

Reducing Genetic Testing Barriers for the Charcot-Marie-Tooth Community

*Hereditary Neuropathy Foundation
Partners with InformedDNA® on CMT
Genie Project*

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/EINPresswire.com/ -- In partnership with InformedDNA®, the Hereditary Neuropathy Foundation (HNF) has added more value to their [Charcot-Marie-Tooth](#) (CMT) Genie Project — a patient-initiated at-home [genetic testing](#) program, providing faster and more equitable access to critical genetic care for the CMT community and their health care providers. CMT is an inheritable, progressive condition that occurs when gene mutations affect all the nerves outside the brain and spinal column. Scientists have now discovered 131 CMT-related genes. Mutations in these genes cause 165 individual subtypes. The most common is CMT1A.

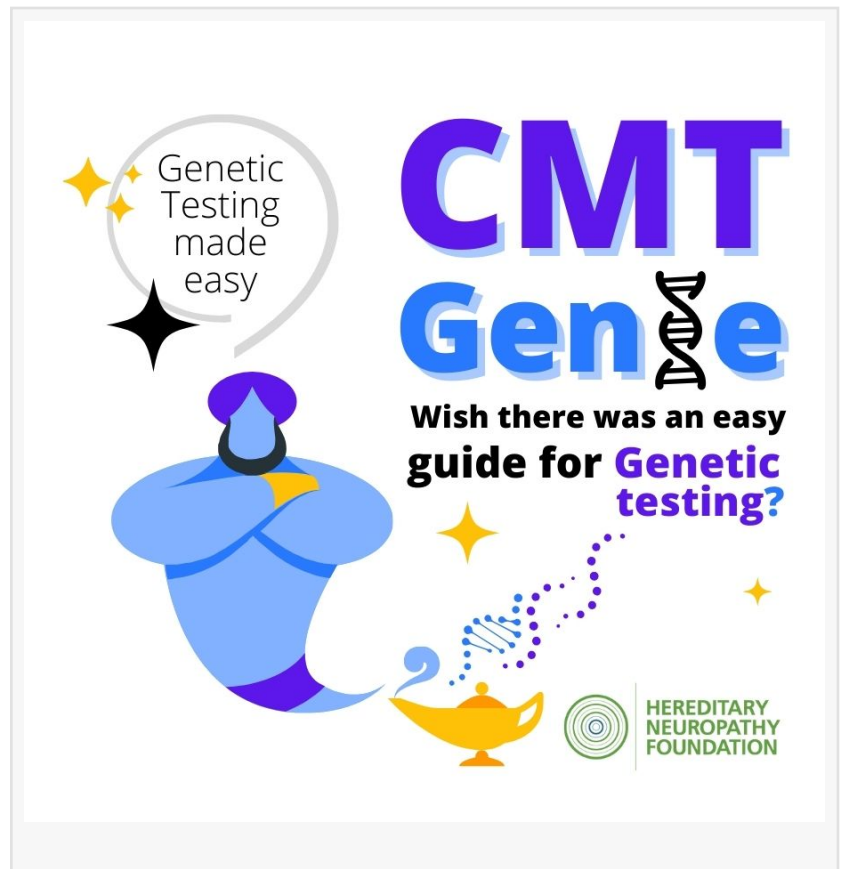


Since its launch in August 2022, over 300 patients have been connected to genetic testing through the [CMT Genie](#). This new partnership is a more comprehensive approach allowing us to more efficiently connect patients with genetic counseling and genetic testing options for an increased diagnosis rate.

“Knowing what to test for, which panel to order, and from which lab to order the test requires a level of expertise previously not widely available to the CMT community. Many commercial labs offer genetic testing for CMT, but they each test for different genes, and many have several different panels, each with different genes. No commercial lab offers testing for all known CMT genes. Unless a patient is within proximity to a CMT Center of Excellence, access to this expertise

isn't an option. With telehealth visits with InformedDNA's genetic counselors, licensed in all 50 states, HNF now has the solution." -Joy Aldrich, HNF Global Registry for Inherited Neuropathies Coordinator.

The CMT community has endured a historical absence of patient education and self-advocacy resources around the importance and availability of genetic counseling, genetic testing, clinical trials, and research participation opportunities. These combine to form a significant healthcare barrier that often prevents many community members from receiving a definitive genetic diagnosis.



Additionally, due to cost-prohibitive genetic testing options, providers are hesitant to order testing for many reasons, including a perceived lack of available treatments and a shortfall of CMT genetic testing expertise, worsening the barrier to a definitive genetic diagnosis. By connecting CMT patients to proper CMT genetic testing, HNF's new partnership with InformedDNA® strengthens our commitment to eliminating barriers to genetic testing and adequate CMT care.

"Since our inception in 2007 as the first telehealth genetic counseling company in the nation, we have remained focused on one vision: to revolutionize the application of genomic insights to enhance patient care and improve outcomes for all. With the largest team of independent genetics experts and board-certified genetic counselors on staff, we specialize in connecting rare disease patients to the information and testing they need to navigate a challenging diagnosis. We are thrilled to add HNF and their CMT patients to our genetics community." - Megan Czarniecki, MS, MS, CGC | Chief Operating Officer, InformedDNA

For more information on the CMT Genie Project, contact Estela Lugo at (212) 860-5405 or estela@hnf-cure.org.

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, CMT and other 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.

About InformedDNA

Established in 2007 as the nation's pioneer telehealth Genetic Counseling company, InformedDNA has evolved into a leading tech-enabled genomic solutions provider. With a team of experienced board-certified genetics experts and proprietary logic technologies, InformedDNA offers cost and clinical management solutions including Genetic Testing Utilization Management, Genetic Counseling, Payment Integrity, and Clinical Trial support. InformedDNA partners with clients across commercial and government health plans, health systems, biopharma, and other risk-bearing organizations to optimize clinical decision-making, reduce risk and downstream costs, and ensure compliance with safety and quality standards. InformedDNA is headquartered in St. Petersburg, FL. For more information, visit www.InformedDNA.com.

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