

Hereditary Neuropathy Foundation Re-launches One-of-A-Kind Patient Registry for Charcot-Marie-Tooth Disease Research

This user-friendly platform allows patients, caregivers, clinicians, and researchers the ability to manage health data to elevate CMT patient care.

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/EINPresswire.com/ --- Charcot-Marie-Tooth (CMT) disease affects 1:2500 in the US, and many are still undiagnosed.

- The Hereditary Neuropathy Foundation (HNF), together with Across Healthcare, has created a powerful patient registry, GRIN, powered by Across Healthcare's rare disease Matrix platform. This user-friendly platform allows patients, caregivers, clinicians, and researchers the ability to manage health data to elevate patient care, advance research, support clinical trial designs, enhance therapy development with industry partners, and improve diagnosis.

Hereditary Neuropathy Foundation's (HNF) mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related

inherited neuropathies and support people living with CMT and their families with critical information to improve quality of life. HNF only funds research that will lead to treatments and cures. Today it re-launched its [Global Registry for Inherited Neuropathies \(GRIN\)](#) on the Matrix



Hereditary Neuropathy Foundation's
GLOBAL REGISTRY
FOR INHERITED NEUROPATHIES



**HEREDITARY
NEUROPATHY
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Matrix

platform by Across Healthcare. The registry's goal is to acquire, record, and analyze patient-reported data and associated genetic reports, Electronic Health Records (EHRs) and clinical notes to identify the burden, diagnostic journey, and prevalence of disease that will aid scientists in their work toward finding a cure.

"Initiatives such as the HNF registry bring together critical data from patients, caregivers and clinicians, including genetic tests and electronic health records. This information can help inform clinical trials of therapies for the 150,000 people in the US who are living with Charcot-Marie-Tooth disease and have no treatment options available," said Shoshana Shendelman, CEO & Founder of Applied Therapeutics.

Originally launched in 2013, GRIN has continued to evolve. The data collected has helped HNF and its partners in industry, academia, and government identify previously unknown genotype/phenotype correlations, uncover important comorbidities such as pain or respiratory issues, and target our research spending based on actual patient need and likelihood of success.

"GRIN data has been essential in clinical trial protocol design, site selection, and efficient patient recruitment for the pivotal Phase III clinical study of our lead asset PXT3003, the PREMIER trial, in development for the most common type of CMT, CMT1A. In addition, the robust data collected in GRIN, together with the ongoing CMT&Me digital survey, will enable a better understanding of the burden of disease, comorbidities, and critical patient demographics as we move forward to a potential commercialization of PXT3003 if approved by the FDA. Topline data of the PREMIER trial are expected in the last quarter of 2023." Xavier Paoli M.Sc. Pharnext, Chief Operating Officer.

HNF had invested an additional \$140,000 funding for the maintenance and expansion of GRIN to include clinicians and links to EHRs, and the migration to the Matrix platform was the result of fundraising campaigns and multiple generous benefactors, including an ongoing [match campaign](#) from an anonymous donor in the amount of \$200,000 (\$400,000 total).

"Pharma and biotech investment in developing therapies for CMT is moving faster than ever before as a result of the HNF hosted EL-PFDD meeting with FDA." said Allison Moore, HNF's Founder & CEO. "HNF is committed to supporting this development with the critical data needed by industry to characterize this disease and define clinically significant outcome measures that are meaningful to patients by continually improving and expanding our GRIN platform. Furthermore, we are on a path to reach and represent a more diverse patient population and are excited that this new platform is available in seven languages and HNF has expanded resources to reach the underserved and underrepresented patient population."

"We are humbled and honored to be working with HNF to empower anyone living with CMT and their families to track and give individualized insights through our Matrix platform while simultaneously continuing the legacy and vision of the GRIN platform to provide a robust regulatory grade international registry." said Jason Colquitt, Across Healthcare's Founder & CEO.

About The 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.

For more information, visit us at www.hnf-cure.org, or on Facebook, Twitter, Instagram, Vimeo and YouTube.

[About Across Healthcare](#)

Across Healthcare was formed in 2012 and has been a trusted partner to many clients by helping them envision, design, and deliver innovative healthcare technology solutions. One of Across Healthcare's flagship products is their innovative rare disease platform, Matrix (www.acrossmatrix.com), that is currently supporting over 45 rare disease foundations and aggregating data from over 50 countries. The core company philosophy is the principle of reciprocity: "Do unto others as you would have them do unto you."

To learn more about Across Healthcare visit www.acrosshealthcare.com or Matrix visit www.acrossmatrix.com.

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