

Dear

The Hereditary Neuropathy Foundation (HNF) declares September as Charcot-Marie-Tooth (CMT) Awareness Month. CMT, the most common inherited peripheral neuropathy, affects 1 in 2,500 people... approximately 2.6 million people worldwide and can strike at any age, and yet most people, even many doctors and CMT sufferers themselves, have never heard of it.

CMT is a disease that causes progressive nerve damage: early signs can include high arched feet, curled toes, and claw-like hands. Many of these signs begin subtly and may go undiagnosed for years, leading to legs and arms becoming deformed and difficult to use. For young children, the earliest signs may be clumsiness, lack of reflexes, and frequent falls, which can lead to bullying, shaming, and injuries, especially when undiagnosed children are pushed into PE and other activities that are not adapted to their special needs.

Over time, those with CMT often lose the ability to walk and may become dependent upon assistive devices to remain mobile. Severe, chronic pain is common. Scientists have discovered over 90 related genes but there are currently no cures and only palliative treatments.

Please join us by declaring September as CMT Awareness Month and support HNF's ongoing efforts to inform the public, medical community, educators, and legislators about this not-so-rare and often misdiagnosed disease. By recognizing September as CMT awareness month, together, we can raise awareness and work to find treatments and a cure.

HNF has a national network designating medical Centers of Excellence (COE) for the hereditary neuropathy patient community, which includes those with CMT and other Inherited Neuropathies (IN). The fourteen designated COEs provide excellence in clinical care and research for this patient community and will collaborate with HNF to expand their role as CMT/IN patient community hubs for clinical care, community engagement, research and education. HNF is honored to have these premier Centers and their leading experts in partnership with us to improve the future for people with hereditary neuropathies.

HNF, a non-profit 501(c) 3 organization whose mission is to increase awareness and accurate diagnosis of CMT and related inherited neuropathies, support patients and families with critical information to improve quality of life, and fund research that will lead to treatments and cures.

HNF developed the Therapeutic Research in Accelerated Discovery (TRIAD) program, a collaborative effort with academia, government and industry, to develop treatments for CMT. Currently TRIAD involves many groups that span the drug discovery, drug development, and diagnostics continuum.

Thank you for your consideration!

Warm regards,