First Ever Biorepository for Charcot-Marie-Tooth, HNF Launches the CMT Biobank

The new CMT Biobank will collect and store patient samples, including blood, tissue, skin fibroblasts, Induced Pluripotent Stem Cells (iPSCs), and more!

NEW YORK, NY, UNITED STATES, August 17, 2023 /EINPresswire.com/ -- Charcot-Marie-Tooth (CMT) disease affects 1:3300, nearly 3 million people worldwide, and many remain undiagnosed.

The Hereditary Neuropathy Foundation (HNF), an advocacy and research 501c3 non-profit, today announces enhancements to their Charcot-Marie-Tooth (CMT) and Inherited Neuropathies (IN) patient registry, Global Registry for Inherited Neuropathies (GRIN). GRIN is an IRB approved, patient consented registry. This research consortium consists of researchers and clinical experts, including various partnerships globally (CMT advocacy groups, data scientists, genetic experts and industry).

CMT is a group of inherited disorders with 128 genes responsible for all the CMT subtypes, CMT1A being the most common. GRIN acquires, records, and analyzes patient-reported data, associated genetic reports, and validated, clinical CMT scales (CMTPeds, CMTInfS) to identify the burden, diagnostic journey and prevalence of disease. CMT impacts the quality of life starting in childhood and is progressively debilitating. Currently, there are no treatments, but there are many potential therapies in the pipeline. There are still gaps in understanding the natural history of the disease correlation of genotype/phenotype, the availability of patient biospecimens for translational research, and validation of drug candidates and biomarkers for CMT.

COMBINEDBrain, a non-profit with a biorepository consortium, represents and partners with 65

rare-disease advocacy groups, including HNF. The CMT Biobank is an enhancement to the GRIN consortium and will offer GRIN patient registrants the opportunity to participate in innovative and translational research to accelerate CMT therapies. The new CMT Biobank will collect and store patient samples, including blood, tissue, skin fibroblasts, Induced Pluripotent Stem Cells (iPSCs), and more!

HNF chose COMBINEDBrain as a partner for their state of art biorepository, dedicated team, and ability to quickly and efficiently fill a research gap and benefit the entire CMT research community.

“For clinical trials to be successful, targets for treatment and biomarkers must be identified. To date, there is no available biorepository of CMT samples for researchers or industry to pull from. Today, HNF has changed that and is excited to advance research and therapy development with the help of COMBINEDBrain,“ states Allison Moore, Founder/CEO HNF.

"We stick to our mission as an organization by collaborating with clinicians, scientists, and industry, and one thing they all agree on is the importance of biomarker discovery for each of these rare communities", said Dr. Bichell, Founder of COMBINEDBrain. "One easy way to start identifying biomarkers is to collect patient samples, often blood or other biofluid, for researchers, clinicians or industry to study and advance the field of CMT/IN research for your families," said Dr. Bichell.

For patient participation: Join GRIN:
Visit: www.JoinGRIN.org

For GRIN questions or to volunteer to provide patient samples:
Contact: registrycoorinator@hnf-cure.org

To request patient samples and/or inquire about partnerships:
Contact: allison@hnf-cure.org

About Hereditary Neuropathy Foundation

The Therapeutic Research in Accelerated Discovery (TRIAD) is a collaborative effort with academia, government, and industry to develop treatments for CMT. As part of TRIAD, the Global Registry for Inherited Neuropathies (GRIN) was established as a patient registry and research consortium to advance knowledge of patient records, analyze patient-reported data, collect genetic reports and clinical CMT validated scales (CMTPeds, CMTInfS). 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 https.www.hnf-cure.org

About COMBINEDBrain

The Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders (COMBINEDBrain) is a non-profit consortium representing more than 65 different neurodevelopmental disorders. Their mission is to expedite meaningful treatments for individuals diagnosed with these disorders by pooling together efforts across clinicians, scientists, advocates, and industry.
For more information, visit https://combinedbrain.org/

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