, and COMPASS programs, to the expansion of our Branches and Centers of Excellence network, it's clear that our community is stronger and more united than ever before. These things happened because you made them happen.

Looking ahead to 2024, I am thrilled to announce a wealth of exciting opportunities for our community to come together, to learn, and to connect with one another. Our calendar is brimming with engaging community events, from quarterly informative Lunch and Learn webinars, to local Branch meetings, to the largest gathering anywhere of CMT community members: our flagship Patient and Research Summit in Denver this September. These community events serve as vital forums for education, advocacy, and support; and I invite each and every one of you to participate and make your voices heard, whether in person, or virtually (when virtual is available).

In addition to our community events, I am excited to share that the CMTA is actively investing in groundbreaking initiatives aimed at accelerating research to bring treatments and ultimately a cure for CMT. Through our Strategy to Accelerate Research (STAR) program and our innovative Patients as Partners in Research, we are harnessing the collective expertise and insights of our community to drive progress and advance the science of CMT.

As we continue this journey together, I want to express my deepest gratitude to each and every member of our community. Your courage, resilience, and unwavering commitment inspire me every day, and it is a privilege to stand alongside you in our shared mission.

Together, there is no challenge too great, no obstacle too daunting. Together, we will continue to make history, driving progress, and transforming the landscape of CMT. Together, we will make CMT a thing of the past.

With warmest regards,

Sue Bruhn, Ph.D.
CMTA CEO

YOU'RE INVITED: Participate in Patients as Partners in Research Today

The CMTA's Patients as Partners in Research program is our initiative to ensure that the community we serve remains an equal partner in our research. Through our Strategy to Accelerate Research (STAR), Patients as Partners in Research is the vehicle by which the CMT community drives the critical research work of our mission to support the development of new treatments for CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure.

Registering today as a CMTA patient partner puts you at the front of the line whenever there is a new research participation opportunity, and it ensures you receive the latest information about your particular form of CMT. Registration is free through our secure registration portal. Visit our website today to register and build your partner profile at: ***www.cmtausa.org/our-research/for-patients-and-families/patients-as-partners/patients-as-partners-profile/***.

"As a community-led and community-driven organization, our strategy is laser-focused on using our broad global reach to accelerate pathways to a treatment and a cure by fostering connections across patients, researchers, and industry partners," says Dr. Sue Bruhn, CEO of the CMTA. "We are grateful to our Patients as Partners in Research for their contributions and openness to participate in opportunities that will have significant impact across the entire CMT community."

PATIENTS AS PARTNERS IN RESEARCH

THERE ARE CURRENTLY 13 CMTA RESEARCH PROJECTS SEEKING PATIENT PARTNERS:

- Donate Your Wisdom Tooth (all CMT subtypes)
- CMT4J Natural History Study
- Stem Cell Biobanking (CMT1A, CMT1B, CMTX1 (aka CMT1X/CMTX), CMT2A, and CMT2E)
- CMT2C and Other TRPV4 Gene-Related Diseases
- Hereditary Sensory Neuropathy Serine trial (SENSE trial for the CMT subtype called HSN1)
- A Retrospective Study of community members whose CMT is caused by mutations of the C12ORF65 Gene (aka MTRFR Gene—different than the MTHFR Gene)
- Stanford Chronic Pain Study (all CMT subtypes)
- Finding Your Gene—The Distant Cousin Project
- Biomarkers and Outcome Measures (CMT1B, CMTX1 (aka CMT1X/CMTX), CMT2A, CMT2F)
- The Inherited Neuropathies Consortium (INC) Study 6601: The Natural History of CMT (all CMT subtypes)
- The Inherited Neuropathies Consortium (INC) Study 6602: The Genetics of CMT—Finding Unknown Genetic Causes of CMT (seeking patient partners whose subtype is unknown)
- Evaluating Gait Changes in Children and Youth who have CMT (all CMT subtypes)
- Accelerate Clinical Trials in Charcot-Marie-Tooth Disease (ACT-CMT) (CMT1A Natural History Study)

Scan this QR code with your mobile device's camera or QR reader app and become a Partner in Research today!

CELEBRATING UNITY IN COMMUNITY:

A YEAR OF GROWTH AND EMPOWERMENT WITH CMTA'S OUTREACH PROGRAMS IN 2023

In 2023, the CMTA's community-led community-driven outreach efforts were buzzing with excitement and activity all year long, bringing together youth and adults alike for a range of engaging community programs and events!

Let's start with our youth programs, where **Camp Footprint** saw a fantastic turnout. In the west, 61 eager campers joined forces with 49 staff members, while the east boasted 80 campers and 69 staff members, making it a lively and fun-filled experience for everyone involved. This year's Camp Footprint registration is just about maxed out at 79 in the east and 73 in the west (max is 80 at both). Our youth programs membership also saw fantastic growth from 261 to 323, highlighting the expanding reach of our youth community.

Our **COMPASS program** had some remarkable achievements as well, holding monthly meetings with an average attendance of 14 young adults. We discussed exciting projects like regional gatherings and even the possibility of a national COMPASS gathering in 2025. Plus, we began forming committees to tackle important tasks like social media, engagement, special projects, fundraising, and content creation for this newsletter.

The **youth council** didn't miss out on the action either, organizing a retreat in Washington filled with memorable community moments. They also launched the CMTA SWAG Store, sent out heartwarming holiday postcards to all our youth, and hosted the 3rd Annual Dance 4 CMT along with three regional youth outings: Dallas, Minneapolis, and Boston.

BOTH OF CAMP FOOTPRINT'S TWO SUMMER PROGRAMS FOR 2024 ARE ALMOST FULLY ENROLLED.

Hannah and Naomi Spencer fishing together at Camp Footprint East 2023

Moving on to our adult community programs and education initiatives, we expanded our **Branches** with the addition of 10 new ones, including Edmonton, Central Mississippi, Miami, and more. These new branches held a total of 76 meetings, fostering connections and support within their local communities.

Our **education** efforts were equally impressive, with highlights like the Patient and Research Summit in Boston, which saw a hybrid attendance of 207 in person and 364 virtually. Our quarterly "Lunch and Learn" webinar series attracted a total of 612 attendees across various topics, providing valuable insights and information to our community members.

Additionally, our **Centers of Excellence** (COE) CMT clinic network added five new centers, expanding to 55 locations, including Seattle, Miami, and San Francisco. Held virtually, we even had our first-ever annual COE clinic directors meeting, bringing together leaders from across the network to collaborate and strategize.

"The CMTA's community-led and community-driven outreach programs not only offer a wide array of services and resources that are essential for everyday life with CMT, but more importantly, are a celebration of community, of our strength, of our resilience, and of the bonds we share through our CMT," says Laurel Richardson, CMTA Director of Community Outreach, emphasizing the enduring spirit that unites us all in our journey with CMT.

Overall, 2023 was a year filled with growth, connection, and empowerment within our community, and we're excited to see what the future holds as we continue to work together to support each other and raise awareness for CMT as we together carry out our mission to support the development of new treatments for CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure.

Cheyenne Alfino (CA) enjoying the outdoors

Allie Dalstrom (NJ) horseback riding

DISCOVER YOUR POWER WITH COMPASS:

JOIN THE MOVEMENT FOR YOUNG ADULTS WITH CMT

Olivia Dennis (GA) is a kid at heart at Disney World

Kathy Chau (UT) completed 250 spin classes

In case you haven't heard, there's a growing group of young adults with CMT who are diving into all things community! If you're between 19-30 years old and seeking connection, empowerment, and the opportunity to make a difference, COMPASS is calling your name!

COMPASS, the CMTA's young adult group, is not just a community—it's a movement. Over the past year, our members have come together in monthly meetings, delving into discussions, sharing stories, and forging bonds that go beyond a diagnosis. These meetings aren't just about finding support—they're about finding strength in solidarity and shared experience.

But COMPASS isn't just about meetings—it's about creating unforgettable experiences. Picture this: a happy hour evening out at the CMTA's summit in Boston, laughter filling the air as you connect with peers who understand your journey. It's moments like these that remind us of the power of community—the power to uplift, connect, and empower.

COMPASS Leadership at Camp Footprint with Camp Director Jonah Berger

Paige Adair (IA) in the annual color battle at Camp Footprint

This year, COMPASS is stepping up its game with the launch of subcommittees focused on advancing the community in different areas. Whether you're passionate about advocacy, social events, or raising awareness, there's a place for you at the table. With COMPASS, you have the power to shape the future of the young adult community and make your voice heard.

We are committed to engaging young adults in all aspects of the organization and addressing the issues that matter most to you. Your experiences, your passions, your goals—they all matter here. Together, we're stronger, louder, and more powerful! COMPASS is much more than a young adults group, COMPASS is a celebration of community, of our strength, of our resilience, and of the bonds we share through our CMT.

Connect with COMPASS today and be part of something extraordinary.

Follow us on Instagram at @cmtacompass.
To join COMPASS, scan this QR code or visit our landing page at www.cmtausa.org/get-involved/cmta-compass/
Together, let's empower each other and build a brighter future for young adults with CMT. Your journey starts here!

COMPASS
NAVIGATING CMT
AS A YOUNG ADULT

Steady hand, Steady heart

A poem by Christina Elliot

straight lines
detailed, tiny sutures
delicate brush strokes
steady application of cosmetics
the steady strong hand no more
I miss the gift of a strong, steady hand

now weakening, tired muscles, tremors
wobbling utensil and pen
muscles misfire, spastic twitches
voice roughens, weak with fatigue
effort to push out words
breathing-to catch breath
to have conversation
beyond soundless air
embarrassed by this struggle
I miss the gift of a strong steady voice

the walk becomes awkward, slowed
pain and weakness, effort creates further fatigue
and I watch as older people pass me by
in disbelief at what my world has become in short time
I miss the gift of a strong, steady walk

processing, accepting
changes to lifestyle and relationships
the losses recent, stacked, profound
to me
this is the body I inhabit
I feel it all keenly
navigate this ungraceful journey with grace and patience
find a new path to new purpose
new direction in details

the strong steady hand, voice, and walk become
a strong steady heart
steadfast determination and perseverance
to find a way to fall back in love with a life
that is forever changing in ability

Christina Elliot is a community member who lives in North Carolina. She is a former funeral director and embalmer learning to come to terms with the changes CMT has brought to her daily life.

BEYOND LIMITATIONS:

Norm Krupp's Path to Empowerment

Norm Krupp's life story is a testament to resilience, perseverance, and the power of the human spirit to overcome adversity. Born and raised in St. Louis, Missouri, Norm's early years were filled with the simple joys of childhood, but his path took a challenging turn when, at the age of 7, he was diagnosed with juvenile diabetes. Little did he know that this would be the beginning of a lifelong journey marked by health struggles and unyielding determination.

Growing up with diabetes presented its own set of challenges for Norm, but he faced them with courage and determination. However, as he entered his teenage years, he began experiencing symptoms of foot drop, a common symptom of CMT. Initially attributing his symptoms to diabetes-related peripheral neuropathy, Norm's journey with CMT had begun.

Despite the physical limitations imposed by his condition, Norm refused to let it define him. While Norm stopped playing baseball and basketball in junior high school, he pursued his passions for sports, excelling in hockey and golf throughout high school and college. While in college, running became increasingly difficult, and he noticed his coordination diminishing, signaling the progression of his CMT.

After graduating from college with a degree in Forest Management, Norm embarked on a career in the timber industry, taking on various roles in Oregon and the Pacific Northwest. Norm's job was physically demanding, and his deteriorating condition posed significant challenges. But Norm remained undeterred, finding success in his career, and embracing new opportunities as they arose.

In his early twenties, with mounting hand function difficulties, Norm underwent a tendon transfer surgery on his right hand, a procedure that proved successful in restoring functionality that had been lost to CMT. Facing the same with his left hand, he opted to postpone a similar operation until later in life, choosing instead to adapt to the limitations imposed by his CMT.

"I've faced numerous challenges due to my CMT over the years," said Norm, "but I've never let it define me or hold me back. Despite the setbacks and surgeries, I remain determined to make the most of life and continue pushing forward."

Norm's left hand continued to worsen over the years since surgery on his right hand. He was even losing the ability to enjoy one of his favorite things: fishing. His journey took a significant turn in 2023 though when he sought treatment at Barnes-Jewish Hospital in St. Louis, Missouri, where he met Martin Boyer, M.D., an orthopedic surgeon specializing in hand surgery. Dr. Boyer offered a ray of hope, proposing a comprehensive approach to address the debilitating effects of CMT on Norm's left hand.

In June 2023, Dr. Boyer performed a series of complex procedures on Norm's left hand, including tendon transfers and a carpal tunnel release. While the road to recovery was challenging, Norm remained resilient, drawing strength from the support of his family, friends, the medical team, and the CMT community.


HAND SURGERY has enabled Norm to regain the ability to perform tasks and hobbies that had become impossible.

Post-surgery, Norm experienced significant improvements in the functionality of his hand, enabling him to perform tasks that had become impossible. "While my hand is far from perfect, I am very happy with the improvement and with the many things I can now do which I couldn't do before, or were at least difficult," says Norm. While challenges remain, Norm is grateful for the progress he has made and remains optimistic about the future.

With the successful hand surgery behind him, Norm's passion for fishing has been reignited with newfound vigor. The improvements in hand functionality allow him to confidently hold the fishing rod and to use necessary tools for handling fish and sharp tackle. No longer hindered by the limitations imposed by CMT, Norm can partake in the therapeutic benefits of fishing once again, casting away any doubts or fears that once hindered his enjoyment of this beloved pastime.

Norm's journey with CMT is a testament to the power of perseverance and the resilience of the human spirit. Despite facing numerous obstacles along the way, he has never lost sight of his goals or allowed his CMT to define him. Instead, he continues to inspire others with his courage, with his strength, and with his relentless drive. Norm serves as a beacon of hope for individuals living with CMT, showing that anything is possible.

MIAMI WALK 4 CMT:

A DAY OF UNITY AND SUCCESS!


Walk Leader, Norma Levy, with Dr. Mario Saporta

Miami, FL, recently witnessed a heartwarming gathering as the first Walk 4 CMT community fundraising event of the year took place. Norma Levy, a dedicated CMTA volunteer, led nearly 40 participants on a scenic walk at Topeekeegee Yugene Park on January 21st. Joining Norma, CMTA Miami Branch Leader, Anne Katz, and me, was CMTA Centers of Excellence CMT Clinic at the University of Miami clinic director Dr. Mario Saporta. We spent the day enjoying the company of the community we hold so dear, and it was the ultimate pleasure to be part of this unforgettable event.

Norma's unwavering commitment was truly inspiring as she led participants through the Miami Walk 4 CMT. This community event served as a powerful symbol of our unity in community spirit, bringing dedicated people together to make a difference in the lives of those living with CMT.

The success of this fundraiser reflects the tremendous impact our collective efforts can have in advancing the CMTA's mission to support the development of new treatments for CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure for CMT. I thank Norma and all for being a part of this meaningful journey and for their invaluable contribution to changing lives and finding a cure for CMT.

I'm thrilled to share that Norma has already enthusiastically signed up to host this community event again next year, and I wholeheartedly encourage all in the area to join!

This event showcased the power of community engagement and its potential to make a significant impact. It's a reminder that by uniting for a common cause, we can achieve remarkable things. If you're inspired by this success story, consider bringing a Walk 4 CMT event to your own community. Together, we can raise awareness and funds to support those living with CMT and continue our journey toward a CMT-free future.

—Jeana Sweeney, Chief Engagement and Gift Officer

GET MOVING! **HOST OR JOIN A WALK 4 CMT IN YOUR AREA**

Supporters gathered on January 21, 2024, to Walk 4 CMT in Miami.

STANDING STRONG:

One Family's Message of Hope and Determination

It was the summer of 2023. At only 15 years old, Kaitlin Siegel was in the throes of kidney failure with her kidneys functioning at only 10%. She couldn't eat. She was very weak. She had no interest in her normal school activities nor in hanging out with her friends. Even if she had any interest in these things, she was too sick to enjoy them. Her diagnosis? Dominant Intermediate CMT-E and a serious inheritable kidney disease called Focal Segmental Glomerulosclerosis Type 5 (FSGS-5). The plan? Major surgery.

THE SIEGEL FAMILY: Kaitlin, Ken, Jennifer, and Jadin

The Siegel family, who are Ken and Jennifer, and their two children, Kaitlin and Jadin, are no strangers to surgery. Ken was diagnosed with CMT in the mid-80s when he was in sixth grade. An avid baseball player until then, his mom had begun to notice Ken was walking differently than his peers. He also suffered frequent ankle sprains that persisted into 8th grade when he met Nicholas Tzimas, M.D., at NYU.

Dr. Tzimas was an orthopedic surgeon who, at the time, was the only surgeon who had experience correcting CMT-induced cavovarus foot deformities. A cavovarus foot deformity is the typical high-arched and twisted-crooked foot many who have CMT experience. Dr. Tzimas got to work on Ken and performed a triple arthrodesis (full ankle fusion) and the needed tendon transfers to rebalance the abnormal muscles forces that cause the cavovarus foot in CMT. And he did both of Ken's feet at the same time.

When in for follow-up on the surgery, they performed routine blood work and a urine test. All blood work was normal, but the urine test showed elevated protein, or what's called, “proteinuria.” Proteinuria (pro-teen-yer-ee-ah) is a hallmark of FSGS. FSGS is a progressive kidney disease that leads to the kidneys no longer working, resulting in dialysis and/or transplant. Subsequent testing showed that Ken's kidneys were worsening and that he would need a kidney transplant.

Ken's dad donated a kidney in 1987. This was Ken's first transplant. He has since had two more. In 2012, Ken's wife, Jennifer, was “Googling” “CMT and FSGS” and came across a connection. Ken's previous genetic testing in 2007 failed to identify the cause of his CMT or his FSGS. This is not uncommon in CMT. Jennifer's searching in 2012 found a connection between CMT and FSGS with the INF2 gene. It was a true AH-HA moment.

In 2011, scientists had discovered that certain autosomal dominant mutations of the INF2 gene cause CMT. They named this type of CMT “Dominant Intermediate CMT-E.” Dominant because it's inherited in an autosomal dominant pattern, and intermediate because of the type of nerve conduction abnormalities caused by this form of CMT. Also, certain mutations of this same gene cause FSGS-5. Jennifer immediately contacted their genetic counselor with this latest information and Ken's subsequent genetic test revealed that he had the INF2 gene mutation Jennifer had happened across. Fast forward to 2018.

ABOUT DOMINANT INTERMEDIATE CMT-E AND FSGS-5

Dominant Intermediate CMT-E and FSGS-5 are both caused by mutations of the INF2 gene. For reasons unknown, some who have this form of CMT also develop FSGS and vice-versa. One does not cause the other and having one does not mean having the other. Many who have this form of CMT do not have FSGS and many who have FSGS do not have CMT. CMT experts recommend that anybody who is diagnosed with this form of CMT should undergo regular testing for proteinuria and follow-up with a kidney specialist should urine protein become elevated. ***To learn more visit: www.cmtausa.org/understanding-cmt/types-of-cmt/intermediate-cmt/***

When Kaitin was about 10 years old, Ken and Jennifer noticed that she was starting to show signs of CMT. They had their doctor order testing and learned that Kaitlin had inherited the INF2 gene mutation. Soon after, Kaitlin would undergo surgery to correct her feet, with CMTA Advisory Board member Glenn B. Pfeffer, M.D., at Cedars-Sinai Hospital in LA, California. Dr. Pfeffer is the most sought-after surgeon working on CMT-induced foot abnormalities.

After having her feet fixed, Kaitlin would again find herself facing foot surgery. Due to the progression of her CMT, she would undergo revision surgery on both feet between September 2022 and January 2023, again with Dr. Pfeffer. This would not be the last surgery of 2023 though.

Kaitlin's overall health started to deteriorate. Fearing the worst, Ken and Jennifer had Kaitlin checked for proteinuria. When the test came back showing high protein levels, they knew a kidney transplant was unfortunately in her future. Kaitlin's doctors learned that her kidneys were functioning at only 10%, that she also had FSGS-5. Jennifer quickly registered as a live donor and learned she was not only a match for Kaitlin but that she matched 4 out of 6 markers.

Kaitlin's kidney transplant took place August 2, 2023, at Cooperman Barnabas Medical Center in Livingston, New Jersey. The results for Kaitlin were positive and immediate. Results were so great, and her health improved so quickly that Kaitlin was able to return to school in September. Recovery from transplants tends to be harder for the donor than the recipient, and Jennifer experienced quite a bit of post-op pain. Says Jennifer, “It was all worth it. Kaitlin is healthy again.”

“She's my twin,” says Ken. “Her CMT presented exactly as mine did—the same time frame and the same symptoms. When we found out she also had FSGS, it was a tough pill to swallow. We didn't want her going to her prom on dialysis, which was a very real possibility, and like I had to go through in high school. When we found out Jennifer was a match, she didn't waste any time setting up the transplant.”

Life has now returned to normal for the Siegel family. Jennifer and Kaitlin have fully recovered. The anti-rejection drug Kaitin has to take causes a slight tremor, but she doesn't let that stop her from doing anything, especially taking in a Broadway show (she's seen Moulin Rouge a dozen times), and she's once again enjoying life as a normal teenager. Kaitlin says she's, “doing pretty good,” with all of this. Talking to her, you would never know she's been through so much in such a short amount of time.

Kaitlin meets with her foot and ankle surgeon, CMTA Advisory Board Member and Director of the Orthopaedic Foot and Ankle Center at Cedars-Sinai Medical Center, Dr. Glenn Pfeffer, the morning of her left foot revision surgery in January 2023.

Ken and Jennifer are deeply engaged in the CMT community while Kaitlin participates as an enthusiastic member of the CMTA Youth Council. The Siegels extend a helping hand to anyone in the CMT community who may feel isolated or overwhelmed, offering support, advocacy, and education. Their commitment fosters a sense of belonging and solidarity, enriching the lives of those they touch. Through their resilience and unwavering dedication, they exemplify the belief that no obstacle is insurmountable.

“We're just lucky to have a disease that's manageable,” says Ken and Jennifer. “We've always had solutions along the way.” “We'll just take care of whatever comes our way, as it happens,” adds Ken. As they continue to navigate life's challenges, the Siegels stand as a beacon of hope, inspiring others to never lose sight of the possibilities that lie ahead, no matter the odds.

HONORING JIM LEA:

The CMTA Legacy Society Gets a New Name

CMTA
JAMES LEA LEGACY SOCIETY
Leave a Legacy That Leaves an Indelible Mark on the World

The Charcot-Marie-Tooth Association (CMTA) met Jim for the first time at a CMTA Seattle Branch meeting in 2012. At 92 years young, Jim was looking for community and a sense of belonging, and that's exactly what he found. Jim quickly became engaged in his local Seattle CMT community and became a close friend of not just the CMTA's but especially a friend of the Seattle community.

James Lea was a pioneer in outdoor camping gear, and he was a strong spirit who left an indelible mark on the world through his groundbreaking work with Cascade Designs and the invention of the Therm-a-Rest camping mattress. Born in Tacoma, Washington, on October 22, 1920, Jim's journey embodies a spirit of determination that has touched countless lives.

Despite his sprightly demeanor and boundless energy, Jim's life was shaped by the challenges of CMT. Just as his father, grandfather, and siblings who also had CMT had done, he navigated life with the aid of canes. Jim first noticed CMT symptoms in his thirties, but it wasn't until his late fifties that neurologists at the University of Washington diagnosed him.

Jim's response to his diagnosis reflected his pragmatic approach to life. "Truthfully, I just try to ignore it, work around my difficulties, go ahead with my day, and do the best that I can every day," he once shared. This attitude of resilience and determination perfectly characterizes his journey.

Upon discovering the CMTA's Seattle Branch, Jim was enamored with how community members developed strategies for living with CMT. He was appreciative of the CMTA's community-led and community-driven commitment to provide critically needed resources and services for all who have CMT so that everybody in the community can live as full of a life as possible, just as he had always strived to do.

"Jim embodied the essence of resilience and the power of community. Despite the challenges of CMT, Jim's determination and zest for life shone brightly, inspiring all who had the privilege of knowing him," says Jeana Sweeney, CMTA Chief Engagement and Gift Officer. "His deep appreciation for the strength found in community and his commitment to living life to its fullest serve as lasting reminders of his remarkable legacy."

In recognition of Jim's enduring legacy and his commitment to community, the CMTA is proud to announce the establishment of the CMTA Legacy Society, named in his honor. The James Lea Legacy Society aims to recognize individuals who, like Jim, have demonstrated exceptional dedication to community, to raising awareness, to accelerating research, and to support for those living with CMT.

As the first member of the CMTA Legacy Society, Jim's impact through his legacy gift will be felt for generations to come. His legacy serves as a beacon of hope and of resilience, reminding us of the power of community and compassion in the face of adversity.

The James Lea Legacy Society stands as a testament to the profound impact that one individual can have on the world. May his story inspire others to join in the fight against CMT and to strive for a future where every individual living with CMT can live a life of hope and of fulfillment until CMT is a thing of the past.

The James Lea Legacy Society is a select group of individuals who have chosen to leave a lasting impact on the fight against CMT by allocating a portion of their estate to the CMTA. The decision to include the CMTA in your planned giving will be instrumental in providing sustained support for the development of new treatments for CMT, for improving the quality of life for people with CMT, and, ultimately, for finding a cure.

Members of the James Lea Legacy Society receive:

- Exclusive invitations to CMTA events, fostering community and networking within the CMTA community
- Complimentary print copy of the CMTA Report that provides updates on CMT research advancements and stories of hope
- With permission, public acknowledgment for their generosity and commitment, inspiring others to join the fight against CMT

To become a James Lea Legacy Society member, go to ***www.cmtausa.org/letterofintent*** and complete the letter of intent and email it to Jeana Sweeney at jeana@cmtausa.org. If you have questions or would like to discuss your legacy giving options, call Jeana at 814-269-1319.

INNERVATORS HONOR ROLL

ACCORDING TO THE DICTIONARY, **an innervator is a nerve stimulator. According to the CMTA, an Innervator is an action-oriented donor who gives monthly to the organization, sustaining STAR (Strategy to Accelerate Research), our premier research initiative, as well as important community initiatives like Camp Footprint, Patient/Research 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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Richard Arsenault
Aaron Baker
David Balbi
Kim Bamford
Kelly Banner
James Barker
Christine Bateman
Chevelle Bazo
Donald Bean
Jonah Berger
Cheryl Bidgood
Aaron Bokmeyer
Robert Bollenbacher
Marilyn Booth
H. Brand
Laurie Brandvold
Deborah Breuer
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Edna Broman
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> ***"I became an Innervator because I believe in a future that has more options for CMT patients."***
>
> **—STEVE REISS**

ASK ELIZABETH

BY ELIZABETH MISENER,
CMTA Advisory Board Member

Elizabeth has been working with clients to alleviate depression and decrease anxiety for more than 18 years. Her passion is listening to her clients' stories and providing evidence-based tools to support them in their journeys with depression, anxiety, grief, suicidal thoughts, life transitions and everyday struggles. She has experience working with a range of individuals, including college students, seniors and adults facing life balance issues, as well as families dealing with disabilities. Elizabeth's 19-year-old-son Ethan and husband David, a board-certified prosthetist and orthotist who is also on the Board of Advisors, both have CMT1B.

Dear Elizabeth,

What are some strategies for living with the emotional impact of CMT corrective foot surgery?

Elizabeth Answers:

This is a great question and one that as a family with two people with CMT1B we have spent many years researching, thinking about, and going through the corrective surgeries. My son, who is nineteen, has had around seven corrective surgeries and will have another one this summer. Each time they were successful and relieved his pain. My husband has had two successful corrective surgeries. So, in full disclosure, my answer is based on my experience as a mother, partner, caregiver, and therapist over the years. Undergoing corrective foot surgery for CMT can be emotionally challenging and here are some strategies that helped us over the years, and I hope might help you too:

- **Acknowledge ALL Your Feelings:** It's normal to feel anxious, scared, or even frustrated about surgery. Acknowledging these emotions can help you process them. We cycled the whole range during the process, and even today as I sit and write this, I can acknowledge I feel scared for what this summer's surgery might bring. I feel hopeful that his pain might be gone, and I feel grateful that I will be able to spend 6-8 weeks taking care of my 19-year-old. Emotions only last about ninety seconds and if you can ride them like a wave, they move on. It's when we get stuck on an emotion that it becomes a mood, and that lasts a lot longer. It's like going swimming and being hit by a big wave. If we go underwater and hold our breath while counting to ten, the wave passes, and we come back up. But if you panic, we can get pulled under and lost. So, feel your emotions, ride the waves, breathe, and move to the next emotion.
- **Seek Support:** Talk to friends, family, or a therapist about your feelings. Sharing your concerns can provide comfort and perspective. Over the years, I have called my mother from the hospital many times in tears when I needed to share my pain as a mother. It allowed me the space to feel my emotions and to then center myself to be supportive for my son. Talking to other parents about the tools they used to navigate the process helped me, and I love to share with them our experiences as the corrective surgeries have been beneficial when the pain got to be too much.
- **Educate Yourself:** Understanding the surgical process, expected outcomes, and recovery can reduce anxiety. We would have so many questions to ask, and this helped us understand the process. We would also share our expertise on pain management and how the CMT impacts pain tolerance. It is so important to stay ahead of the pain.
- **Stay Positive:** Focus on the benefits of the surgery and the improvements it can bring to your quality of life. We also focus on doing "fun things" like watching movies or eating ice cream to help us stay positive.
- **Practice Relaxation Techniques:** Techniques like deep breathing, meditation, or yoga can help reduce stress and anxiety. I would have post-surgery meditations on my phone that I would play to help my husband and son sleep in the hospital. Meditation is a great relaxation tool and you can find free ones on YouTube or Insightimer. I encourage you to start practicing now for 2 minutes a day. It can help support a healthy mindset in everyday life.
- **Stay Connected and Set Realistic Expectations:** Stay connected with your support network before, during, and after the surgery. Their support can be invaluable. Understand that recovery may take time, and there may be ups and downs along the way. Set realistic goals for yourself.

continued on page 24

> "The difference between misery and happiness depends on what we do with our attention"
>
> *—Sharon Salzburg*

ASK ELIZABETH A QUESTION AT:
info@cmtausa.org

PEDALS OF INCLUSION: HOW ADAPTIVE CYCLING FOSTERS COMMUNITY FOR THOSE WITH CMT

BY JENNIFER WAYNE

For individuals with CMT, the journey to adaptive cycling often starts with a desire for independence and a longing to reconnect with the great outdoors. CMT affects each person differently, but one common challenge is the loss of muscle strength, particularly in the lower limbs. As a result, simple activities like walking and running become increasingly difficult over time. However, cycling offers a low-impact alternative that allows individuals with CMT to maintain their mobility and engage in physical activity without putting excessive strain on their joints.

As I reflect on my own experience with adaptive cycling, I am reminded of the initial trepidation I felt when considering whether it was a feasible option for me. Like many with CMT, I worried about the physical exertion required and whether I would be able to navigate my beloved trails safely. However, with the support of my local community and the guidance of experienced cyclists like my friends Tony Luparella and Wes Hall, who are the co-founders of North Carolina Adapted Sports, a company specializing in adaptive technologies for cycling, I soon discovered that adaptive cycling was not just accessible, but immensely rewarding.

One of the most significant benefits of adaptive cycling for somebody who has CMT is the sense of freedom it provides. Adaptive cycling is a method by which individuals who have mobility impairments can enjoy cycling. For me, adaptive cycling affording the ability to explore nature and traverse rugged terrain is nothing short of transformative. Whether it's the thrill of conquering a challenging trail or the serenity of cruising along a scenic path, adaptive cycling offers moments of joy and exhilaration that are unmatched by any other form of exercise.

Perhaps more impactful than the physical benefits of cycling are the emotional and social rewards. Cycling has a way of bringing people together, fostering connections, and creating a sense of belonging to a community. Through shared cycling experiences, individuals with CMT forge bonds with fellow cyclists, forming a supportive community that celebrates triumphs and encourages one another through their challenges.

Due to the growing availability of adaptive cycling, the future of cycling for individuals who have CMT is bright. With advances in technology and a growing awareness of the needs of individuals with disabilities, the possibilities are endless. From adaptive mountain bikes to electric-assist "E-Bikes" and "E-Tricycles, there are more options available than ever before for individuals with CMT to enjoy the thrill of cycling.

> **Perhaps more impactful than the physical benefits of cycling are the emotional and social rewards.**

Cycling is not just a sport or a recreational activity—it's a way of life. It's about embracing challenges, pushing boundaries, and discovering what's possible. So, to anyone with CMT who has ever dreamed of hitting the trails on two wheels, or who has dreamed of getting back on a bike, I say this: don't let your CMT hold you back. With any adaptive equipment that might be needed, a supportive community, and a sense of determination, the world is yours to explore. Get out there and enjoy it! Happy cycling!

Manitowoc, WI, Branch Cycle and Walk Event, September 2023

ADAPTIVE CYCLING includes an almost endless array of accommodations such as electric bikes (eBikes), recumbent three-wheeled cycles, four-wheeled cycles, hand-cycles, and so much more.

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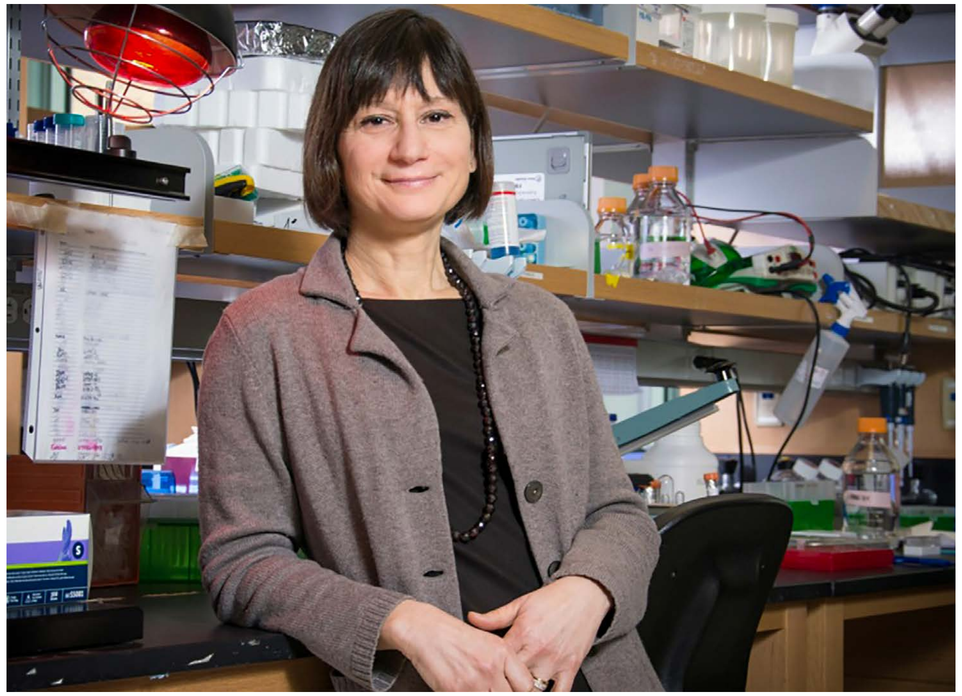
THE CMTA MOURNS THE LOSS OF SCIENTIFIC ADVISORY BOARD MEMBER AND ESTEEMED CMT CLINICAL RESEARCHER

It is with the heaviest of hearts that the Charcot-Marie-Tooth Association (CMTA) mourns the loss of our friend and Strategy to Accelerate Research (STAR) Scientific Advisory Board (SAB) Member, Dr. M. Laura Feltri. Dr. Feltri passed away December 25, 2023, at home in her native Milan, Italy, surrounded by family and friends, after a long battle with cancer. She was just 60 years old.

M. Laura Feltri, M.D., was a highly regarded Professor of Biochemistry and Neurology in the Jacobs School of Medicine and Biomedical Sciences at the State University of New York in Buffalo, NY, where she also served as director of the university's Institute for Myelin and Glia Exploration.

Dr. Feltri was an original member of the CMTA's SAB and helped shape the direction of our research. She and her husband, Lawrence Wrabetz, M.D., who is himself a respected Charcot-Marie-Tooth disease (CMT) researcher at the same university as Dr. Feltri, often spoke at CMTA Buffalo Branch community meetings, and were always available to share knowledge, to spread awareness, and to spend time with the CMT community. She was elected president of the Peripheral Nerve Society in 2021, in recognition of her leadership in this international community.

In a statement, the Peripheral Nerve Society said, “Dr. Feltri was an unwavering supporter of the Peripheral Nerve Society (PNS), serving on the Scientific Program and Education Committees, and the Journal of the Peripheral Nerve Society (JPNS) Editorial Board. She was a PNS Board Member between 2009 and 2013 and President-Elect/President between 2021 and 2023. As a mentor and colleague, she trained and inspired many of us. She was determined and passionate in both life and science, as well as calm and generous, always lending a helping hand or simply a smile. Laura Feltri will be deeply missed.”



M. Laura Feltri, M.D., in her beloved lab at SUNY's Institute for Myelin and Glia Exploration in Buffalo, NY.

Dr. Feltri was a dedicated supporter of our mission to support the development of new treatments for CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure. “Laura consistently had wonderful things to say and possessed the kindest soul, and she was always standing proudly by the CMTA and how we serve our community,” said Jeana Sweeney, CMTA Chief Engagement and Gift Officer, who was also a longtime friend of Dr. Feltri's. “Her presence at the STAR Advisory Board meetings will be deeply missed, but her legacy of compassion will continue to inspire us.”

“There are enough wonderful things to say about Laura Feltri that stating them all would fill a book,” says Michael Shy, M.D. “She was a warm caring friend who would go out of her way to do anything to help a friend or colleague. She always cared about science-ego and never let it get in the way. Finding the truth was what counted.”

Dr. Feltri built two great Myelin programs: the first in Milan, Italy and the second in Buffalo, NY. Following her training in Philadelphia, Laura and her husband returned to Milan where they developed and ran the internationally recognized glial biology group at San Raffaele Hospital. During this time, Dr. Feltri trained many of the investigators who are today active CMT scientists. “Despite her dislike of the cold,” says Dr. Shy, “Laura and Larry then moved to Buffalo where they again built an institute for myelin and glia exploration from scratch.”

Dr. Feltri continued to raise her family while running the Buffalo myelin and glia group and became the world expert in what is known as the extracellular matrix that surrounds and helps regulate myelination. Dr. Feltri was a pioneer in developing genetic mouse models of multiple causes of CMT and shared the animals widely. Dr. Shy adds, “Laura took an existing system of co-cultures of Schwann cells and neurons and modified it so that these co-cultures became great models to evaluate CMT in a dish.”

Over the course of her career, Dr. Feltri published over 140 peer-reviewed research papers, advancing the understanding of CMT, and moving us closer to achieving the CMTA's vision of a world without CMT. She was highly collaborative and worked with a wide variety of researchers. She also trained a number of scientists who continue to work in the CMT field.

“I have known Dr. Laura Feltri since she was a post-doctoral fellow at Penn in 1990,” says Steven S. Scherer, M.D., Ph.D. “It was a special time in our lives, and at the very beginning of the discovery of the genetic causes of CMT. Laura, Larry Wrabetz, Michael Shy, John Kamholz, Kurt Fischbeck, and I were all drawn to study CMT, which we realized was an important and solvable problem. Our focus on CMT altered our careers.” Dr. Scherer continues, “Laura and I worked closely on two projects, and I admired her in every way. Even though we all went our separate ways within a few years, we continued to collaborate and remained friends ever since. We met regularly at various meetings, catching up on each other's lives, and I was fortunate to have visited Laura and Larry (who were now married) in Milan, Italy, and in Buffalo, NY.”

What would be Dr. Feltri's final piece of research is a CMTA-funded project to develop a treatment for both CMT1A and CMT1B. Through this project, Dr. Feltri created a promising approach to potentially treat these forms of CMT with a combination of two drugs, one of which the US-FDA has previously approved and is in wide use.

> Over the course of her career, Dr. Feltri published over 140 peer-reviewed research papers, advancing the understanding of CMT, and moving us closer to achieving the CMTA's vision of a world without CMT.

Building on Dr. Feltri's breakthroughs and continuing her important work, her colleagues, led by Jordan VerPlank, Ph.D., are planning research to find the optimal treatment strategy in a mouse model of CMT1A, planning forward, ultimately to human trials.

Dr. Shy, who was a mentor of Dr. Feltri, recalls “Laura was unfailingly warm and friendly, though there were a few things one knew not to do. First, it was to invite trouble by saying anything bad about Bruce Springsteen, whom she idolized, having traveled on at least one occasion to the Stone Pony in New Jersey in the hope that he would show up and play.” Dr. Shy continues, “I also learned quickly that she was not a fan of American soft drinks and fast food. I offered her grape soda, root beer, and a cheesesteak when she first arrived in Philadelphia as a postdoc. It then took me an hour to talk her out of getting on the next plane home if this is how American's eat. Laura Feltri was one of the truly great people I have met in my life and things won't feel the same without her as part of it. I'm sure I'm not alone in these sentiments.”

“I have many stories, but let me just say that Laura and Larry were full partners, in their lab and in their life together,” says Dr. Scherer. “They were inseparable and published many important papers. They raised their family and fostered a new generation of neuroscientists. Laura made a huge impact that will be with us forever. She was my close colleague and I love her dearly.”

The loss of Dr. Feltri is tragic, and she will be deeply missed by all. Her legacy lives on through her work and through the countless lives she touched as a scientist, as a CMT research community member, as a wife, and as a mother. Dr. Feltri's contributions to CMT are immeasurable. The CMTA is honored to have known Dr. Feltri and to call her a friend. Rest well, Dr. Feltri, rest well.

With contributions from CMTA Chief Engagement and Gift Officer, Jeana Sweeney, CMTA Scientific Advisory Board Chair, John Svaren, Ph.D., CMTA Clinical Expert Board Chair Michael Shy, M.D., CMTA Scientific Advisory Board & Clinical Expert Board member, Steven S. Scherer, M.D., Ph.D., and the Peripheral Nerve Society.

ACCELERATING RESEARCH AIMED AT BRINGING TREATMENTS AND A CURE

CMT-SORD

In February, Applied Therapeutics announced positive interim results from its INSPIRE Phase III trial for CMT-SORD. The trial, evaluating the company's experimental drug, govorestat, confirmed CMT-SORD patients showed significant reductions in sorbitol levels and improvements in the CMT Health Index (CMT-HI) score after 12 months. Secondary outcomes, including enhanced mobility and reductions in foot drop severity, were also observed. CMT-SORD, caused by mutations in the Sorbitol Dehydrogenase (SORD) gene, leads to the accumulation of toxic sorbitol levels in nerve cells leading to CMT symptoms. These findings suggest that lowering sorbitol levels could reduce symptoms and improve quality of life for individuals with CMT-SORD.

Investing Over $700K Between Three Cutting-Edge Projects

The CMTA has invested over half a million dollars to fund two significant research projects aimed to accelerate bringing treatments to CMT patients. Led by renowned scientists including the CMTA's STAR Advisory Board Chair, Professor John Svaren, Ph.D., and STAR Advisory Board members, Drs. Maurizio D'Antonio and Bruce Conklin, the projects focus on developing small molecule drugs to lower PMP22 expression in CMT1A and exploring gene editing therapies for demyelinating forms of CMT.

In a third initiative, the CMTA has invested over $200,000 in pioneering organoid research led by the legendary CMT researcher, Professor Vincent Timmerman, Ph.D. This new way of doing things aims to develop a standard way of creating tiny organ-like CMT models (grown in a lab and called "organoids") of CMT1A. These models will help scientists to test treatments that fix problems with peripheral myelin, the covering around nerves.

Dr. Laura Feltri's Legacy

CMTA STAR Advisory Board original member, M. Laura Feltri, M.D., passed away in late 2023 after a lengthy battle with cancer. Dr. Feltri was a pioneer in CMT who never stopped working on bringing treatments to those living with this disease. The following is a brief summary of what would be her final CMTA-supported research project.

Dr. Feltri and her colleagues, including Jordan VerPlank, Ph.D., in the Institute for Myelin and Glia Exploration at the State University of New York in Buffalo, found a new way to possibly treat CMT1A and CMT1B. These types of CMT happen because of changes in the PMP22 and MPZ genes, respectively. These genes make proteins needed for healthy nerves. But when they're changed, they make "bad" proteins that build up, leading to problems.

Dr. Feltri tried two drugs on models of CMT1A and CMT1B for three weeks. These drugs helped clear away the bad proteins. With this, they saw improvements in the models' CMT symptoms. Dr. VerPlank plans to do more research to make sure this could work in people, too. The CMTA remains committed to furthering this important work.

While embarking on cutting-edge research that accelerates bringing treatments and ultimately a cure to CMT patients, we also celebrate our alliance partners' achievements, such as Applied Therapeutics' CMT-SORD trial good news. As we mourn the loss of Dr. Feltri, we celebrate and lift her up as the legacy of her work continues to shine via her colleagues.

Driven by You

These initiatives underscore the CMTA's community-led, community-driven role as a leading global philanthropic funder of CMT research aimed at bringing treatments and a cure to our beloved patient community. By uniting the community with clinicians and industry experts, the CMTA accelerates the development of new treatments, improves the quality of life for people with CMT, and works tirelessly towards finding a cure for this rare and debilitating disease.

CLINICAL TRIALS IN A DISH

The CMTA is investing in the creation of new stem cells lines to cover more types of CMT and ensure we have representation from both sexes. **We need adults from the CMT community who have specific types of CMT to volunteer to donate a small blood sample and a small skin sample.**

The CMTA is working with the world-renowned New York Stem Cell Foundation (NYSCF) on this project. Our joint mission is to accelerate cures for CMT. NYSCF's independent laboratory is a non-profit accelerator that reduces the cost, time, and risk of developing new treatments and cures. NYSCF uses samples from CMT patients to create stem cells and stores and shares samples and cells with the CMTA's researchers worldwide to help us accelerate the development of treatments.

To learn which subtypes and their related specific mutations we're looking for and to participate, visit: www.cmtausa.org/our-research/for-patients-and-families/patients-as-partners/clinical-trials-in-a-dish/

THE CMTA APPOINTS PROFESSOR CHARLOTTE SUMNER, M.D., TO ITS SCIENTIFIC ADVISORY BOARD

The Charcot-Marie-Tooth Association (CMTA), the largest philanthropic funder of Charcot-Marie-Tooth disease (CMT) research aimed at bringing treatments and a cure to patients, is pleased to announce the appointment of Dr. Charlotte Sumner to its Strategy to Accelerate Research (STAR) Scientific Advisory Board (SAB) this past February. Charlotte J. Sumner, M.D., is a Professor of Neurology, Neuroscience and Genetic Medicine at Johns Hopkins University School of Medicine in Baltimore, MD. She is a Daniel Nathans Scientific Innovator and the Vice Chair for Clinical Research in the Department of Neurology. Dr. Sumner is also President of the Peripheral Nerve Society.

The CMTA's SAB, comprising top experts in CMT, provides scientific input, evaluates ongoing or proposed CMTA-funded research projects, and guides the Association's research strategy.

"I am so pleased to join the CMTA STAR Scientific Advisory Board at a time when the CMTA is gaining real momentum in developing disease modifying therapeutics for patients," says Dr. Sumner. "The CMTA's research investments and advocacy have been an essential part of this progress, and I am thrilled to be part of this fantastic organization."

"The CMTA is delighted to welcome someone of Dr. Sumner's stature and experience to our STAR Scientific Advisory Board," says Dr. Sue Bruhn, CMTA CEO. "We look forward to working with her on strategies to accelerate treatments for the CMT community."

Dr. Sumner cares for patients with inheritable neuromuscular diseases and co-directs the Johns Hopkins Muscular Dystrophy Association Care Center, the Spinal Muscular Atrophy (SMA) clinic, and most importantly, co-directs the CMTA's Centers of Excellence CMT clinic, which delivers multidisciplinary clinical care, engages in international natural history studies, and provides cutting edge therapeutics.

Dr. Sumner's research laboratory focuses on the genetic and cellular pathogenesis of motor neuron and peripheral nerve disorders with particular attention to identification of disease genes, characterization of molecular and cellular disease mechanisms, and preclinical development of therapeutics. Her work has contributed to the discovery of several CMT-causal genes and to the scientific foundations leading to three new approved gene-directed therapeutics. The CMTA proudly welcomes Dr. Sumner and her expertise to its SAB.

CHARITY NAVIGATOR ★★★★ Four Star Charity

Know that your donations are being used wisely. Charity Navigator awarded us its highest 4-star rating and a Perfect 100 score based on our exceeding industry standards and outperforming other organizations that do similar work. It's a distinction enjoyed by less than 1 percent of the nonprofits rated by Charity Navigator.

FUELING HOPE, FIGHTING CMT: EVERY CONTRIBUTION POWERS PROGRESS!

YES! I want to support the CMTA's mission in the fight against CMT!

○ $1,000 ○ $500 ○ $250 ○ $100 ○ $50 ☐ Other: $__________ ○ Make my gift a recurring monthly donation.
○ Please charge my credit card. ○ Visa ○ MasterCard ○ American Express
○ Check enclosed, payable to the Charcot-Marie-Tooth Association.

Name__________ Email __________

Card #__________ Exp. Date__________ CVV#__________

Signature__________ Billing Address__________

City__________ State__________ Zip__________ Phone__________

Dedicate this gift to: __________ *Honoree's Email:*__________

For information on how to make a multi-year pledge or donating securities, email Jeana Sweeney at jeana@cmtausa.org.
The CMTA is registered as a 501(c)(3) non-profit organization.

Mail this form to the CMTA, PO Box 105, Glenolden, PA 19036

DONATE ONLINE AT: www.cmtausa.org/donate

UNDER THE MICROSOPE

BY KATHERINE FORSEY, Ph.D.
CMTA Chief Research Officer

In "Under the Microscope," CMTA Chief Research Officer, Katherine Forsey, Ph.D., takes a closer look at topics related to the CMTA's Strategy to Accelerate Research (STAR). Dr. Forsey oversees STAR and the CMTA's STAR Advisory Board, comprising over 30 world-leading experts in CMT who provide scientific input, evaluate ongoing or proposed CMTA-funded research projects, and guide the CMTA's research strategy. Through STAR, the CMTA currently has more than 50 active research projects, including sponsored research grants with academic labs and preclinical testing studies with biotech/pharma Alliance Partners.

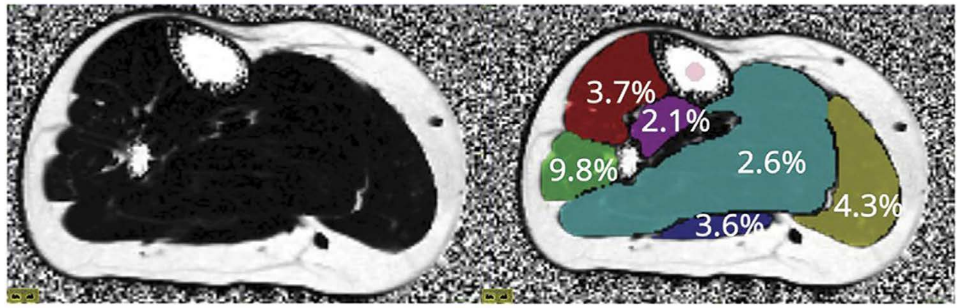
UNVEILING THE PROMISE OF MRI CALF FAT-FRACTION IN TRACKING CHARCOT-MARIE-TOOTH DISEASE

Our Mission to Track CMT

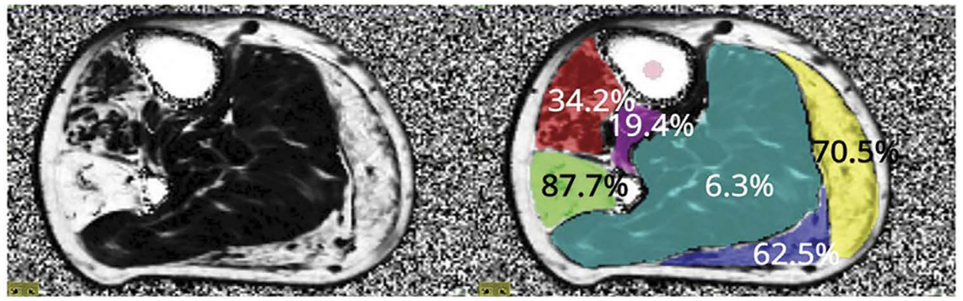
Charcot-Marie-Tooth disease (CMT) causes muscle weakness, atrophy, and sensory loss (numbness, temperature sensation, etc.) by damaging the peripheral nerves responsible for transmitting signals between the spinal cord and the rest of the body. Robust monitoring tools and repeatable measures are needed to track the progression of CMT over time. Researchers need to know how the disease is progressing and which parts of the body are affected—this is known as "Natural History," and some of the measures are known as "biomarkers." These tools and measures are essential for use in clinical trials—we use them to provide evidence that a new treatment is working or is indeed not working.

The CMTA has supported the development of next-generation functional outcome measures (CMT-FOM and the pediatric equivalent, CMT-PedS) and Natural History data collection over several years to help increase the understanding of the disease and to prepare for future clinical trials. Functional tests of strength, dexterity, walking, stair climbing, sit-to-stand time, and balance have been developed, supported by nerve conduction study result changes over time. Biomarkers, measured in blood samples and small skin biopsies, are also in development with CMTA support. If these biomarkers go up or down in a way that is linked to the results of the functional tests, they can be useful predictors of how the disease is affecting our bodies and show whether a treatment is working.

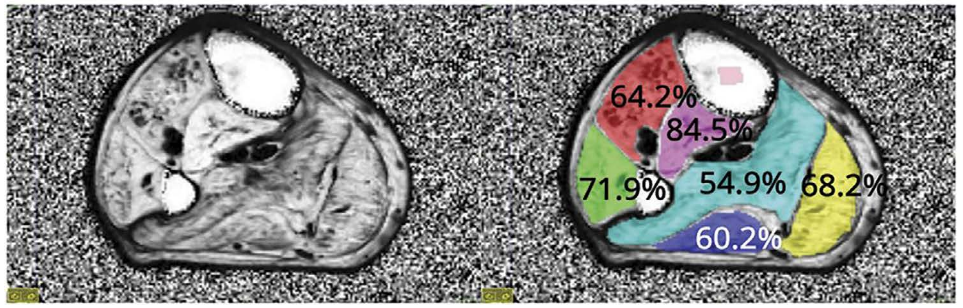
35-year-old female with CMTNS 5



43-year-old male with CMTNS 19



64-year-old male with CMTNS 23



One of the challenges with CMT is that, in many, the disease progresses very slowly. It can be difficult to measure small changes in a useful time period, say within one year, meaning clinical trials have to last several years to track changes and are therefore both expensive to run and burdensome to patients. This puts off biopharma and drug development companies from choosing CMT as a disease they want to develop treatments for.

An innovative new development in CMT tracking, which has recently been added to the CMTA's collection of next-generation measures, is the use of MRI lower limb Fat-Fraction. Specifically, the protocol developed at The Queen Square Institute of Neurology (QSION), London, UK, to provide a non-invasive and measurable approach to assess and track CMT progression.

What is MRI Calf Fat-Fraction?

The MRI lower limb Fat-Fraction protocol developed at Queen Square uses magnetic resonance imaging (MRI) to measure fat levels within foot, calf, and thigh muscles of CMT patients. When there is muscle atrophy as is seen with CMT, the muscles are gradually replaced with fat and this fat-fraction can be very accurately measured by MRI. Professor Mary Reilly, M.D., and the London group initially showed that this technique could accurately measure progression of CMT over a period of one-year in adults with CMT1A. The London group have also shown similar results over a period of one-year in additional forms of CMT including CMT1B, CMT2A, CMTX1 (aka CMT1X, CMTX), and Hereditary Sensory Neuropathy type 1 (HSN1—despite its name, this is a type of CMT), and the results have been reproduced in multiple international sites.

The MRI studies have shown that the fat-fraction increases over time (by repeat scans) and correlates with disease progression, i.e. more fat infiltration (atrophied muscle tissue replaced by fat) is seen in people with more severe CMT symptoms. The London group have even developed an AI (artificial intelligence) tool to make the MRI scans analysis much quicker.

> *"Our team in London has developed an accurate way of measuring progression in CMT using MRI fat-fraction of the lower limb muscles. I am delighted that working with many international colleagues we have now shown this method to be the most responsive outcome measures in many forms of CMT including the most common forms of CMT1A, 1B, 1X, and 2A. I am very grateful to all the patients that have willingly given their time to help us do these important biomarker and natural history studies and to all my colleagues internationally who have helped with these studies. I am especially grateful to the CMTA for funding the first trial in CMT where our MRI fat-fraction protocol is the primary outcome measure."*
>
> **—Professor Mary M Reilly, M.D., London, UK**

What are the advantages of MRI Calf Fat-Fraction?

- **Patient Friendly:** MRI is safe, painless, and non-invasive.
- **Objective:** The technique eliminates subjectivity, providing an objective measure of muscle degeneration that is linked to the severity of CMT symptoms.
- **Reproducible:** High reproducibility ensures consistent results across multiple scans, crucial for accurately monitoring changes over time.
- **Quantifiable:** The numerical Calf Fat-Fraction values quantitatively measure disease progression, providing a clear indication of treatment impact.

What is the Potential Role of MRI Fat-Fraction in Clinical Trials?

Research in CMT1A, 1B, X1, and 2A community members (these four types account for approximately 90% of all genetically confirmed cases of CMT) has confirmed MRI Calf Fat-Fraction is highly responsive over a period of 12 months. This potentially reduces the length (and cost) of clinical trials. CMT sites in several countries have now been trained in this technique. The CMTA is currently funding the SENSE Trial in London, the first ever clinical trial using MRI Calf Fat-Fraction as the primary outcome measure (see below for a link to the trial). Combined with other published works from the developers of this technique, the results of the SENSE Trial will be instrumental in guiding the design of future CMT clinical trials.

Driven by You

In the realm of advancing CMT research and upcoming clinical trials, the MRI Calf Fat-Fraction technique stands out as a valuable tool. Its non-invasive, objective, and quantifiable nature will help to shape future clinical trials in CMT.

References: Doherty, C.M., Morrow, J.M., Zuccarino, R., Howard, P., Wastling, S., Pipis, M., Zafeiropoulos, N., Stephens, K.J., Grider, T., Feely, S.M.E., Nopoulous, P., Skorupinska, M., Milev, E., Nicolaisen, E., Dudzeic, M., McDowell, A., Dilek, N., Muntoni, F., Rossor, A.M., Shah, S., Laura, M., Yousry, T.A., Thedens, D., Thornton, J., Shy, M.E. and Reilly, M.M. (2024), Lower limb muscle MRI fat fraction is a responsive outcome measure in CMT X1, 1B and 2A. Ann Clin Transl Neurol. https://doi.org/10.1002/acn3.51979

The CMTA is only able to support the work described above because of the generous donations we receive from CMT community members, either donating money or donating time to take part in studies and trials. We thank every patient partner who has enabled this research, and we are grateful to those who will support it through the years to come. To donate to CMTA-STAR and help us continue this essential work visit *www.cmtausa.org/ways-to-give/donatecmta/* or scan this QR code with your mobile device's camera or QR reader app.

To learn more about the SENSE trial, visit our Patients as Partners in Research portal for this study: *www.cmtausa.org/our-research/for-patients-and-families/patients-as-partners/hsn-serine-trial/*

BRANCH NOTES


Cincinnati Branch

EDMONTON, AB

The Edmonton, AB Canada Branch met on December 2nd with members attending virtually all over Canada to welcome guest speaker Julie Stone. Julie led the Branch in a CMT-friendly exercise session. She also shared some exercises with the group that may help them stay active. The Edmonton Branch will continue to meet regularly throughout the year.

CENTRAL ARKANSAS

The Central Arkansas Branch held its inaugural meeting on January 22nd. Members gathered to introduce themselves and share their connection to CMT. They discussed the goals of the Central Arkansas Branch and plans for future meetings. It was a successful first meeting. The Central Arkansas Branch is excited about the newfound CMT community.

JACKSONVILLE, FL

The Jacksonville, FL Branch gathered in-person on December 9th with 16 members in attendance to welcome guest speakers Elliot Dimberg, M.D., and Tamara Brooks, MSW, LCSW, from the Neurology Department at Mayo Clinic. The guest speakers discussed the numerous resources offered at the Mayo Clinic, the importance of genetic testing, and bracing options. The Branch enjoyed learning from Tamara Brooks and Dr. Dimberg. The Jacksonville Branch is looking forward to the next meeting.

CHICAGO, IL

The Chicago, IL Branch gathered virtually on December 19th for their monthly meeting. They discussed the mental and emotional aspects of being diagnosed with CMT and ways to cope. The group ended the meeting by sharing ideas to help reduce the pain of leg cramps and comfortable shoe recommendations. The Chicago Branch is looking forward to the next monthly meeting.

SOUTHEASTERN, KY

The Southeastern Kentucky Branch held an in-person Branch meeting on January 27th. Members brought gadgets and accessibility aids they found helpful for a CMT show and tell. The Southeastern Kentucky Branch is excited for a virtual meeting next month.

SYRACUSE, NY

The Syracuse, NY Branch held its first in-person meeting since Covid on November 18th. Members enjoyed catching up, sharing their experiences from the 2023 CMTA Patient and Research Summit, and discussing the resources offered at the CMTA Center of Excellence at Strong Hospital.


Syracuse Branch


Jacksonville Branch

RESEARCH TRIANGLE AREA, NC

The November 18th meeting of the Research Triangle Area Branch was held in-person and welcomed guest speaker Sharon Cournoyer, a certified yoga instructor. Sharon led the Branch in a chair yoga session, which included breathing techniques for relaxation and stretches we could do safely in our chairs. The members of the Research Triangle Area Branch loved this experience so much that they plan on participating in yoga frequently.

CINCINNATI, OH

The Cincinnati, OH Branch gathered in person on January 10th to welcome guest speaker Hani Kushlaf, M.D. Dr. Kushlaf is the Director of Neuromuscular Research at the UC Muscular Dystrophy Association Care Center and the Neuromuscular Medicine Fellowship. Branch members enjoyed hearing all the resources he shared. The Branch concluded its meeting by discussing possible fundraising efforts for 2024.

SEATTLE, WA

The Seattle Branch welcomed guest speaker Christyn Edmondson, M.D., to a virtual meeting on January 13th. The CMTA Centers of Excellence director shared the resources, education, and services available to those living with CMT at the clinic. The Seattle Branch members were thrilled that Dr. Edmondson was able to join them.

ASK ELIZABETH

continued from page 14

- **Take Care of Yourself:** Prioritize self-care by eating well, drinking lots of water, getting enough rest, and engaging in activities that bring you joy.
- **Stay Informed and Join a CMT Group:** Stay informed about the latest treatments and advancements in CMT. The CMTA has a vast network of local Branches and the CMTA's Facebook group is the largest social media CMT community there is. Connecting with others who have gone through similar experiences can provide understanding and encouragement.

Remember, it's okay to feel a range of emotions. Be kind to yourself during this time and reach out for support when you need it. It's normal to experience a range of emotions before and after surgery. Be patient with yourself and give yourself permission to feel whatever you're feeling and know you are not alone in this. You have a whole community with the CMTA. The community is there to support you if you reach out and ask. Try to focus your attention on the benefits of the surgery and on one or two tools you can use to support yourself during this time.

CMTA BRANCHES

ALL CMTA BRANCHES CAN BE ACCESSED ONLINE AT www.cmtausa.org/branches

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610-405-9291
Harrisburg
Erin Weierbach
717-379-7504
Northwestern Area
Joyce Steinkamp
814-833-8495
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Leader Needed—Call:
800-606-2682

SOUTH CAROLINA
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Kyle Bryant
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Greenville Area
Rebecca Lauriault
864-918-2437

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Tami Delmark
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Central Virgina
Karen Dyer-Smith
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Emily Osborne
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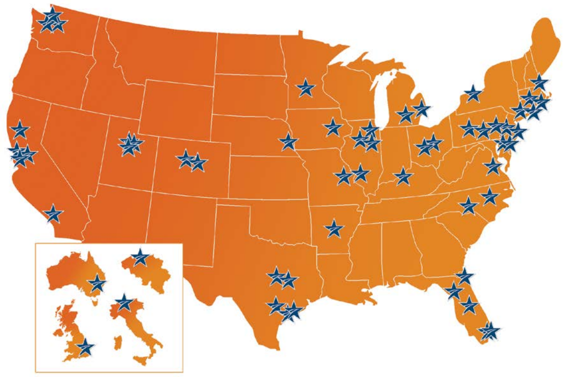
INTERESTED IN STARTING A BRANCH IN YOUR AREA?
Contact CMTA Director of Community Outreach Laurel Richardson at **laurel@cmtausa.org**

CMTA CENTERS OF EXCELLENCE

One of the CMTA's primary missions is improving the quality of life for those with CMT, and one way we accomplish this mission is by sponsoring patient-centric, multi-disciplinary CMT clinics, staffed by some of the highest quality CMT clinicians and researchers in the world. Through these CMTA Centers of Excellence, children, adults, and families affected by CMT can be assured of receiving comprehensive care by a team of CMT experts.

Although all the Centers of Excellence listed below include multi-disciplinary teams of CMT specialists, the CMTA's Centers of Excellence affiliated with the Inherited Neuropathy Consortium or INC (marked with an asterisk), go a step further by collecting and recording genetic, biologic, and other data from people with the disease.



ARKANSAS

LITTLE ROCK (PEDIATRIC)
Arkansas Children's Hospital
Clinical Director:
Aravindhan Veerapandiyan, M.D.
Appts: 501-364-1850

CALIFORNIA

LOS ANGELES (ADULT & PEDIATRIC)
Cedars-Sinai Medical Center
Clinical Director: Richard A. Lewis, M.D.
Appts: 310-423-4268

PALO ALTO (PEDIATRIC)
Stanford Children's Health*
Clinical Directors: John Day, M.D., Ph.D., and Ana Tesi Rocha, M.D.
Appts: 650-723-0993

PALO ALTO (ADULT)
Stanford Neuromuscular Program*
Clinical Director: John Day, M.D., Ph.D.
Appts: 650-723-6469

SAN FRANCISCO (ADULT)
University of California, San Francisco
Clinical Director: Mark Terrelonge, M.D.
Appts: 415-353-2273

SAN FRANCISCO (PEDIATRIC)
University of California, San Francisco
Clinical Director: Alex Fay, M.D. , Ph.D.
Appts: 415-353-7596

COLORADO

AURORA (ADULT)
University of Colorado*
Clinical Director: Vera Fridman, M.D.
Appts: 720-848-2080

AURORA (PEDIATRIC)
Children's Hospital Colorado
Clinical Director: Michele Yang, M.D.
Appts: Alison Ballard, 720-777-3907

CONNECTICUT

FARMINGTON (PEDIATRIC)
Connecticut Children's Medical Center, Farmington*
Clinical Director: Gyula Acsadi, M.D., Ph.D.
Appts: Nanci Stolgitis, RN, 860-837-7500

NEW BRITAIN (ADULT & PEDIATRIC)
Hospital for Special Care
Clinical Director: Kevin J. Felice, DO
Appts: Sharon McDermott, 860-612-6305

NEW HAVEN (ADULT)
Yale School of Medicine
Clinical Director: Sasha Zivkovic, M.D.
Appts: 203-785-4085

FLORIDA

ORLANDO (PEDIATRIC)
Nemours Children's Hospital*
Clinical Director: Omer Abdul Hamid, M.D.
Appts: 407-650-7715

GAINESVILLE (ADULT & PEDIATRIC)
University of Florida
Clinical Director: James Wymer, M.D., Ph.D.
Appts: 352-294-5400

JACKSONVILLE (ADULT)
Mayo Clinic Florida
Clinical Director: Christopher Lamb, M.D.
Appts: 904-953-0853

FLORIDA (CONT.)

MIAMI (ADULT)
University of Miami*
Clinical Director: Mario Saporta, M.D.
Appts: 305-243-9173

MIAMI (PEDIATRIC)
Nicklaus Children's Hospital
Clinical Director: Migvis Monduy, M.D.
Appts: 786-624-2154

ILLINOIS

CHICAGO (ADULT & PEDIATRIC)
Northwestern Memorial Hospital
Clinical Director: Daniela Maria Menichella, M.D., Ph.D.
Appts: 312-695-7950

University of Illinois at Chicago
Clinical Director: Charles K. Abrams, M.D., Ph.D.
Appts: 312-996-4780

Rush University
Clinical Director: Ryan D. Jacobson, M.D.
Appts: Sherri Taylor-Kennedy, 312-942-4500

O'FALLON (ADULT AND PEDIATRIC)
HSHS St. Elizabeth's Hospital
Clinical Director: Raghav Govindarajan, M.D.
Appts: 618-641-5803

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Clinical Director: Michael E. Shy, M.D.
Appts: 319-384-6362

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Clinical Director: Zeng Y. Wang, M.D., Ph.D.
Appts: Anson Ashburn, 502-588-4800

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Johns Hopkins University*
Clinical Directors: Charlotte Sumner, M.D. and Bipasha Mukherjee-Clavin, M.D., Ph.D.
Appts: (Adult) 410-614-1196, (Pediatric) 410-955-4259

MASSACHUSETTS

BOSTON (ADULT & PEDIATRIC)
Massachusetts General Hospital*
Clinical Director: Reza Seyedsadjadi, M.D.
Appts: Tamika Scott, 617-726-3642

MICHIGAN

DETROIT (ADULT)
Wayne State University School of Medicine and Detroit Medical Center*
Clinical Director: Ryan Castoro, M.D.
Appts: 313-745-3000

ANN ARBOR (ADULT & PEDIATRIC)
University of Michigan
Clinical Co-Directors: Gary Gallagher, M.D. & Brett McRay, M.D.
Appts: 734-936-9020

MINNESOTA

MAPLE GROVE (ADULT)
University of Minnesota*
Clinical Director: David Walk, M.D.
Appts: 763-898-1000

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ST. LOUIS (ADULT & PEDIATRIC)
Washington University School of Medicine
Clinical Director: Stefanie Geisler, M.D.
Appts: 314-362-6981

NEBRASKA

OMAHA (ADULT)
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Clinical Director: Yu-Ting Chen, M.D.
Appts: 402-717-0070

NEW JERSEY

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Hackensack University Medical Center
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Appts: Annerys Santos, 551-996-1324

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Appts: 585-275-2559

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University of North Carolina*
Clinical Director: Rebecca Traub, M.D.
Appts: 984-974-4401

CHARLOTTE (ADULT & PEDIATRIC)
Atrium Health Neurosciences Institute
Clinical Director: Urvi Desai, M.D.
Appts: 704-446-1900

OHIO

COLUMBUS (ADULT & PEDIATRIC)
Nationwide Children's Hospital
Clinical Director: Zarife Sahenk, M.D., Ph.D.
Appts: 614-722-2203

COLUMBUS (ADULT & PEDIATRIC)
Ohio State University, Wexner Medical Center*
Clinical Director: Michael Isfort, M.D.
Appts: 614-293-4969

PENNSYLVANIA

HERSHEY (PEDIATRIC)
Penn State Health Hershey Medical Center
Clinical Director: Ashutosh Kumar, M.D.
Appts: 717-531-2908

PHILADELPHIA (ADULT)
Hospital of the University of Pennsylvania*
Clinical Director: Steven Scherer, M.D., Ph.D.
Scheduling for Clinic Visits: Shana Millner, 215-662-3606
Scheduling for Research Visits: Pooja Patel, 215-898-0180

PHILADELPHIA (PEDIATRIC)
Hospital of the University of Pennsylvania*
Clinical Director: Sabrina Yum, M.D.
Appts: Hannah Borger, 215-590-1719

PITTSBURGH (PEDIATRIC)
Children's Hospital of Pittsburgh
Clinical Director: Hodas Abdel-Hamid, M.D.
Appts: 412-692-6106

TEXAS

AUSTIN (ADULT)
Austin Neuromuscular Center
Clinical Director: Yessar Hussain, M.D.
Appts: 512-920-0140

DALLAS (PEDIATRIC)
University of Texas Southwestern
Clinical Director: Kaitlin Batley, M.D.
Appts: 214-456-2768

BEDFORD (ADULT 16+)
Kane Hall Barry Neurology
Clinical Director: Sharique Ansari, M.D., MPH
Appts: 817-267-6290, option 4

HOUSTON (ADULT)
Baylor College of Medicine
Clinical Director: Thomas Lloyd, M.D.
Appts: 713-798-2273

HOUSTON (ADULT)
Houston Methodist Hospital
Clinical Director: Jun Li, M.D.
Appts: 713-441-3763

UTAH

SALT LAKE CITY (ADULT & PEDIATRIC)
University of Utah*
Clinical Director: Russell Butterfield, M.D., Ph.D.
Appts: 801-585-7575

SALT LAKE CITY (PEDIATRIC)
Primary Children's Hospital
Clinical Director:
Russell Butterfield, M.D., Ph.D.
Appts: 801-213-7756

SALT LAKE CITY (PEDIATRIC)
Shriner's Hospital
Clinical Director: Russell Butterfield, M.D., Ph.D.
Appts: 801-536-3564

WASHINGTON

SEATTLE (ADULT)
University of Washington Medical Center*
Clinical Director: Michael Weiss, M.D.
Appts: Gail Schessler, 206-598-7688

SEATTLE (ADULT)
Swedish Neuroscience Institute
Clinical Director:
Christyn Edmundson, M.D.
Appts: 206-320-3494

SEATTLE (PEDIATRIC)
Seattle Children's Hospital
Clinical Director: Seth Perlman, M.D.
Appts: Kara Smith, BSN, 206-987-6678

WASHINGTON, DC

(ADULT)
Medstar Georgetown University
Clinical Director: Nicholas Streicher, M.D.
Appts: 202-444-1774

(PEDIATRIC TO AGE 21)
Children's National Hospital
Clinical Director: Diana Bharucha-Goebel, M.D.
Appts: Kathleen Smart, 202-476-6193

INTERNATIONAL LOCATIONS:

AUSTRALIA

WESTMEAD (PEDIATRIC)
The Children's Hospital at Westmead*
Clinical Director: Manoj Menezes, M.D.
Research Director: Joshua Burns, Ph.D.
Appts: (02) 98451325
daralyn.hodgson@health.nsw.gov.au

BELGIUM

B-2650 EDEGEM (ADULT & PEDIATRIC)
Antwerp University Hospital
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ENGLAND

LONDON (ADULT)
University College London Hospitals*
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ITALY

MILAN (ADULT & PEDIATRIC)
C. Besta Neurological Institute*
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Appts: +39-02-70631911
sara.nuzzo@istituto-besta.it

* Denotes the CMTA Centers of Excellence that are included in the National Institutes of Health Inherited Neuropathy Consortium (INC). The INC is co-sponsored by the CMTA and the Muscular Dystrophy Association. Worldwide more than 10,000 patients with CMT have been enrolled in protocols, and their data, de-identified to protect patient privacy, is housed in a common repository. As a result of this collaboration, a new CMT evaluation scale for children has been established, along with a new evaluation system for adults, and an infrastructure has been developed to perform natural history studies and clinical trials for CMT.

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STAR ADVISORY BOARD

The CMTA's Strategy to Advance Research (STAR) Advisory Board is overseen by Katherine Forsey, Ph.D., the CMTA's chief research officer, and comprises a Scientific Advisory Board (SAB), a Therapy Expert Board (TEB) and a Clinical Expert Board (CEB). Each plays a critical role in furthering the CMTA's mission to support the development of new treatments for CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure.

The SAB provides scientific input for ongoing and proposed projects, the TEB evaluates the translational quality of ongoing and proposed projects and the CEB provides expert guidance and support to the CMTA's Alliance Partners around clinical trial planning and delivery. The CMTA expanded its Advisory Board by two members in 2023-24 (denoted by an asterisk on the list below) to reflect the evolving needs of STAR.

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Diana Bharucha-Goebal, M.D., Ph.D., CEB
Children's National Hospital Washington DC and the National Institutes of Health (NIH)

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Maurizio D'Antonio, Ph.D., SAB
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St. Jude Children's Research Hospital, Memphis, Tennessee

Vera Fridman, M.D., CEB
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Martine Garnier, Ph.D., TEB*
MG Pharma Consulting

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University of Rochester

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Cyprus Institute of Neurology & Genetics

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Discovery Pharma Consulting LLC, Cambridge, UK

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University of Miami

Stephan Zuchner, M.D., Ph.D., SAB
University of Miami

Email the CMTA at info@cmtausa.org

Charcot-Marie-Tooth Association
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1-800-606-CMTA (2682)
FAX (610) 499-9267

cmtausa.org

KAY PRINTING
TO ADD NEW
INDICIA

WHAT IS **CMT?**

More than 3 million people worldwide have CMT. It is one of the most commonly inherited nerve disorders and affects the motor and sensory nerves.

CMT is slowly progressive, causing the loss of muscle function and/or sensation in the lower legs and feet, as well as hands and arms.

People in **all ethnic groups may be affected by CMT.**

CMT is genetic, but it can also develop as a new, spontaneous mutation.

CMT can vary greatly in severity, even within the same family.

CMT causes structural deformities such as high-arched or very flat feet, hammertoes, hand contractures, scoliosis (spinal curvature) and kyphosis (rounded back).

CMT can also cause foot drop, poor balance, cold extremities, cramps, nerve, muscle and joint pain, altered reflexes, fatigue, tremor, sleep apnea, hearing loss and breathing difficulties.

CMT rarely affects life expectancy.

Some medications are neurotoxic and pose a high risk to people with CMT, notably vincristine and paclitaxel.

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-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.

Donating to
STAR RESEARCH
keeps hope alive
for everyone
living with CMT.

DONATE TODAY.
GIVE THEM THE FUTURE THEY DESERVE!
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