

# HNF Launches Groundbreaking 'ABCs of CMT Pain Management' Guide

*A transformative resource in addressing pain within Charcot-Marie-Tooth Disease (CMT) has arrived, propelled by the voices & experiences of the CMT community.*

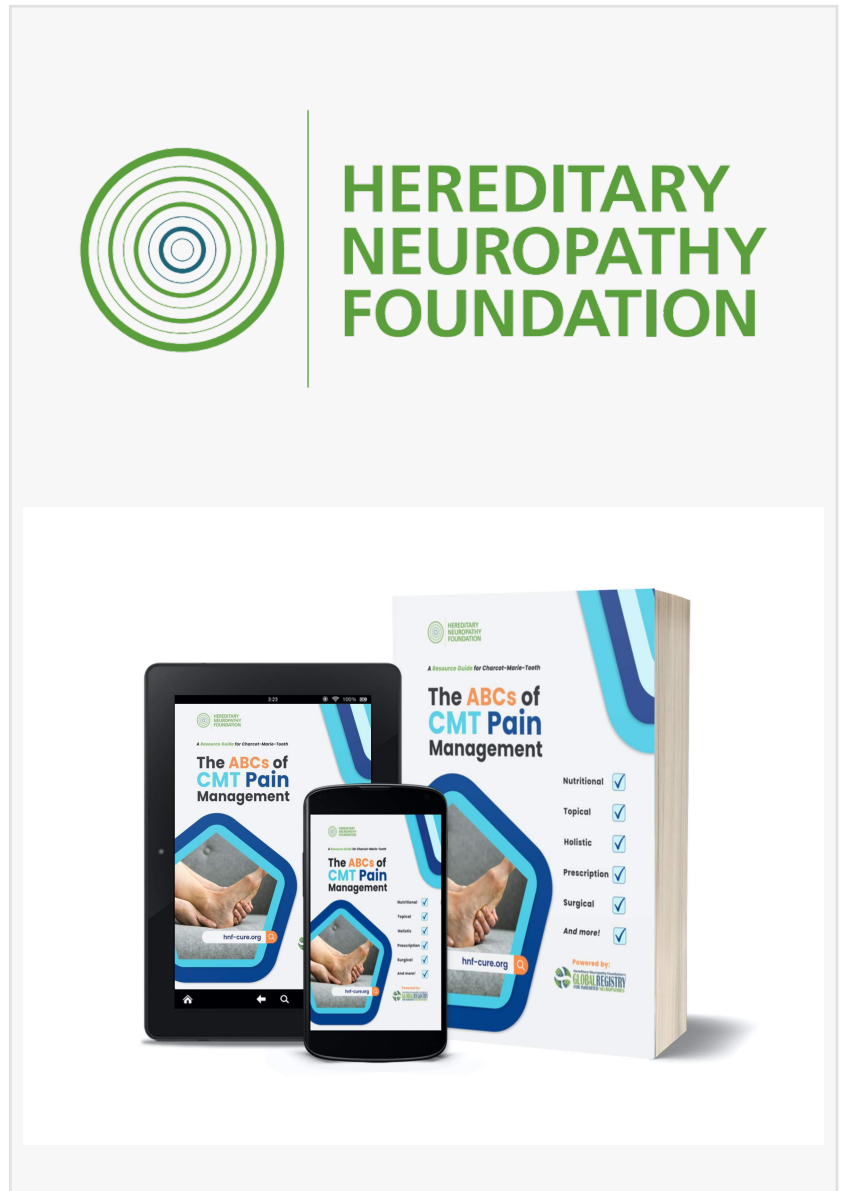
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/EINPresswire.com/ -- The Hereditary Neuropathy Foundation is thrilled to introduce the "ABCs of CMT Pain Management," a comprehensive guide. This guide embodies the power of collective stories through patient-reported data and an unwavering commitment to reshaping the narrative of pain in CMT.

This 90-page guide comes free as a PDF or can be purchased on Amazon in paperback or Kindle, where 40% of proceeds go back to CMT Research. It is the first comprehensive resource of its kind and provides an accessible support system designed to help individuals find personalized ways to manage their pain effectively.

[View the Guide](#)

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In 2020, HNF fundraised to match a grant from the Orphan Disease Center at UPenn for the Million Dollar Bike Ride. The grant was awarded to Florian P. Thomas, MD, PhD, Director, Hereditary Neuropathy Foundation Center of Excellence, and Chair & Professor, Department of Neurology, Hackensack Meridian School of Medicine & Hackensack University Medical Center.

Our aim was to analyze Global Registry for Inherited Neuropathies ([GRIN](#)) data to identify previously unrecognized correlations for future research. The following study was the result of our collaboration: Patient-Reported Psychosocial Outcomes in Charcot-Marie-Tooth Disease.

The study found that most patients with CMT experience mild to moderate pain at least once per week. Pain severity was associated with heightened social isolation and diminished life satisfaction.

“These findings suggest addressing neuropathic pain will go a long way in improving the quality of life & community participation in people with CMT” Dr. Thomas said. “We can make a difference in CMT patients' lives if we find ways to address their pain.”

The "ABCs of CMT Pain Management" is a resource for informed decisions. Safety and well-being take precedence above all else. HNF emphasizes the importance of using this guide in conjunction with the guidance of certified healthcare professionals.

“It's time to erase any doubts surrounding the authenticity of pain in CMT. Pain is not just a fleeting discomfort but a genuine, significant aspect of CMT. This guide empowers individuals with knowledge, resources, and strategies to effectively manage pain and reclaim their quality of life.” - Estela Lugo, HNF Program Development Manager

"As a pharmacist, I appreciate the value and necessity of medications to help combat pain. Even more so, however, I advocate for a multimodal approach as pain management is so individualized. In my own experience with CMT, I am continuously discovering and tweaking what works best for me, whether it's homeopathic, physical therapy, exercise, or medications. It is not one-size-fits-all, but it's encouraging to have options for all." - Corrine Weinstein, Pharm.D

"This is an excellent comprehensive guide addressing pain in those with CMT and peripheral neuropathies. Pain is a crucial component of CMT and must be addressed appropriately in CMT centers. This guide helps physicians and patients recognize and understand important treatments for neuropathic pain." - Dr. Nivedita Jerath, AdventHealth, HNF CMT Center of Excellence

“HNF continues to collect pain data to address the gaps in measuring pain in clinical trial designs and advocates including pain scales as additional endpoints. We are grateful to the CMT Community for their continued support and participation in driving vital CMT research forward through GRIN. We invite all patients to enroll and/or complete the latest surveys to bring more vital research, resources, and clinical trials to fruition.” - Allison Moore, HNF CEO & Founder

#### 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, 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](http://www.hnf-cure.org).

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