CMTA
Charcot-Marie-Tooth Association

35 Years
Serving the CMT Community

1983-2018

35 years of progress, thanks to generations of dedicated CMTA members & partners!

1983 Carolyn Redell organizes a meeting of CMT families and physicians in NYC. One of the invitees, Dr. Howard Shapiro, creates a CMT organization: The National Foundation for Peroneal Muscular Atrophy (NFPMA).


1983: The First CMT Gathering
Carolyn Redell

1985/1989 With a mailing list of 24 people, Dr. Shapiro publishes the first newsletter! He then organizes patient/family gatherings, establishes a database of CMT clinicians and focuses on CMT research.


Dr. Shapiro

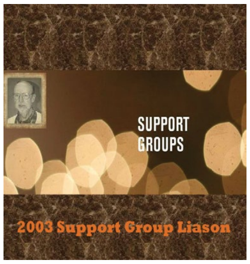
1987/1996 Although we knew CMT was caused by genetic mutations, the exact genetic causes were unknown. Within a 9-year period, the genetic causes of CMT1A, HNPP, CMT1B, CMT1D and CMT1X are pinpointed.

1990 Name Change! The NFPMA becomes the Charcot-Marie-Tooth Association (CMTA).

1995 The CMTA Board of Directors begins awarding $35,000 fellowship grants to CMT researchers.

2001 In conjunction with Wayne State University, Dr. Michael Shy and the CMTA establishes the North American CMT Database.

2003 CMT advocate and volunteer Bob Budde becomes the liaison for CMTA support groups.



2003 Support Group Liason

2006 Joining forces with the MDA, the CMTA funds the first-ever ascorbic acid clinical trials.

2008 In a vote of confidence for the CMTA's new research initiative, two CMTA families make large contributions and kick start fundraising campaigns to support the **Strategy to Accelerate Research (STAR).**

STAR
STRATEGY TO ACCELERATE RESEARCH

2009 Less than one year after STAR is set into motion, the first CMT1A cell line is grown. Using High Throughput Screening (HTS) at the National Institutes of Health, CMT1A drug discovery begins.

The CMTA is Treatment-Driven and Partner-Focused

Research and Strategic Partnerships

Dr. John Svaren,
CMTA STAR Advisory
Board Member

To advance CMT research, the CMTA:

- Spent over $8M in recent years and expects to spend $10M more to bring CMT drugs to market.
- Currently has over 25 active research projects with top labs around the world.
- Has a STAR Scientific Advisory Board with 25 of the best CMT scientists from around the world.
- Has partnership agreements with more than 20 pharmaceutical, biotech and service companies.
- Actively works with the patient community in the drug development process through the Patients as Partners in Research program.

Support for 60,000 Patients and Families

Ava stands to end CMT

The #1 trusted resource for information about CMT, the CMTA provides support through:

- An Advisory Board with 22 expert contributors
- 29 CMTA Centers of Excellence (COE)
- 70+ CMTA Branches
- Biannual Patient Family Conferences
- Camp Footprint for children living with CMT
- The CMTA Report and other publications
- The CMTA Emotional Support Group
- CMTA Webinars
- In-person and on-line community engagement
- National CMT Awareness Month

Active Fundraising and Stewardship of Donations

CMTA board member
Steve O'Donnell at the
2002 Swim for the Cure

The CMTA is community powered:

- In addition to annual campaigns, the CMTA community supports our research and our programs through the national Walk 4 CMT campaign, fundraisers held by CMTA board members, and grassroots events organized by CMTA community members.
- The CMTA makes efficient use of your donations - more than 85% of every dollar goes directly to support our mission.
- We earned a top rating by Charity Navigator six years in a row and received a 100% score for governance and transparency.

2010	The CMTA brings together globally recognized CMT specialists for a CMT Type 2 research symposium in San Diego, CA.
2011	CMTA board member Elizabeth Ouellette organizes the first CMT Awareness Week. Her effort sparks an international movement and becomes an annual month-long celebration to spread awareness about CMT
2012	The CMTA establishes 11 Centers of Excellence to help ensure CMT patients receive the best possible evaluation and care, and their information is collected for possible recruitment into clinical trials.
2013	Dr. John Svaren, from the University of Wisconsin, creates state-of-the-art cell lines employing genome editing technology, while other scientists in the CMTA network develop and utilize human stem cells in CMT research.
2014	Thanks to generous community support of STAR, the CMTA adds types 1X, 1B, 2A, 2E and 4 to its research platform. The CMTA supports creation and analysis of new animal models for CMT2E, CMT2A and CMT1B.
2016	The CMTA establishes Camp Footprint - the first camp in the US for children living with CMT.
2017	In collaboration with Ionis, the CMTA announces a major breakthrough in CMT1A research.
2018	The CMTA STAR consortium continues to grow and is currently partnered with more than 20 pharmaceutical, biotech and service companies across three continents.
2019 & BEYOND	With your continued support, we will capitalize on the amazing momentum we are now seeing with STAR. We have made CMT an attractive field for biotech companies thanks to the pre-clinical and clinical infrastructure we have developed with your help. This will allow us to be a major promoter of innovative research technologies and their implementation into clinical trials. Breakthroughs in gene and broad-based therapies, even for rare types of CMT, can now be accelerated into the clinic!

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