Hereditary Neuropathy Foundation Launches New Website and Webinar to Support Charcot-Marie-Tooth Disease Research

HNF's website provides CMT community, academia, and biotech industry a hub for exploring research, clinical trials, vital resources, and ways to get involved.

Join our webinar on March 1, 2023 at 7pm ET

NEW YORK , NEW YORK , UNITED STATES , February 8, 2023 /EINPresswire.com/ -- – Charcot-Marie-Tooth (CMT) disease affects 1:3300, nearly 3 million people worldwide, and many remain undiagnosed.

– The Hereditary Neuropathy Foundation has redesigned its website to provide the CMT community, academia, and biotech industry a user-friendly hub for exploring current research, clinical trials, vital resources, and ways to get involved. In addition, it offers translation from English into eight languages.

The Hereditary Neuropathy Foundation's (HNF) mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related inherited neuropathies (IN), support the CMT community with critical information to improve quality of life, and fund research that will lead to treatments and cures. Today it launched an exciting and user-friendly website focusing on growing global interest in research and therapy development for CMT. Interest in such work has grown since HNF hosted its Externally-led Patient-Focused Drug Development Meeting for the FDA in 2018, followed by the publication of the "Voice of the

Patient" report. This groundbreaking meeting identified the lack of understanding of CMT and the subsequent barriers to treatments, such as; access to genetic testing and patient registry data, poor clinical trial design, and identification of symptoms that matter most to patients. Since then, HNF has been ultra-focused on eliminating these barriers. The well-designed and functional website provides the latest updates on research, clinical trials, and vital patient resources - including the CMT Genie for diagnosis and the Global Registry for Inherited Neuropathies (GRIN) patient registry. Valuable patient data is collected in the enhanced GRIN registry platform which was made possible with a large contribution by Brian and Katie McCormack, Chicago-based investors and philanthropists.

Please visit our new website

"I am happy to support this patient registry which now includes research regarding comorbidities with the NIH-funded ClinGen surveys. I believe this will lead to a better understanding of CMT - the way it impacts families dealing with this disease - and prioritize treatments for kids prior to any significant deterioration."

On March 1, 2023, at 7:00pm ET, HNF will host a webinar, "Making Sense & Science of CMT Symptoms." The webinar will provide resources for various CMT-related symptoms and highlight CMT patients' key role in accelerating important research. Without patient participation, researchers won't have the essential patient information to develop drugs, gene therapies, and clinical trials for CMT and IN. HNF will present how the CMT community can turn their symptoms into science, enabling better clinical trial design.

Registration for webinar:
https://us02web.zoom.us/webinar/register/WN_U5BeUJbeRLKOo3niUYl2nA

About Hereditary Neuropathy Foundation

HNF is the Patient-Centered CMT Advocacy group driven by patients, for patients. HNF developed the Therapeutic Research in Accelerated Discovery (TRIAD) as a collaborative effort with academia, government, and industry to develop treatments for CMT. The Global Registry for

Inherited Neuropathies (GRIN) has provided critical patient-reported data to TRIAD partners since 2013. This data was also critical in supporting the HNF-hosted Patient-Focused Drug Development meeting to inform the FDA about the burden of CMT and the critical, unmet need for treatment in 2018. In 2022, HNF launched the CMT Genie Program to accelerate genetic diagnosis and offer virtual genetic counseling to patients to explain the sometimes complicated genetic reports, as well as to increase the number of participants in GRIN.

Source: https://medlineplus.gov/genetics/condition/charcot-marie-tooth-disease/#frequency
https://www.fda.gov/media/130387/download

Allison Moore
Hereditary Neuropathy Foundation
+1 917-648-6971
email us here
Visit us on social media:
Facebook
Twitter
LinkedIn
Instagram
YouTube
