SPRING 2025

# THE CMTA REPORT

Charcot-Marie-Tooth Association

cmtausa.org

# EMPOWERING INDEPENDENCE: SMALL TOOLS, BIG IMPACT

## WALK 4 CMT THIS SPRING!

**FIND A WALK AT:**
**cmtausa.org/walk**

CONTENTS

# SPRING 2025




**THE CMTA REPORT | SPRING 2025**

**Kenny Raymond,** *Editor*
**Karlyn Rosen Aires,** *Designer*





**ISSN #1067-0181 Vol. 40, No. 1**


**Email CMTA at info@cmtausa.org**


Charcot-Marie-Tooth Association

P.O. Box 105
Glenolden, PA 19036
(800) 606-CMTA (2682)
FAX (610) 499-9267

cmtausa.org


CMTA
Charcot-Marie-Tooth Association

## Dear CMTA Family,

**2025** is already shaping up to be a year of incredible progress for our community, and I could not be more inspired by what lies ahead. You make every step forward possible in our mission to accelerate research, improve quality of life, and find a cure for CMT.

This year, we are building on the momentum of CMTA-STAR, our collaborative research model, driving groundbreaking work across all types of CMT. From genetic therapies to innovative clinical trials, our investment of nearly $30 million since 2008 has brought us closer to transformative treatments. With your support, we continue to open new doors to progress daily.

Our purpose also focuses on creating practical solutions that can be used right now to empower the community in their everyday lives. Resources like the CMTA Gadget Store provide tools recommended by people with CMT to help navigate daily challenges, from cooking and dressing to mobility and beyond. By embracing assistive technology, we are helping community members maintain independence and improve their quality of life.

The strength of the CMTA community is what drives us forward. Around the globe, our online and social media presence brings information to help the community and inspire researchers. CMTA Branches are bringing people together to build connections and share strength. At Camp Footprint, the only sleep-away camp dedicated to kids with CMT, our youth inspire us all with their creativity and leadership, giving rise to projects like *Shooting Star*, a news broadcast that brings CMT research to life in an accessible and engaging format.

As we continue this journey, we honor the legacy of those who have paved the way for progress. Leaders like Bob Buuck, whose vision and generosity advanced CMT2A research, remind us of the transformative power of determination and the importance of continuing this work with renewed purpose.

I am continually amazed by the collective power of our community. From the thousands of participants in our *Patients as Partners in Research* program to the everyday champions who share resources, build connections, and support one another, you are the heart of everything we do.

Together, we are forging a brighter future defined by hope, progress, and the unwavering strength of the CMT community. Thank you for being an essential part of this journey. I look forward to building momentum together in 2025.

With gratitude and hope,

**Sue Bruhn, PhD**
*Chief Executive Officer, Charcot-Marie-Tooth Association*

## A MESSAGE FROM SUE: *BUILDING MOMENTUM TOGETHER IN 2025*

# MAKING LIFE EASIER:
## ASSISTIVE TECHNOLOGY FOR PEOPLE WITH CMT

Assistive technology (AT) can make a world of difference for people with CMT. Simple daily activities, like opening jars, gripping utensils, or reaching for items on high shelves, often require strength and coordination that can be challenging. These tasks, which many take for granted, can turn into frustrating hurdles, but thanks to innovative tools and thoughtful design, there are solutions that help make life easier.

"With over 14 years of experience in assistive technology, and as someone living with CMT myself, I've seen how even the simplest devices can make a huge difference in helping people maintain independence and well-being," said Ashley McLeroy, Alabama's Assistive Technology Act Program Director, and a rehabilitation engineer.

However, finding the best tools can feel overwhelming, especially with so many options to explore. That's why resources like CMTA's Gadget Store are so valuable. The Gadget Store features products recommended by people with CMT, reflecting real-world feedback from the community. From adaptive jar openers and ergonomic kitchen tools to dressing aids and long-reach grabbers, the store offers a curated collection of tools designed to help with daily challenges. These products empower individuals to maintain their independence and improve their quality of life in big and small ways.

Whether you're looking for something to help with meal preparation or a device to assist with mobility, CMTA's Gadget Store is a great place to start. Discover tools that work for you and take a step toward making daily life a little easier.

*Visit CMTA's Gadget Store for Curated Products Recommended by the CMT Community*
***cmtausa.org/gadgets***

***Have a cool tool or gadget you'd like us to add to the store? Send it to us at marketing@cmtausa.org.***

### *Discover More About Assistive Technology*

*Ashley McLeroy (pictured above) joined us for a CMTA Lunch and Learn last year, showcasing the benefits of assistive technology and useful gadgets for people with CMT.*

***Watch the recorded session on CMTA's YouTube channel: youtube.com/@CMTAssociation***



# CMTA BRANCHES:
## BUILDING CONNECTIONS AND COMMUNITY

The Seattle, WA branch (pictured above) launched 2025 with an engaging and heartfelt meeting on January 11, led by branch leaders Denise Snow and Emily Osborne. The event fostered community connection and shared purpose by bringing together attendees of all ages and CMT types.

Michael Weiss, MD, Director of the CMTA Center of Excellence at the University of Washington Medical Center, delivered a powerful presentation on the clinic's multidisciplinary approach to CMT care. One parent shared how learning about these resources gave their son a renewed sense of empowerment in managing his CMT. Dr. Weiss's discussion of research trials energized attendees, offering hope for future breakthroughs.

CMTA branches like Seattle's are the heart of the CMT community. These branches connect individuals and families, provide resources, and foster friendships that make living with CMT easier.

Whether you seek support, information, or a chance to meet others with CMT, CMTA Branches are here for you. Check out the complete list of CMTA Branches on page 15 to find one near you!

### *Connect With Your Local CMTA Branch*

Ready to get involved with your local CMTA Branch? Register today to connect with CMTA Branch leaders, access resources, and join a supportive community near you. Scan the QR code or visit **cmtausa.org/branch** to register and contact your local branch.

### *Start A CMTA Branch Today*

*Want to make a difference in your community? Starting a CMTA Branch is a great way to connect people, share resources, and build a supportive network for those living with CMT. You'll have access to guidance, tools, and a passionate community to help you every step of the way.* ***Contact CMTA Director of Community Outreach to learn more: laurel@cmtausa.org***

# REMEMBERING BOB BUUCK:
## A LEGACY OF COMMITMENT AND IMPACT

The CMTA family honors the life and legacy of Bob Buuck, who passed away on January 5, 2025, after a battle with Alzheimer's disease. Bob's journey with CMTA began when his son, John, was diagnosed with CMT2A as a young child. Determined to drive progress, Bob and his wife, Gail, attended their first CMTA Patient/Family Conference in Detroit in 1997, where they met CMTA-STAR Clinical Expert Board Co-Chair Michael Shy, MD. Inspired by the event, the Buucks made their first grant to CMTA research soon afterward.


Gail and Bob Buuck in 2019

In 2011, Bob and Gail provided the original seed funding for CMTA's newly established CMT2A research fund, marking the start of groundbreaking advancements in research. Soon after, the first CMT2A research project commenced, leading to the development of the first CMT2A rat model in 2013. Over the next several years, the Buucks continued championing progress, funding key initiatives such as developing induced pluripotent stem cells (iPSCs) in 2014, stem cell models in 2015, and drug screening on CMT2A cell lines by 2017.

Recognizing the power of collective action, Bob and Gail introduced a $1 million challenge grant in 2019, continuing their long-standing commitment to accelerating research. This grant inspired others to support critical initiatives, including CMTA's earlier development of a CMT Type 2 genetic therapy strategy in 2018. Together, these efforts have paved the way for transformative progress in CMT2A research, exploring cutting-edge approaches such as CRISPR-based gene editing, specific gene-targeting drugs, and advanced stem cell technologies, laying the groundwork for transformative treatments.


Great conversations, great company! Bob Buuck (above), Jeana Sweeney, and Dr. Michael Shy catch up in MN.

Bob's passion for creating meaningful change extended beyond CMTA, shaping the philanthropic initiatives of the Buuck Family Foundation. Yet, his work with CMTA held special significance—a way to honor his son, help countless families, and advance the search for treatments and a cure.

Bob's dedication, generosity, and determination to make a difference will be deeply missed. His enduring contributions fuel the progress needed to achieve a world without CMT.

*Bob's recognition of CMTA and the potential of CMTA-STAR all those years ago sparked a journey that has changed the landscape of CMT2A research. When his son was diagnosed, Bob reached out to CMTA with a vision and determination to make a difference—not just for his son but for countless others living with CMT.*

*I've had the privilege of meeting and chatting with Bob and his wife, Gail, several times, and each encounter left a lasting impression. Bob's unwavering dedication to CMTA's mission radiated through every conversation. I still cherish the time he shared a few captivating WWII stories with me during our last meeting in 2023—his presence was one of wisdom, warmth, and quiet strength.*

*Bob's impact on the CMT community is profound, and his legacy of passion and progress inspires us all. I am deeply grateful to him and profoundly thankful to Gail for her steadfast support. Together, they've shown us the power of love, hope, and determination in creating a better future for all living with CMT.*

***—Jeana Sweeney, CMTA Chief Engagement and Gift Officer***

# The Sky

I brace myself for what's ahead
Prepare for what's to come
I can feel the eyes
Staring with judgment
I can hear the voices
Speak of my weakness
Why am I different?
Who am I to you?
My body isn't as strong
Flexible
Pleasant to look at
But my mind
Strengthened
Proving my abilities
Showing my persistence
I work twice as hard to get the normal minimum
I find other ways to be better
I try and try and try
Going around all my hurdles
Not thinking of what my limits are
Through one quote I live and believe
"The sky is the limit"
No matter what or who is your enemy

**ABOUT THE AUTHOR:**

***Susanna is a community member with CMT2C who empowers others by sharing her journey and perspective through poetry. "I never let CMT2C limit me," says Susanna. "I use it to strengthen myself mentally, which builds confidence and determination, leading to physical strengthening. Remember, the sky is the limit."***

# THANK YOU FOR YOUR GIFTS...

## IN MEMORY OF:

**Jack Anderberg**
Kay Carlson
Brent & Cynthia Clark
Regina Gottschalk
Ronald & Donna Kuehn
Gerald & Lorraine Lutgen
B. E. Magnuson
Pagel Foundation

**Allan Archer**
Elizabeth Archer

**Paul & Mona Barkley**
Richard & Peg Hodel

**Anna Mae C. Berlin**
Colleen Becker

**Marty Berger**
Mary Alvord
Nalini P. Anand
Mr. Marilyn J. Berger
Cheryl West Bindeman
David Brandt
Mitchell & Erica Brandt
Mary Carlton
Mr. Robert Derosa
Mario Estrada
The Leventhal Family
Barry & Carole Forman
Jennifer Garfinkel
Ms. Georgine Gaul
Mr. Kenneth J. Handel
Rachel Heffron
Joui Hessel
Mrs. Kim A. Hughes
Denise Kahn
Elyse Kaplan
Jeremy Klass
Amy Lebowitz
Carolyn Levine
Bruce Levine
Robyn Margolies
Rabbi Steven Mason
Ms. Kristen McKnight
Roger Mermelstein
Lola Peres
Daniel Pines
Adele & Bill Redisch
Michael Reiter
Darren Roberts
Jane Rosenthal
Lisa Sanchez
Mr. Wayne Snyder
Jerry Sperling
Kelly Stahlman
Mr. Melissa Walsh
Ann & Richard Young

**Angie Bridger**
Catherine Abernathy

**Boyd Brinegar**
Robert Brinegar

**James L. Buckler**
Susan Morgan

**John Buhl**
Pamela & Henry Smith III

**Ivan Butler**
Francine Butler

**Robert Buuck**
Deborah Hanson

**Edward Carhart, Esq**
Maureen Magee

**Enzo Cavides**
Jenna Bernardino
Carteret Special Services Dept
Namrata Chinchanker
Debbie Damato
Dental Family Jr.
Ariella Fekete
Susan Hague
Angela Kiss
Krystina Montalvo
Jessica Nebelsick
Melanie Pardun
Dawn Phillips
Abigail Rausch
Lisa Steiner
Matthew Thies
Mark Willis
Wireless Technology Solutions, LLC

**Patricia Claypool**
David Claypool

**Ryan Clayton**
Karen Brown

**Celia Clemente**
Rick Clemente
Sister Rita Gesue, SCN

**Robert Cochrane**
Cathy Altenberger
Sara Green
Holly Lambert

**Esther R. Cohen**
Mr. & Mrs. Marc Rotenberg

**Bud Cole**
Robert & Kathleen Cole

**Jennie DaSilva**
Ronald DaSilva

**Connie Deller**
Tony Deller

**Frank T. Eckman**
Frank & Debbie Tamburello

**Ford Farabow**
Jean Fordis

**Sara C. Fuhrman**
Colleen Becker

**Kay Flynn**
Nancy Homyak

**George Gal**
Frank & Harriet Weiss

**Thomas Galaty**
Jackie Corso
Julie Holzman

**Donald Gangloff**
Richard Baylor

**David Gordon**
Diane Kosik

**Grady Alan Harpe**
Joe Abernathy
Charles Gibson
Amy McLaurin
Lawrence Rubin

**Louis Herndon**
Sandra Herndon

**Russell Higginson**
Dawn Higginson

**Keith R. Homersham**
Ken Homersham

**Janice Howe**
Sylvia McAlpine

**Audrey Illhardt**
Susan Adams

**Max Krueger**
Maryanne Krueger

**Kenneth Konstalid**
Catherine Konstalid

**Rudolf R. Larsen**
Robert Larsen

**Helene Lenet**
Ann & Gil Abramson
Marc & Debra Attman
Roz & Jeff Barr
Myra & Jimmy Rothbard & Beam
Jody & David Berg
Howard & Barbara Berg
Amy & Richard Berg
Daniel & Joan Cagan
Lawrence & Suzanne Castine
Multilingual Welcome Center
Victor Cohen
Daniel & Suzanne Crone, III
Walter Donovan
Barbara Gordon & Family
Sue, Allan, & Frank Sober
Beverly & Lowell Penn & Glazer
Brian & Eileen Goldman
Toby & Randy Goodman
Nancy Gordon
Sarah & David Hirshfeld
Annette & Bruce Ingerman
Harriet Jacobs
Alvin & Elaine Katz
Beth, Stu, & Margie Kay
Leslie Kempler
Daniel Kempler
Dr. Boris & Lucia Kerzner
Marlene Zerden & Dan Kessler
Bunny Kohn
Bernard Krieger
Richard & Joan Lessans
Barbara Marshall
Jamie Miller
Cynthia Rosenstein
Rochelle Rudo
Betsy & John Sachs
Bonnie Schwartzberg
Eileen Shear
Carol Sher
Stuart & Faye Silberg
Harriet & Mark Silver
Lynda & Gary Slayen
Kellie Smeresky
Jeff Snyder
Lisa Sopher
Ellyn Sutton
Fran & Bill Taub
Eileen & Ralph Weiner, D.D.S.
Jay & Diane Weiss
Abigail M. Wilkins
Maury Wilkins
Karen Zale
Gerald & Terry Zimlin
Lisa & Morry Zolet

**Karen Lewis**
James Lewis

**James Lindsay**
Diane Lindsay

**Susan Barbour McDaid**
Julie Cooper

**Crystal G. MacDonald Roberts**
Douglas MacDonald
Doreen Verity

**Deardra D. MacDonald**
Douglas MacDonald

**James E. Meadows**
Ashley Robey

**Melanie Messersmith Martin**
Melinda Vento

**David A. Mills**
Shirley & Gene Mills

**Verna Moon**
Nancy Kirschner

**Frank Northrop**
John Northrop

**Rocco Lewis Pignone**
Rosanne Schloss

**Lloyd Purbaugh**
Tom & Shirley Johnson

**Joseph & Nida Raffaelli**
John Raffaelli

**Deb Razey**
Kelli Pfeifer

**Deanna Richey**
Patrick Richey

**Crystal Roberts**
Judith Butler
Carol & Spencer MacDonald

**Christopher Rodriguez**
James A. Gallagher, Jr.
Charles Swanson
Jacqueline Van Rossen

**Charles Rotenberg**
Mr. & Mrs. Marc Rotenberg

**James Sauerwald**
Denise Sauerwald

**Fred Simpson**
Lisa F. Pierce

**Billie J. Smith Gabbard**
Julian Gabbard

**Veronica Sperato**
Theresa Skunda

**Herbert Sperry**
Susan & Christopher Kuebler

**Donna Stamey**
Stanley Harris

**Rebecca Stevens**
Laura Peterson

**Claire Sullivan**
Elizabeth Wilkinson

**Kevin Sutherland**
Douglas & Terry Sutherland

**Samantha Lynn Toland**
Tracy Evans
Linda Kanthak
Dr. Paul Lisnek
Margaret Vis

**Michelle Tressel**
Lydia Elliott

**Ellen Vogler**
Theresa Skunda

**Jack & Ethel Walfish**
Jerome Walfish

**Sidney Wilkin**
Maia A. Teresi

**Matty Williams**
Thelma Williams

**Ed Young**
Terry Miller

**Anthony Zahn**
Emily Maitin
Betsy Thorpe

## IN HONOR OF:

**Jodi Ackerman**
Susan Ackerman

**Nora Amanshauser**
Angelika Amanshauser

**Sarah Andrusko**
Sarah Han

**Cheyenne Alfino**
Gary Perdum

**Laina Amoroso**
Marc Luperini

**Austin Anderson**
Rita Anderson

**Edgar James Anderson**
Beth Prince

**Frank Badillo**
Jesus Rivera

**Steven Bailie**
Valarie Bailie

**Miss Kaelyn Balbi**
Charlene McClanahan

**Camden Baker**
Jen Anderson
Oliver Stevens
Debbie & Steve Tufts

**Larry Beem**
Lara Bunkers

**Amelia Berger**
Jane Mulder

**Ray Bergstresser Family**
Cindy Mori

**Eric Black**
Nancy Douthwaite
Peggy Twohig

**Jeanne Boehlecke**
Elena Vizvary

**Yohan Bouchard**
Will Hess & Family

**Madeleine Brown**
Mel Ross

**Robert Campbell**
Deborah Campbell
Kathleen & Edward O'Dowd

**John Carlson**
Annette Mitchell

**Barbara Castle & Gregg Merrill**
Thomas Bird
Louise Dudley

**Cindy Chadwick**
Shannon Leutzinger

**Jai Chopra**
Samir Chopra

**CMT Youth Community**
Henry Russell

**Eileen B. Cullen**
Laura E. Moss

**Kathy Curtis**
Charles F. Webb

**Linda Dobosh**
Eric Brink

**Michael Driedger**
John Adare

**Hampton Elliott**
Emily Oliver

**Jaden Ellman**
Marianne Ellman

**Chris & Connor Eng**
William Wise

**Ann & Lauren Fairchild**
Betty Ann David

**Tami Flores**
Frances G. Rogers

**Douglas Frey**
Regan Frey

**Dr. Ron Friedlander**
Janice Kane

**Karen Garr**
Suellen Beaulieu

**Irene Gavrila**
Jennifer Thibodeau

**Tosca Giamatti**
Anna Kole

**David Gibbs**
Annette Dixon

**Marcia Gibson**
Matthew Gibson

**Patzi Goldberg**
Marty Goldberg

**Sonny & Stella Granger**
Chris Palmer

**Mike Grant**
Teresa Grant

**Adam & Lynnanne Groebner**
Catherine Anderson-Buzzard
Teresa Fleischhacker

**Elsa Groenink**
Jill Lemon

**Courtney Halldorson**
Edward Halldorson

**Andrew W. Hartman**
Diane Spray

**Heather Hawk Frank**
Mary Frank

**Pamela Hawkins**
Michael McKee

**Jan Heinrich**
Marion Birdsall

**Pete Henriksen**
Pace Analytical

**Rosalie Hempfling**
Jeff Hempfling

**Gerry & Walter Hett**
Barry Hett

**Barry Hett**
Kenneth & Monica Mittag

**Christine Helmke**
Bradley Silverman

**Joshua Hubbard**
Lucy Tsai

**Teddy Johnston**
Ann Jordan
Jessica & Tim Ogilvie
Zibby Owens
Andrea Tien

**Richard Karon**
Mark Chester

**Lance Kasinecz**
Linda Salisbury

**Davi Keynes-Levinson**
Jeff Merkowitz

**Jeffrey Klafter**
Ellis Lesser
Luba Nisenbaum

**Caden Kornberger**
Sue McKenna

**Russ Kovar**
Jen Kovar

**Kristen Kulik**
Anna Klaiber

**Frank S. Kramer**
Carole Horne

**Lynne Krupa**
Timothy & Eileen Smith

**Karen Kukwa**
Sandra McGrath

**Robert Larson**
Jennifer Morgan

**Ken & Elda Layton**
Karl Layton

**Jessica & Emma Leamer**
William Leamer

**Maddie Leard**
Ann & Bob Croyle

**Gaia LeDonne**
Judy Moore

**Brad Lewis**
Marty Goldberg

**Jameson Lewis**
Mary Santoro

**Mat Lewis**
Marty Goldberg

**Diane Lindsay**
William Katzer

**Mary Louie**
Erica Menard

**Nona Maxwell**
Mark Maxwell

**Jeanne McConkey Smith**
Gary & Becky McConkey

**Janet McCormack**
Leo Belmonte

**Beverly Meridian**
Linda Simpson

**Karen Midkiff**
Russell Midkiff

**Scott Moldoff**
Stephie Fine

**James W. Montgomery**
Ellen Montgomery

**Dan Morgan**
Susan MacDonald

**James F. Morgan**
Richard Schleifer

**Margaret Mullery**
Stephen Mullery, III

**Steve O'Donnell**
Andrew McKissick

**Leah O'Laughlin**
Hannah O'Laughlin

**Lia O'Sullivan**
Robert Mitchell

**Barbara & Tom Peisch**
Edward Stimer

**Paolo Perrone**
Faith Ponterotto

**Doreen Pomykala**
Edith Pomykala

**Robert W. Popek, Jr.**
Ellen Popek Ashley

**Thomas J. Popek**
Ellen Popek Ashley

**Candice Burtman Regalado**
John Porter

**Vittorio Ricci**
Brett & Elizabeth Joseph
Lina Storm
Deborah Woodard

**Rev. James C. Ries**
Bonnie Long

**Jonathan Ries**
Bonnie Long

**Rhonda Ries Shumaker**
Bonnie Long

**Rachel Rivlin**
Fred Lasky

**Laura Romano & Hueng Loww**
Michael O'Leary, Jr.

**Gordon Rosenthal**
Bernice Alaniz

**Deborah Rozanski**
Andrew Volovar

**Henry Russell**
Lynn Cowen
Maureen & Ken Middaugh

**Prudence Ryan**
Joan Porta

**Lily Sander**
Robert & Susan Sander

**Ethan Kyle Sargant**
Tammy Adkins

**Dr. Steven Scherer**
Bob Christensen
Carolyn Mann
Maureen Weir

**Jennifer Scott**
Alice Scott

**McRae Scott**
Alice Scott

**Thomas Scott**
Alice Scott

**Mary Shields**
Richmond Vernon

**Peter Smith**
Marty Goldberg

**Denise Snow**
Ruth Snow

**Amy & Danny Solomon**
The Solomon Family Fund

**Veronica Sperato**
Michele Sperato

**Herbert Sperry**
Susan & Christopher Kuebler

**Edward Stimer**
Barbara Peisch
Karen Vigil
Diane Wittenberg

**William Stuhlmueller**
Jane Stuhlmueller

**Jeana Sweeney**
Sebastian
Bob DeRosa

**David Tannenbaum**
Jennifer Scarlott

**Betsy & Bob Thorpe**
Guy Zahn

**Kayla Tschida**
Kristin Tschida

**Cece Vanden Langenberg**
Bryan Bethel
Ashlee Noel
Brittany Vanden Langenberg

**Dan Verdelli**
Jennifer Hurter

**Angela Walters & Jonathan Moczygemba**
Nancy Day

**Edie Rose Ward**
Tasha Ward

**Missy Warfield & Family**
Salliann Dougherty
Lynn & Bob Holtzclaw
Nicole Lallande
Mary Maechling
Chuck Mangold, Jr.
Aleksandra Myers

**Anita Weaver**
Church of Christ Enon Valley

**Maureen Weir**
Donald Weir

**Tom Weseli**
Vincent Weseli

**Gail Whitehouse**
Aaron Whitehouse

**Ryan Whitman**
Carol Rise

**Jordan Wilke**
Cameron Wilke

**Wittenberg Family**
Judith Kelly

**Diane Wittenberg & Tom Liston**
Edward Stimer

**The Wonderful Volunteers & Employees of the CMTA!**
Steven Khosrova

**Erin Woodbridge**
John Costello
Jeff Woodbridge

**Amanda Young**
Meredith Ogden

**Jeanie Zibrida**
Rhonda, Henry, & William O'Neill

**Gretchen Zimmerman**
Jan Zimmerman

**Joyce, Janice, & Emily**
Barbara Green

**Kevin, Jayden, Ronnie, & Marie**
Robert & Patricia Wheeler



**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.***

## TOGETHER, WE CURE CMT: YOUR GIFT DRIVES RESEARCH FORWARD

◯ $50 ◯ $100 ◯ $250 ◯ $500 ◯ $1000 ◯ Other: $_____

◯ Please charge my credit card. ◯ Visa ◯ MasterCard ◯ American Express ◯ Make my gift a recurring Monthly Donation.

◯ Check enclosed, payable to the Charcot-Marie-Tooth Association.

◯ I am interested in learning more on how to make a major gift or a multi-year pledge. ◯ I would like information on donating securities.

Name_____ Email _____

Card #_____ Exp. Date_____ CVV#_____

Signature_____ Billing Address_____

City_____ State_____ Zip_____ Phone_____

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

The Charcot-Marie-Tooth Association (CMTA) is a registered 501(c)(3) nonprofit organization.
Your donation is tax-deductible to the fullest extent allowed by law. Tax ID: 22-2480896.

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

**DONATE ONLINE AT: cmtausa.org/donate**


Brody Conroy welcomes campers to 2024 Camp Footprint East.

SUPPORT CAMP FOOTPRINT 2025 TODAY!

# *Building Confidence, Changing Lives: Why Camp Footprint Matters to Me*

The decision to support Camp Footprint was not a difficult one. I know from experience that camp settings can sometimes be more effective than others in bringing about lasting changes in attitudes. The total immersion in the camp program reinforces the desired support for the youth recently diagnosed, or not so recently diagnosed.

To be able to involve themselves in camp activities without self-consciousness holding them back is priceless. The ability to try and learn new things is a huge ego boost. The friendships made with campers and staff alike can last for a lifetime

I was lucky to have a very slow progression of my CMT diagnosis. Hopefully, supporting the efforts of Camp Footprint can slow the progression for some campers by giving them success and support—at least for a while.

In 2025, Camp Footprint celebrates 10 years of empowering kids and teens with CMT. This milestone is a testament to Camp Footprint's life-changing impact on every camper who attends. Let's make this anniversary year the biggest and best yet!

Will you join me in supporting Camp Footprint and ensuring every child with CMT has this priceless experience? Together, we can make memories and impacts that will last a lifetime.

***—John Kauth***



# INNERVATORS HONOR ROLL

**According to the dictionary, an innervator is a nerve stimulator. CMTA INNERVATORS, however, are action-oriented game-changers that sustain CMTA with monthly gifts throughout the year. Life-changing initiatives like Camp Footprint, treatment-focused research, and invaluable education initiatives depend on steady, reliable support from committed and reliable donors. Add your name to the INNERVATORS Honor Roll by visiting cmtausa.org/cmta-innervators and joining today!**

Tracy Adamson
Richard Arsenault
Aaron Baker
David Balbi
Kim Bamford
Kelly Banner
Richard Barger
Mackenzie Barnhizer
Juan Barrera
Christine Bateman
John Baun
Chevelle Bazo
Donald Bean
Jonah Berger
Cheryl Bidgood
Aaron Bokmeyer
Robert Bollenbacher
Marilyn Booth
William Boreham
H. Brand
Laurie Brandvold
Deborah Breuer
Cor Broekhuijse
Tiffany Brokaw
Edna Broman
Mary Ann Brothers
Karen Brown
Ningning Brown
Raelene Brown
Gail Browne
Nancy Buchanan
Brenda Buckle
Adriana Burchard
Danielle Burwell
Patricia Camp
John Carlson
Cynthia Carroll
Eric Case
Carmen Castro
Adrian Cervantez
Sharon Chase
Judith Chin
Daniel Chrovian
Christopher Clarkin
Rick Clemente
Ann Coffin
DJ Colbert
David Coldiron
Peter Cole
Randall Cole
Kate Connelly
James Copeland
John Cordonnier
Diane Covington
Erin Crawford
David Crowe
Donna Curcio
John Czerwein
Kelly Demonte

Linda Depadilla
Laura Dillon
Marilynn Dodge
Jacky Donahue
Laura Douglas
Denisa Dragu
Edward Dudash
Rojeanne Dunn
Karen Earhart
Bruce Egnew
Kevin Emch
Mia Everett
Laura Favret
Mitchell Fedde
Rick Fender
John Ferraro
Tera Fey
Jim Fiorentino
Karen Fleming
Tom Fornoff
Efthimios Foundakos
Ellen Fraser
Angela Freeland
Terry Froysland
Susan Fugelsang
Maria Fulmino
Sarah Gentry
Kathy Giles
Trisha Glover
Jie Gong
Peter Grassi
Rebeka Green
Rob Greenstine
Peter Greeves
Stacy Groenink
Leanne Guido
A Hadley
Kathleen Hagedoorn
David & Nancy Haines
Mary Harris
Patsy Harris
Pamela Hawkins
Brian Hearn
Steven Helmke
William Helmke
Kathy Herzog
Christopher Hilbert
Kenneth Hill, Jr.
Austin Hinners
Richard Homol
Joseph Hornick
Stacy Hoyle
Elaine Hudson
Nicole Hudson
Stephen Hudson
Justus Hughes
Bonnie Iler
Laurie Irwin
Anthony Jensen

Lynda Jensen
Danielle Jolicoeur
Staffan Jondelius
Katherine Jones
Kelsey Jones
John Kanarr
Carol Keene
Jean Keller
Heather Kercher
Craig Kesack
Paul Kettner
Eric Kightlinger
Sonae Kim
Sharon Kindschy
Scott Knabe
Alana Kohler
Frank Kramer
Jane Krukar
Linda Ladd
Luciana Lamberto
Doug Lane
Kristen Lange
Jennifer Larkin
Lars Larsen
Iman Latifpour
Cara Leath
Nancy Leets
Norma Levy
Nathan Lewis
Richard Lewis
Jiang Li
Matt Lindsay
Kim Lipchik
Barbara Lloyd
Richard Lodge
Linda Long
Rosa Loparo
Robert Louden
Abbey Loy
Miguel Lyons
Noel Magee
Robert Marton
Marty Mayer
Steve Mayer
Matthew Mcallister
Cady Mcclellan
Ryan Meloni
Sam Melton
Ronnie Mendoza
Jennifer Mersing
Milton Milazzo
Louis Milia
William Millar
Richard & Kathleen Miller
Kim Misener
Stephanie Montisanti
Alba Moratinos
Carlos Moreno
George Morris

Fred Mueller
Jacob Mullins
Diane Navarrete
Patrick Nelson
Michael Newell
Robert Nigro
Mirna Nusbaum
Francis O'Donnell
Terrence O'Grady
Dawn Orr
John Otto
Laurie Otto
Jeannie Palmero
Joseph Pascale
Bob Paulsen
Elizabeth Payne
Cristina Penas
Doreen Pomykala
Alan Ponikvar
Jere Poole
Meredith Powers
Suzanne Powers
Ellen Presnick
Jonathan Preston
Beth Prince
Marcia Probasco
Rosemarie Rauh
Kenneth Raymond
Steve Reiss
Susan Rems
Bobby Richardson
Laurel Richardson
Carol Ris
Barbara Roberts
Tyler Ronish
Mauricio Rosas
Raymond Roth
Mary Russell
Yvonne Russell
Nik Salomon
Margery Sayward
Karen Scacco
Mario Scacco
Margaret Schaefer
Richard Schaeffer
Donald Schlosser
Philip Schols
Margarita D. Shackelford
Deborah Shapiro
Loraine Shields
Lynn Shirey
Norman Shulman
Diane & Vic Shustak
Nellie Sicher
Debbie Sinclair
Nicole Sleeper
Margaret Smith
Winston Solomon
Bruce Spackman

Jennifer Stahl
Joyce Steinkamp
Gary Stender
Jim Stetor
Madilyn Stone
Richele Stroop
Robin Stroschin
Barbara Stuck
Sharon Sullivan
Per Stefan Svensson
James Sweeney
Jeana Sweeney
Jessica Szempruch
Brett Taylor
Ashley Terrell
Kelly Terrell
Donna Terrill
Virginia Thiel
Mike Timmons
Elizabeth Tipton
Vicky Townsend
Jordan Truxall
Gail Tschanz
Dan Tuman
Jane Twaddell
Lynn Upton
Alexander Van Riper
Bruce Vieira
Tasha Ward
Tammy Weatherford
Judy Weinsheimer
Kathleen Weinstein
Robert Weis
Candace White
Gary Whitney
Cameron Wilke
Tom Williams
Debra Willis
Mark Willis
Rebecca Willis
Zachary Willis
Margot Willis-Doyle
Robert Wills
Daniel Woltjer
Chansik Yang
Jeannie Zibrida

BECOME AN INNERVATOR TODAY!

# CMTA YOUTH PROGRAM IGNITES *SHOOTING STAR*

The CMTA Youth Program is reaching new heights with Shooting Star, a lively YouTube broadcast that takes complex CMT topics and makes them easy for everyone to understand. Produced and hosted by CMTA's youth, Shooting Star combines creativity and enthusiasm with important updates on CMTA programs, initiatives, and community impact.

The idea for Shooting Star was born at CMTA's Camp Footprint, where youth gather to connect, share experiences, and inspire one another. The campers' creativity and passion for making a difference sparked the vision for a broadcast that could strengthen the CMT community while sharing research and resources in an accessible, fun format.

The first episode introduces CMTA's Strategy To Accelerate Research (CMTA-STAR), describing its collaborative effort to bring together researchers, clinicians, industry leaders, and community members to tackle CMT. With nearly $30 million in investments since 2008, CMTA-STAR is accelerating progress through more than 50 active projects focused on advancing treatments and improving the quality of life for people with CMT.

The second episode explores CMTA's Patients as Partners in Research program, a groundbreaking platform that connects individuals with CMT to research opportunities and researchers to community members. The program's more than 7,000 patient partners represents the largest patient-reported CMT dataset in the world. Their contributions have supported over 30 studies and helped advance CMT research worldwide.

By blending humor, creativity, and patient-empowering messages, Shooting Star underscores the critical role of the CMT community in accelerating progress and shaping the future of research.

**Join this inspiring journey and catch Shooting Star on CMTA's YouTube channel: youtube.com/@CMTAssociation.**

***SHOOTING STAR IS A BRILLIANT EXAMPLE of what makes CMTA's Youth Program so special: young leaders using their creativity and passion for building community, sharing knowledge, and inspiring action. By making CMTA-STAR and CMTA resources fun and accessible, they're not just educating but shaping the future of CMT advocacy and research.***


UNDER THE MICROSCOPE

# REPRODUCTIVE CHOICES AND FAMILY PLANNING

**BY KATHERINE FORSEY, PhD**
***Chief Research Officer, CMTA***

Charcot-Marie-Tooth disease (CMT) is a hereditary disease caused by mutations in DNA. The risk of passing CMT on to your children can be as high as 50:50, depending on the genetic subtype, the same as the result of flipping a coin. When considering starting a family, it is helpful to understand the inheritance pattern of the CMT in question and available family planning options to support informed decision-making. It is important to note that this article covers several family planning options. Which options are available or acceptable to any individual depends very much on where you live, your personal perspectives, your unique medical history, and the healthcare support/funding available.

## Genetic Counseling

Before making family planning decisions, consulting with a genetic counselor can be very helpful and is highly recommended. Certified genetic counselors are professionals who can provide detailed information about your specific type of CMT, its inheritance pattern, and the associated transmission risks to children. They can also discuss family planning options tailored to the individual.

## Preimplantation Genetic Diagnosis (PGD)

PGD is a technique used in conjunction with in vitro fertilization (IVF) to prevent the transmission of genetic disorders like CMT. In this process, eggs are fertilized in a laboratory, and embryos are genetically tested for the specific CMT mutation. Only embryos without the mutation are implanted into the uterus. Studies have shown that PGD can be effective for CMT, resulting in successful pregnancies and the birth of healthy children *(Hereditary Neuromuscular Disorders in Reproductive Medicine: https://pmc.ncbi.nlm.nih.gov/articles/PMC11593801/)*

## Prenatal Testing

For those already pregnant, prenatal testing options are available to determine if the fetus has inherited the CMT mutation:

- **Chorionic Villus Sampling (CVS):** Performed between the 10th and 12th weeks of pregnancy, CVS involves taking a small sample of placental tissue for genetic testing.
- **Amniocentesis:** Conducted after the 15th week of pregnancy, this test involves extracting a sample of amniotic fluid to analyze for different genetic conditions.

## Alternative Reproductive Options

For individuals concerned about passing CMT to their children, alternative options include:

- **Use of Donor Gametes:** Utilizing sperm or egg donors without the CMT mutation can eliminate the risk of transmission.
- **Adoption:** Adopting a child allows individuals to build a family without the concern of passing on CMT.

## Conclusion

Navigating family planning options with CMT involves carefully considering various factors, including genetic risks, available medical technologies, and personal views. It is also important to note that the tests and procedures described each have their own risks. Consulting with healthcare professionals, particularly genetic counselors, can provide valuable guidance tailored to individual situations, enabling informed and empowered decision-making.

*Dr. Katherine Forsey was trained as a biologist in the UK, and her PhD is in reproductive biology and IVF. Dr. Forsey oversees STAR and 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 CMTA's research strategy. Through STAR, 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.*

# CMTA-STAR: KATHERINE'S KORNER

*Katherine's Korner explores the heart of CMTA's Strategy To Accelerate Research (CMTA-STAR) and its impact on advancing treatments for CMT. Led by Katherine Forsey, PhD, CMTA's Chief Research Officer, CMTA-STAR unites world-renowned scientists, clinicians, industry leaders, and the CMT community to accelerate CMT research. Since its launch in 2008, CMTA-STAR has invested nearly $30 million in research, supporting groundbreaking discoveries that bring us closer to effective therapies and, ultimately, a cure for CMT.*

*This edition highlights the latest projects fueled by CMTA-STAR, including advancements in genetic therapies, innovative therapeutic approaches, and the search for reliable biomarkers. We also share active opportunities to contribute to critically important CMT research.*

# PARTICIPATE IN ONGOING RESEARCH

## CMTA-STAR Alliance Partner Launches Phase II SYNAPSE-CMT Trial

CMTA-STAR Alliance Partner NMD Pharma A/S has launched the SYNAPSE-CMT Phase II clinical trial, a groundbreaking study designed to evaluate the safety, tolerability, and potential effectiveness of NMD670, an investigational medicine aimed at improving nerve-to-muscle communication. This trial is enrolling adults with genetically confirmed CMT Types 1 and 2 and includes key functional measures like the six-minute walk test (6MWT) and the timed-up-and-go (TUG) test to assess mobility and strength.

By participating in the SYNAPSE-CMT trial, you'll play a key role in advancing research that could make a real difference for everyone living with CMT.
Visit this CMTA Patients as Partners opportunity to learn more about eligibility, trial locations, and how you can support this important research effort. **Visit cmtausa.org/synapse today.**

## CMTA-STAR Alliance Partner Launches CMT2S Research Study

CMTA-STAR Alliance Partner Vanda Pharmaceuticals is advancing research on CMT Type 2S (CMT2S), a severe axonal form of CMT caused by recessive mutations in the IGHMBP2 gene. Vanda has received FDA approval for an investigational new drug (IND) to explore VCA-894A, an antisense oligonucleotide (ASO) therapy designed to target and address these specific genetic mutations. This study is a critical first step in identifying individuals who may benefit from this innovative approach.

By participating, you'll contribute to discovering potential treatment options for CMT2S and help shape future clinical trials. Visit this CMTA Patients as Partners opportunity to learn more about how to participate and how your involvement can accelerate CMT research. **Visit cmtausa.org/vanda2s to learn more.**

## Inherited Neuropathies Consortium (INC) Study 6603: Evaluation of the CMTPedS Tool

Through its strategic alliance with the Inherited Neuropathy Consortium (INC), CMTA supports a groundbreaking longitudinal study to refine the Charcot-Marie-Tooth Pediatric Scale (CMTPedS). This study aims to develop a reliable method to measure impairment and progression in children with CMT, addressing a critical gap in pediatric care and research.

Families with children under 21 diagnosed with CMT1, CMT2, or CMT4 are encouraged to participate.
**Visit cmtausa.org/cmtpeds to learn more about this vital research opportunity and how your family can contribute to advancing pediatric CMT care.**

## Inherited Neuropathies Consortum (INC) Study 6611: Evaluation of the CMTInfS Tool

Through its strategic alliance with the Inherited Neuropathy Consortium (INC), CMTA supports a study to develop and validate the Charcot-Marie-Tooth Infant Scale (CMTInfS). This innovative tool will assess disease severity in children from birth to 3 years old, addressing the critical need for early measurement to support future treatments.

Families with children aged 0–4 years, both with and without CMT, are invited to participate.
**Visit cmtausa.org/infant to learn more about this vital research opportunity and how your family can help shape the future of pediatric CMT care.**



# CMTA-STAR PROJECT UPDATES

## Gene Therapy for CMT1A, CMT1B, and CMTX1: Progress in Nanoparticles

In a collaborative effort funded by CMTA and the Muscular Dystrophy Association (MDA), Alexia Kagiava, PhD, and her team at the Cyprus Institute of Neurology and Genetics are pioneering nanoparticles to deliver genetic therapies directly to Schwann cells. This novel approach focuses on addressing mutations in the GJB1 gene for CMTX1 and holds potential for treating other Schwann cell-related CMT types, including CMT1A and CMT1B.

Dr. Kagiava's team has already developed nanoparticles capable of targeting peripheral nerves and begun testing their distribution in a CMT model.
**Learn more about this groundbreaking research here: cmtausa.org/news/nanoparticles-type1/**

## CMTA-STAR Collaboration Marks a Decade of CMT Genetic Discovery

The GENESIS genomic research platform, launched in 2012 by CMTA-STAR Advisory Board Member Stephan Züchner, MD, PhD, has transformed CMT gene discovery, leading to over 25 new gene identifications, including the landmark CMT-SORD discovery. Supported by CMTA-STAR since its inception, GENESIS empowers researchers worldwide with over 20,000 datasets, including nearly 2,700 from the CMT community, fostering breakthroughs that shorten diagnostic journeys and advance treatment development.

**Learn more about CMTA's commitment to CMT gene discovery here: cmtausa.org/news/decade-of-genesis/**

## Advancing Treatments for CMT1A and CMT1B Through CMTA-STAR Research

CMTA-STAR-funded research led by Jordan VerPlank, PhD, at the Uniformed Services University of the Health Sciences, has uncovered promising advancements for CMT1A and CMT1B. The study, published in *Cellular and Molecular Life Sciences*, demonstrated that raising cGMP levels with CYR119, an experimental drug, improved nerve function, motor coordination, and myelin thickness in CMT models.

These findings highlight the transformative potential of CMTA-STAR's collaborative research model.
**Visit our website to learn more about this groundbreaking work and its impact: cmtausa.org/news/verplank-1a1b/**

## BECOME A PARTNER IN PROGRESS: JOIN CMTA PATIENTS AS PARTNERS IN RESEARCH

CMTA's Patients as Partners in Research program connects community members with critical research opportunities that drive innovation and bring us closer to effective treatments for CMT. Whether you're interested in participating in a clinical trial or contributing to natural history studies, your involvement is essential in shaping the future of CMT research.

***Visit CMTA's Patients as Partners in Research and register today to discover how you can make a meaningful impact in advancing research for everyone living with CMT: cmtausa.org/pap***

# CMTA-STAR ALLIANCE PARTNER NEWS

## CMTA-STAR Alliance Partner Alesta Therapeutics Advances CMT Research

Alesta Therapeutics, a CMTA-STAR Alliance Partner, has made exciting progress toward treating CMT2 subtypes caused by mutations in tRNA synthetase genes, such as GARS1 in CMT2D. With its therapeutic candidate ALE2, Alesta is exploring how to target a persistent cell stress signal linked to ongoing nerve damage in these CMT types. Early lab studies with ALE2 have shown encouraging results.

**Learn more about Alesta's innovative approach and its potential impact on CMT here: cmtausa.org/news/alestatype2**

## CMTA-STAR Alliance Partner NMD Pharma Receives FDA Orphan Drug Designation

NMD Pharma A/S, a CMTA-STAR Alliance Partner, has announced FDA orphan drug designation (ODD) for NMD670, the investigational drug being studied in its ongoing Phase II SYNAPSE-CMT trial. According to the company, NMD670 targets the ClC-1 chloride ion channel to address muscle weakness and fatigue, two common symptoms of CMT.

**This FDA designation marks an important step in developing NMD670 as a potential treatment for CMT. Read the full story here: cmtausa.org/news/nmd670-odd**

**TOGETHER, WE DRIVE PROGRESS**

**CMTA-STAR's impact is made possible by the generosity of our community. Every research breakthrough, clinical trial, and scientific discovery is fueled by donors who believe in a future without CMT. Your support accelerates research, accelerates treatment development, and brings hope to everyone living with CMT.**

**Be part of the progress. Donate today at cmtausa.org/give2star to support CMTA-STAR and help drive the next breakthrough.**

# CMTA BRANCHES

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

**ALABAMA**
**Northern Alabama**
Julie Barnett
northernalabamacmta-branch@cmtausa.org
Kimberly Parry
757-235-6260

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

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

**ARKANSAS**
**Central Arkansas Area**
Becky Bandy
832-689-1089

**CALIFORNIA**
**Antelope Valley Area**
Donna Murphy
661-317-6332
Danielle Metzger
661-317-6533
**Los Angeles Area**
Alani Price
310-710-2376
John Ramos
951-318-5669
Cheyenne Alfino
747-232-4604
**Orange County Area**
Beth Dorin
949-929-2908
**San Diego Area**
Kendall Trout
760-632-5654
**San Fran/Bay Area**
Lisa Weiner
415-994-3744

**COLORADO**
**Denver Area**
Ron Plageman
303-929-9647

**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**
**Destin Area**
Ted Spring
850-368-1097
**Jacksonville Area**
Tim Nightingale
904-504-1953
Stephanie Burkhalter
904-710-3771
**Miami Area**
Norma Levy
Anne Katz
Jessica Villalon
miamifloridacmtabranch@cmtausa.org
**Naples**
Roy Behlke
239-682-6785
**Palm Beach County**
Ilene Meckley
palmbeachcmtabranch@cmtausa.org
**Sarasota Area**
Rachel Rivlin
941-284-0766
**Tampa Bay Area**
Edward Linde
813-712-4101

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

**HAWAII**
**Honolulu Area**
Monica Rocabado
831-207-5050

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

**ILLINOIS**
**Chicago Area**
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

**KENTUCKY**
**Southeastern Kentucky**
Branch Leader Needed
Call 800.606.2682

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

**MARYLAND**
**Baltimore**
Sarah Wilson
301-615-9589

**MASSACHUSETTS**
**Boston**
Jill Ricci
978-887-1014
Vittorio Ricci
978-476-5369

**MICHIGAN**
**Central Michigan Area**
Megan Berger
517-256-5854
Jonah Berger
303-827-4218

**MINNESOTA**
**Minneapolis Branch**
Lynn Anne Groebner
952-393-3188
Angela Christensen
612-695-3864

**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

**NORTH CAROLINA**
**Charlotte Area**
Mona Doshi
980-339-8560
Scott Roehrig
980-297-1449
**Durham Area**
Jeanne Boehlecke
919-942-7909
**Wilmington Area**
Laurel Richardson
910-515-8488

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

**NEW JERSEY**
**Central New Jersey**
Mark Willis
732-252-8299

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

**NEW YORK**
**Buffalo Area**
Maryann Ciskal
716-435-3899
**Long Island**
Alessandro Cacciani
772-882-8319
**Syracuse Area**
Michael Casey
315-898-6819
**Westchester Area**
Beverly Wurzel
Frank Wurzel
201-224-5795

**OHIO**
**Cincinnati Area**
Josh Marsh
330-268-6436
**Cleveland Area**
Jessica Diamond
216-570-6432
**Columbus Area**
Angela McCabe
937-831-5968

**OREGON**
**Portland**
Rachel Tessier
portlandocmtabranch@cmtausa.org

**PENNSYLVANIA**
**Bucks County Area**
Julie FitzGerald Schell
315-573-3919
**Chester County**
Carol Aruffo
610-405-9291
**Harrisburg**
Erin Weierbach
717-379-7504
**Northwestern Area**
Joyce Steinkamp
814-833-8495
**Pittsburgh**
Erin Wood
pittsburghcmtabranch@cmtausa.org

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

**TENNESSEE**
**Central Tennessee Area**
Branch Leader Needed
Call 800.606.2682

**TEXAS**
**Austin Area**
Nate Halk
512-415-6097
**Dallas/Fort Worth**
Stephanie Jackson
dallascmtabranch@cmtausa.org
**Houston Area**
Tami Delmark
houstoncmtabranch@cmtausa.org

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

**VIRGINIA**
**Southwestern Virginia**
Karen Brown
540-558-5043
**Central Virgina**
Karen Dyer-Smith
434-882-7030

**WASHINGTON**
**Seattle Area**
Denise Snow
206-321-1261
Emily Osborne
425-220-4225

**WISCONSIN**
**Madison Area**
Debi Weber
608-712-8709
**Manitowoc Area**
Barry Hett
920-388-9992

**CANADA**
**Eastern Canada**
Traci Williams
514-685-5038
**Western Canada**
Victoria Berezovich
westerncanadacmta-branch@cmtausa.org
**Toronto Area**
Branch Leader Needed
Call 800.606.2682

**MEXICO**
**Guadalajara, Jalisco Area**
Tomas Luis Lopez Valenzuela
+52 1 33-18-28-17-07
Guadalupe Valenzuela Cazares
+52 1 33-17-94-53-21

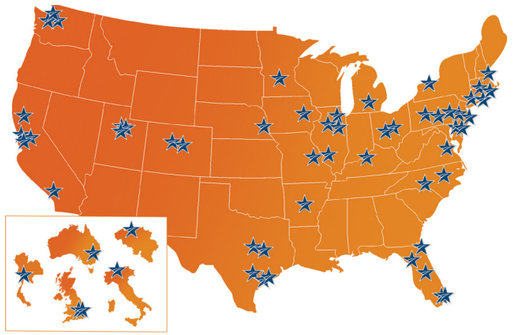
## INTERESTED IN STARTING A BRANCH IN YOUR AREA?

Contact CMTA Director of Community Outreach Laurel Richardson at **laurel@cmtausa.org**

# CMTA CENTERS OF EXCELLENCE

**CMTA's mission is 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. One of the many ways we implement this mission is by sponsoring patient-focused, multi-disciplinary Centers of Excellence CMT clinics. World-renowned CMT care specialists and researchers staff each CMTA Center of Excellence, ensuring those living with CMT receive only the best comprehensive care for themselves and their loved ones.**

**CMTA Centers of Excellence affiliated with the Inherited Neuropathy Consortium (INC), marked below with an asterisk, go further by collecting and recording genetic, biological, and other data from individuals with CMT as part of CMTA-funded research. For more information, visit cmtausa.org/coe.**



### ARKANSAS

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

### CALIFORNIA

**LOS ANGELES (ADULT & PEDIATRIC)**
Cedars-Sinai Medical Center
Clinical Directors: Richard A. Lewis, MD, and Melody Badii, MD
Appts: 310-423-4268

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

**PALO ALTO (ADULT)**
Stanford Neuromuscular Program*
Clinical Director: John Day, MD, PhD
Appts: 650-723-6469

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

**SAN FRANCISCO (PEDIATRIC)**
University of California, San Francisco
Clinical Director: Alex Fay, MD, PhD
Appts: 415-353-7596

### COLORADO

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

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

### CONNECTICUT

**FARMINGTON (PEDIATRIC)**
Connecticut Children's Medical Center, Farmington*
Clinical Director: Gyula Acsadi, MD, PhD
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, MD
Appts: 203-785-4085

### FLORIDA

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

**GAINESVILLE (ADULT & PEDIATRIC)**
University of Florida
Clinical Director: James Wymer, MD, PhD
Appts: 352-294-5400

**JACKSONVILLE (ADULT)**
Mayo Clinic Florida
Clinical Director: Christopher Lamb, MD
Appts: 904-953-0853

### FLORIDA (CONT.)

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

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

### ILLINOIS

**CHICAGO (ADULT & PEDIATRIC)**
Northwestern Memorial Hospital
Clinical Director: Daniela Maria Menichella, MD, PhD
Appts: 312-695-7950

**University of Illinois at Chicago**
Clinical Director: Charles K. Abrams, MD, PhD
Appts: 312-996-4780

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

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

### IOWA

**IOWA CITY (ADULT & PEDIATRIC)**
University of Iowa Hospitals & Clinics*
Clinical Director: Michael E. Shy, MD
Appts: 319-384-6362

### KENTUCKY

**LOUISVILLE (ADULT)**
University of Louisville
Clinical Director: Zeng Y. Wang, MD, PhD
Appts: Anson Ashburn, 502-588-4800

**LEXINGTON (ADULT)**
University of Kentucky
Clinical Director: Nakul Katyal, MD
Appts: 859-323-5661

### MARYLAND

**BALTIMORE (ADULT & PEDIATRIC)**
Johns Hopkins University*
Clinical Directors: Charlotte Sumner, MD, and Bipasha Mukherjee-Clavin, MD, PhD
Appts: (Adult) 410-614-1196, (Pediatric) 410-955-4259

### MASSACHUSETTS

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

### MICHIGAN

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

### MINNESOTA

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

### MISSOURI

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

### NEBRASKA

**OMAHA (ADULT)**
Chi Health Clinic Neurology Institute
Clinical Director: Yu-Ting Chen, MD
Appts: 402-717-0070

### NEW JERSEY

**HACKENSACK (ADULT & PEDIATRIC)**
Hackensack University Medical Center
Clinical Director: Florian Thomas, MD, PhD
Appts: Annerys Santos, 551-996-1324

### NEW YORK

**ROCHESTER (ADULT & PEDIATRIC)**
University of Rochester*
Clinical Director: David Herrmann, MD
Appts: 585-275-2559

### NORTH CAROLINA

**CHAPEL HILL (ADULT & PEDIATRIC)**
University of North Carolina*
Clinical Director: Rebecca Traub, MD
Appts: 984-974-4401

**DURHAM (PEDIATRIC)**
Duke University Hospital
Clinical Director: Natalie Katz, MD
Appts: 919-613-6832

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

### OHIO

**COLUMBUS (ADULT & PEDIATRIC)**
Nationwide Children's Hospital
Clinical Director: Zarife Sahenk, MD, PhD
Appts: 614-722-2203

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

### PENNSYLVANIA

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

**PHILADELPHIA (ADULT)**
Hospital of the University of Pennsylvania*
Clinical Director: Steven Scherer, MD, PhD and Chafic Karam, MD
Scheduling for Clinic Visits: Kari Roberts, Kari.Roberts@pennmedicine.upenn.edu
Scheduling for Research Visits: Pooja Patel, 215-898-0180

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

### PENNSYLVANIA (CONT.)

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

### TEXAS

**AUSTIN (ADULT)**
Austin Neuromuscular Center
Clinical Director: Yessar Hussain, MD
Appts: 512-920-0140

**DALLAS (PEDIATRIC)**
University of Texas Southwestern
Clinical Director: Kaitlin Batley, MD
Appts: 214-456-2768

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

**HOUSTON (ADULT)**
Baylor College of Medicine
Clinical Director: Thomas Lloyd, MD
Appts: 713-798-2273

**HOUSTON (ADULT)**
Houston Methodist Hospital
Clinical Director: Jun Li, MD
Appts: 713-441-3763

### UTAH

**SALT LAKE CITY (ADULT & PEDIATRIC)**
University of Utah*
Clinical Director: Russell Butterfield, MD, PhD
Appts: 801-585-7575

**SALT LAKE CITY (PEDIATRIC)**
Primary Children's Hospital
Clinical Director: Russell Butterfield, MD, PhD
Appts: 801-213-7756

**SALT LAKE CITY (PEDIATRIC)**
Shriner's Hospital
Clinical Director: Russell Butterfield, MD, PhD
Appts: 801-536-3564

### WASHINGTON

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

**SEATTLE (ADULT)**
Swedish Neuroscience Institute
Clinical Director: Christyn Edmundson, MD
Appts: 206-320-3494

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

### WASHINGTON, DC

**(ADULT)**
Medstar Georgetown University
Clinical Director: Nicholas Streicher, MD
Appts: 202-444-1774

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

### VIRGINIA

**HENRICO (ADULT & PEDIATRIC)**
Virginia Commonwealth University
Clinical Director: Nicholas Johnson, MD
Appts: 804-828-9571

## INTERNATIONAL LOCATIONS:

### AUSTRALIA

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

### BELGIUM

**B-2650 EDEGEM (ADULT & PEDIATRIC)**
Antwerp University Hospital
Clinical Director: Prof. Dr. Peter De Jonghe
Appts: +32 3 821 34 23
Neuromusculaire@uza.be

### UNITED KINGDOM

**LONDON (ADULT)**
University College London Hospitals*
Clinical Director: Mary M. Reilly, MD
Appts: Mariola Skorupinska, (0044)2034488019
mariola.skorupinska@uclh.nhs.uk

**St. George's University Hospital**
Clinical Directors: Niranjanan Nirmalananthan, PhD, and Emma Matthews, PhD
Email: nervemuscle@stgeorges.nhs.uk

### ITALY

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

### THAILAND

**BANGKOK**
Siriraj Hospital
Clinical Director: Oranee Sanmaneechai, MD
Appts: +66-24192660







**Email CMTA at info@cmtausa.org**

Charcot-Marie-Tooth Association

P.O. Box 105
Glenolden, PA 19036
1-800-606-CMTA (2682)
FAX (610) 499-9267

cmtausa.org

KAY PRINTING
TO ADD
INDICIA

# WHAT IS **CMT?**

Named after the three doctors who first described it in 1886: Charcot (shar-coh), Marie, and Tooth, Charcot-Marie-Tooth disease (CMT) is an inheritable peripheral neuropathy that includes many motor and/or sensory neuropathies, axonopathies, myelinopathies, and neuronopathies.

Due to the effects on the nerves, people with CMT suffer lifelong progressive muscle weakness and atrophy of the arms and legs, and/or progressive sensory loss; and CMT can affect other parts of the body. There is no treatment or cure for this debilitating and often overlooked disease.

CMT leads to problems with balance, walking, and hand use. CMT can cause foot drop, chronic nerve pain, chronic muscle and joint pain, abnormal reflexes, fatigue, tremors, sleep apnea, hearing loss, breathing difficulties, and much more.

Early signs of CMT can be toe-walking, especially in children; frequent trips and falls, frequent ankle sprains, and difficulty with handwriting, tying shoes, or buttoning a shirt.

**Visit CMTA's What is CMT webpage today: cmtausa.org/cmt**

**The Charcot-Marie-Tooth Association is a community-led, community-driven 501(c)(3) nonprofit organization with a 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. As the leading global philanthropic funder of CMT research, CMTA unites the community with clinicians and industry experts to accelerate the advancement of treatments, with investments of nearly $30 million since 2008.**


Walk 4 CMT and Cycle 4 CMT are annual community-based nationwide fundraising events for the Charcot-Marie-Tooth Association that have continued for more than a decade. These community events bring together the CMT community to raise awareness about Charcot-Marie-Tooth disease and generate funds for research and patient programs.

Learn more and get involved today at **cmtausa.org/4cmt**