



## **CMTA and INC Forge Groundbreaking Alliance to Accelerate Comprehensive Research Across All Charcot-Marie-Tooth Disease Types**

- **CMTA strengthens its role as the leading force in comprehensive CMT research, forging a new strategic alliance with the Inherited Neuropathy Consortium (INC)**
- **Together, CMTA and INC are driving research to accelerate the path toward effective treatments for every type of CMT**

**GLENOLDEN, PA, UNITED STATES, November 13, 2024**—The Charcot-Marie-Tooth Association (CMTA), the largest philanthropic funder of Charcot-Marie-Tooth disease (CMT) research aimed at bringing treatments to patients, today announced a landmark strategic alliance with the Inherited Neuropathy Consortium (INC), positioning CMTA at the forefront of CMT research and patient care worldwide. With a \$1.2 million annual funding commitment, this partnership strengthens INC, a global network of over 20 clinical research sites dedicated to CMT, and positions CMTA as the partner of choice for pharmaceutical companies engaged in clinical trial design. The CMTA-INC alliance will drive research progress from the lab to the clinic, accelerating trials and treatments that offer real hope to the entire CMT community.

This new strategic alliance builds on CMTA's long-standing support for INC, strengthening a relationship grounded in a shared dedication to accelerating CMT research on the pathway to a cure. With NIH funding for INC sunsetting in 2024 after 15 years by an NIH rule, this significant investment provides vital support for biomarkers, clinical outcomes, and natural history studies to support clinical trial readiness, genetic testing and new gene discovery, and training the next generation of CMT researchers. The collective knowledge and data from the collaborative network of INC investigators will spur rapid drug development and provide crucial tools that accelerate therapies from trials to treatment, tools pharmaceutical partners depend on to bring innovative medicines to market.

### **A Commitment to Every Person with CMT**

CMTA's mission is rooted in a commitment to improving the lives of everyone affected by CMT. By uniting the patient community, researchers, clinicians, and drug developers, the CMTA-INC alliance is a collaborative force multiplier, accelerating progress toward effective treatments.

Sue Bruhn, PhD, CEO of CMTA, said: “Sustaining INC’s work through the new CMTA-INC strategic alliance means we can address the needs of every individual affected by CMT, regardless of type. This transformational partnership represents a new chapter for the CMT community, offering real help today and genuine hope for tomorrow. We are proud to play this role in shaping a new era of CMT research.”

Michael Shy, MD, principal investigator (PI) of INC and a pre-eminent leader in the CMT clinical research space, shared his vision: “INC’s journey has always been about empowering patients through research and clinical innovation. This new alliance provides our work with a sustainable path forward, ensuring that each of our over 20 international centers can continue the vital research that brings us closer to transformative treatments and a world without CMT. This partnership bridges an essential funding gap and opens new collaboration and scientific discovery opportunities. Together, we’re building a future that changes the trajectory of CMT research and patient care.”

### **A New Era for CMT Research**

The CMTA-INC strategic alliance sets a bold precedent in CMT research, drug development, and patient care. Gilles Bouchard, Chairman of the Board of Directors for CMTA, emphasized, “Thanks to CMTA’s Strategy To Accelerate Research (STAR) investments over the past decade, 100% funded by the CMT community, we now have a rich ecosystem and pipeline in CMT research, and we are starting to see promising clinical trials emerging. The CMTA-INC alliance is setting the stage for the next phase of STAR, where we engage with pharmaceutical partners in clinical trial design to support testing potential treatments with patients. This is truly an exciting time.”

### **About CMT**

Named after the three doctors who first described it in 1886: Charcot, Marie, and Tooth, CMT affects one in every 2,500 people—a rare disease subdivided into multiple subtypes, each with a lower prevalence. Due to the degradation of their nerves, people with CMT suffer lifelong progressive muscle weakness and atrophy of the arms and legs, and can affect other parts of the body. This leads to problems with balance, walking, hand use, and more. There currently is no treatment or cure for this debilitating disease.

## **About INC**

INC is a collaborative network of CMT investigators from multiple academic medical centers who currently follow over 8,300 individuals with CMT. Since its inception in 2009, INC has published over 300 manuscripts defining the natural history of multiple CMT subtypes and developing the clinical outcome measures and biomarkers that allow investigators to perform these natural history studies and make the subtypes “Clinical Trial Ready.” INC has identified thirty new genes that cause CMT to date and trained more than twenty outstanding young investigators devoting their careers to CMT research.

## **About CMTA**

CMTA 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. For more information, visit [cmtausa.org](http://cmtausa.org)

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