

HNF Announces the CMT Clinical Trial Readiness Summit

A two-day summit focused on preparing for Charcot-Marie-Tooth (CMT) Disease clinical trials.

NEW YORK , NEW YORK , UNITED STATES , May 7, 2024

/EINPresswire.com/ -- HNF is thrilled to announce its first CMT Clinical Trial Readiness [Summit](#) to be held June 7-8 in San Diego, CA. As new clinical trials emerge for CMT, optimizing outcome measures, endpoints, and the participant experience has never been more urgent! HNF is committed to derisking upcoming trials by bridging the gap between clinical trial study teams and patient perspectives and experiences.

As HNF focuses on accelerating access to critical research data and specimens, this summit will include on-site CMT [Biobank](#) collection and a digital wearable pilot study sponsored by BioSensics™ and HNF using FDA-registered wearable devices. HNF will conduct objective assessments of gait, balance, fall risk, mobility, and upper limb function.

Attendees will also have opportunities for 1-on-1 consultations with CMT experts like Glenn Pfeffer, MD, on surgery and Mitchell Warner, CPO, on Helios Bracing. InformedDNA is providing discounted



HEREDITARY NEUROPATHY FOUNDATION June 7-8, 2024 **SAN DIEGO, CA**

LIVE ▶ IN-PERSON
HNF Patient-Centered
CMT + Clinical Trial Readiness Summit

Reserve your seat today! **CMT Patient Voices**

Loews Coronado Bay Resort

- Share your patient perspective for upcoming CMT clinical trials
- Donate specimens to the CMT BioBank
- Learn what it takes to be part of a CMT clinical trial
- Connect with others living with CMT

hnf-cure.org 4000 Coronado Bay Rd, Coronado, CA 92118

Clinical Trial Readiness Summit

 **HEREDITARY NEUROPATHY FOUNDATION**

Hereditary Neuropathy Foundation

telehealth visits for genetic counseling and access to patient-initiated genetic counseling during this event. CMT Lounges will be open across both days for building friendships and connecting with CMT resources like genetic testing, adaptive exercise, mental health, the [GRIN](#) patient registry, and more.

This impact-driven summit is a chance for all patients, caregivers, clinicians, industry, and regulatory representatives to connect with one another, exchange ideas, and engage in open discussions about the obstacles of designing and conducting successful CMT clinical trials.

The summit will be an all-in-one event for CMT Clinical Trial readiness with patients at the heart and center!

Attendees can expect to:

- *Have the chance to participate in a pilot study sponsored by BioSensics and HNF using FDA-registered wearable devices for objectively assessing gait, balance, fall risk, mobility and upper limb function.
- *Share their lived experience and patient/caregiver perspective during clinical trial design brainstorming sessions with industry partners currently planning human trials.
- *Donate blood/urine samples to the CMT Biobank for expedited access to researchers currently working on CMT treatments.
- *Connect and socialize with other individuals living with CMT.
- *Learn what it takes to be part of a CMT clinical trial and the latest CMT research.

Speakers include:

Shoshana Shendelman, PhD, CEO/Founder, Applied Therapeutics
Klaus Romero, MD, MS, FCP, CEO, Critical Path Institute
Kayla Cornett, PhD, University of Sydney
Tina Doung, PhD, Stanford Medicine
Ashkan Vaziri, PhD, Founder/CEO, BioSensics™
Allison Moore, Founder/CEO, Hereditary Neuropathy Foundation
Glenn Pfeffer, MD, Cedars-Sinai Orthopaedic Center
Matthew Jarpe, PhD, Scientific Advisor, Hereditary Neuropathy Foundation
Anna Pfalzer, PhD, CSO, COMBINEDBrain
Lori Sames, Founder, Founder/CEO, Hannah's Hope Fund
Joy Aldrich, GRIN Registry Coordinator, Hereditary Neuropathy Foundation
Robert Moore, GRIN Data Manager, Hereditary Neuropathy Foundation
Jason Colquitt, CEO, AcrossHealth Care
Gideon Shapiro, PhD, Founder/CSO, Miralinc Pharma
Shannon Strom, PhD, RAC, Drug Development Expert

Session Titles include:

- *Putting CMT Blood Samples to Work
- *For Industry & Researchers Only: Surrogate Biomarkers
- *For Patients & Caregivers: Workshop Managing Mental Health & CMT
- *Measuring CMT with Wearable Technology
- *Revolutionizing CMT Clinical Trials with Video
- *Is CMT Surgery Right for You?
- *Identifying Roadblocks to CMT Clinical Trials
- *Turning Symptoms into Science
- *What Does it Take? A Fighter Mom's Journey from Kitchen Table to Injection!
- *What's Next for Gene Therapies in CMT?
- *Overview: Upcoming CMT Pipeline & Clinical Trials
- *Philanthropic & Investment Opportunities

For more information and to register, visit: <https://HNFSummit.givesmart.com>

A special thanks to HNF's Summit Sponsors: Applied Therapeutics, NMD Pharma, Novartis, BioSensics™, Miralinc Pharmaceuticals, Matrix, EveryLife Foundation For Rare Diseases, Helios Bracing, InformedDNA and COMBINEDBrain.

Summit sponsorships are still available. Please email Courtney Hollett at courtney@hnf-cure.org to learn more.

About Hereditary Neuropathy Foundation

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, and CMTInfS and the collection and curation of genetic reports. The data has been instrumental in identifying the burden, diagnostic journey, and prevalence of CMT. In 2022, HNF launched the CMT Genie, a patient-initiated genetic testing program to support genetic diagnosis by offering patients virtual genetic counseling with an option to obtain a prescription to seek a genetic diagnosis. For more information, visit www.hnf-cure.org.

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