

Hereditary Neuropathy Foundation & University of Missouri Present The Nerve to Cure: CMT Social + Science Day and Dinner

*Uniting Research, Care, and Community
for Charcot-Marie-Tooth Awareness and
Progress*

COLUMBIA , MO, UNITED STATES,
August 28, 2025 /EINPresswire.com/ --
The Hereditary Neuropathy Foundation
(HNF), in partnership with Dr. Ryan
Castoro, Dr. Kathryn Moss and the
entire University of Missouri CMT
research community, is proud to
announce [The Nerve to Cure](#): CMT
Social + Science Day with Evening
Fundraiser Dinner on Saturday,
October 4, 2025, at the Roy Blunt
NextGen Precision Health Building,
1030 Hitt Street, Columbia, MO.

This [landmark event](#) brings together
patients, families, researchers, and
healthcare providers to accelerate
progress in Charcot-Marie-Tooth
disease (CMT) research and
care—combining groundbreaking
science with vital community
connection.

A Day of Connection, Education & Discovery

From 12:00 PM to 5:00 PM, the event will feature:

- Check-in & Welcome Packet (12:00–12:30 PM)



**HEREDITARY
NEUROPATHY
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Hereditary Neuropathy Foundation



NEXTGEN
PRECISION HEALTH



**MEDICAL
CENTER**

The University of Kansas

- Orientation & Booth Overview (12:30–12:40 PM)

- Opening Remarks by Dr. Ryan Castoro, D.O., University of Missouri, and Allison Moore, CEO of HNF (12:40–12:50 PM)

Expert Presentations: (12:50 - 1:30 PM)

- Genetics and CMT – Dr. Constantine Farmakadis, M.D., University of Kansas

- Myelin Dysfunction in CMT Type 1 – Dr. Kathryn Moss, Ph.D., University of Missouri

- Models of CMT – Dr. Curtis Nutter, Ph.D., University of Missouri

- Clinical Outcome Measures in CMT Trials – Dr. Kris Kelly, DPT, NCS, CPT, University of Missouri

Explore Event Zones (1:30–2:45 PM):

- CMT Resource Booths: offering genetic counseling, bracing/AFO solutions, adaptive tools, PT/OT strategies, and more.

- Research in Motion Zone: Learn about ongoing clinical trials, donate to the CMT Biobank, and enroll in the CMT DEPLOY Natural History Study

- Closing Announcements (2:45–3:00 PM)

Building Community Through Shared Experience

From 3:00–5:00 PM, join the CMT Social Community Meet-Up (Atkins Seminar Room)—a warm, inclusive gathering for individuals living with CMT and their families featuring:

- Kids Corner: OT-inspired sensory play, adaptive toys, and shoe try-ons

- Parent Connection Circle: Share with others, connect with experts, and learn advocacy tools

- CMT Library Lounge: Curated resources on pain, fatigue, self-care, mental wellness, and youth-friendly literature

^aFree 1-on-1 Expert Consultations: Meet with providers specializing in bracing, surgery, PT & OT evaluations

Evening Fundraiser Dinner to Support CMT Research (5:00–8:00 PM)

Cap off the day with an elegant evening (ticketed separately):

- Cocktail Hour (5:00–6:00 PM)
- Dinner Service (6:00–6:30 PM)
- Presentations: Updates from HNF and NextGen leaders (6:30–7:30 PM)
- Dessert & Gratitude Ceremony (7:30–8:00 PM)

[Register here](#)

On-Site Research Opportunities

To ensure full participation, research appointments will be available on Friday, October 3, and Saturday, October 4, from 8:00 AM – 6:00 PM at NextGen Precision Health.

“All of us—patients, families, scientists, and clinicians—have a role in advancing the mission to find treatments and ultimately a cure for CMT,” said Allison Moore, CEO of HNF. “This event is about bringing science and community together to fuel progress.”

“Our goal is to make NextGen Precision Health a hub for collaboration and innovation in neuromuscular disorders,” said Dr. Ryan Castoro, D.O. “We are honored to host this day of discovery, empowerment, and connection.”

About the Hereditary Neuropathy Foundation (HNF)

HNF’s mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related inherited neuropathies, support people living with CMT and their families with critical information to improve quality of life, and fund research that will lead to treatments and cures. HNF’s Therapeutic Research in Accelerated Discovery (TRIAD) is a collaborative effort with academia, government, and industry to develop treatments for CMT. As part of TRIAD’s research consortium, the Global Registry for Inherited Neuropathies (GRIN) was established as a patient registry to collect and analyze patient-reported data and clinical scales, including the ONLS, CMT-FOM, CMTpedS, CMTInfS, Digital Health Technologies, and the collection and curation of genetic reports. The data have been instrumental in identifying the burden, diagnostic journey, and prevalence of CMT.

About NextGen Precision Health

The University of Missouri is home to a growing, collaborative community of investigators dedicated to advancing research and therapies for Charcot-Marie-Tooth disease (CMT) and related neuromuscular disorders. This effort spans basic science, translational research, and clinical expertise. Within the NextGen Precision Health initiative, multiple neuroscience groups are studying CMT and developing translational pipelines from bench to bedside, including Dr. W. David Arnold (clinical and preclinical neuromuscular physiology), Dr. Ryan Castoro (axonal degeneration, sensory dysfunction, and ultrasound biomarkers), Dr. Kristina Kelly (motor

function, fatigue, and clinical outcomes), Dr. Kathryn Moss (myelin biology and mechanisms of CMT Type 1), and Dr. Curtis Nutter (central nervous system dysfunction in CMT). Complementing these efforts, Dr. Christian Lorson at the Christopher D. Bond Life Sciences Center brings extensive experience in developing and testing gene-based therapies for CMT. These initiatives are amplified by additional neuromuscular expertise from Dean of the School of Medicine Dr. Richard Barohn, together with Dr. Smita Saxena, Dr. Hiroshi Nishimune, and Dr. Andrea Sierra-Delgado, whose diverse perspectives accelerate translation and broaden the program's impact. Together, this integrated group is accelerating the path from discovery to clinical trials and working to build a vibrant local patient community, through events such as The Nerve to Cure, to ensure that scientific progress translates directly into improved care for individuals living with CMT.

About University of Kansas

The University of Kansas is an important regional partner in advancing CMT care and research. Dr. Constantine Farmakadis brings expertise in medical genetics and patient diagnosis, strengthening the collaborative network between MU, KU, and the Hereditary Neuropathy Foundation to improve outcomes for individuals with CMT across the Midwest.

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