



HEREDITARY  
NEUROPATHY  
FOUNDATION

# 2021 - 2022 Financial Report

Annual Update

Prepared by  
Hereditary Neuropathy Foundation





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# Impact That Matters.



## OUR MISSION

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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.

## OUR RESEARCH - TRIAD

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Therapeutic Research In Accelerated Discovery (TRIAD)

TRIAD = Academia + Government + Industry

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.



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Hereditary Neuropathy Foundation's  
**GLOBAL REGISTRY**  
FOR INHERITED NEUROPATHIES

## TRIAD & GRIN

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As part of TRIAD, in 2013, the Global Registry for Inherited Neuropathies (GRIN) was developed to conduct patient-focused research & development for treatments and cures. The patient voice is at the forefront of all we do. By incorporating the patient voice from the beginning, our research programs have the greatest potential for success. HNF funds research with one goal in mind; advancing to clinical trials for Charcot-Marie-Tooth research.

## TRIAD COUNCIL

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The TRIAD Council is composed of CMT thought leaders, experts, and consultants engaged in collaborative planning and decision-making to provide regular guidance and direction to our research strategy. This network of professionals reviews grant proposals, provides expert guidance, and assesses project outcomes to advance therapeutic development for CMT.

## GLOBAL REGISTRY FOR INHERITED NEUROPATHIES (GRIN)

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

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.

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.







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## CMT GENIE

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Trying to get a genetic confirmation of CMT can be overwhelming, and you might not have access to health care providers who are familiar with all the choices out there. HNF's CMT Genie is designed to assist you and your health care provider determine what the best option is for you!

## THE CMT BIOBANK

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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!

## CENTERS OF EXCELLENCE

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The designated COEs demonstrate strengths in providing excellence in clinical care and research and will collaborate with HNF to expand their role as CMT/IN patient community hubs for clinical care, community engagement, research, and training/education.

HNF strongly believes CMT patient care and prognosis could be significantly improved if health care practitioners (HCPs) could demonstrate and enhance their proficiency in managing CMT patient care.

## TEAM CMT

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Team CMT is a grassroots community fundraising program with hundreds of participants across the globe. Choose from HNF-partnered events or create your own event! No action is too small! Every bit of effort can have an impact on our community.



# ADVISORY COUNCILS



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## GRIN

## TRIAD

- Lucia Notterpek, PhD
- Said Atway, DPM
- Renée JG Arnold, PharmD, RPh
- Wayne Berberian, MD
- Robert D. Bell, PhD
- Robert Burgess, PhD
- Jahannaz Dastgir, DO
- Erik Ensrud, MD
- Joseph J. Higgins, MD, FAAN
- Tara Jones, CGC
- Peter B. Kang, MD
- Brett Langley, PhD
- Nadia Litterman, PhD
- James Nussbaum, PT, PhD, SCS, CSCS, EMT
- Glenn B. Pfeffer, MD
- Sindhu Ramchandren, MD, MS
- Michael Sereda, MD, PhD
- Amro Stino, MD
- Florian P. Thomas, MD, MA, PhD, MS
- Mitchell Warner, CPO
- Dianna E. Willis, PhD

- SeoYoun Chang Hackensack University Medical Center
- Catherine Imossi Hackensack University Medical Center
- Florian Thomas, MD, MA, PhD, MS Hackensack University Medical Center Corinne Weinstein Clinical Oncology Pharmacist at Cancer Centers of Colorado-Good Samaritan, Denver, Colorado Professor
- Joshua Burns Head of School and Dean of the Sydney School of Health Sciences
- Kayla Cornett, PhD University of Sydney and Children's Hospital at Westmead

## HNF BOARD

- Allison Moore, Founder, CEO
- Matthew Downing, Chairman
- Brooke Warren, Secretary
- Kara Sprague, Treasurer
- Joy Kaye
- Gretchen Cappiello
- Debi Houliars
- Robert A Kauffman
- Deborah Newcomb
- Kerin Reilly
- Dominic Hadeed
- Natalia Salejko
- Sital Bhavsar

## STAFF

- Allison Moore Founder, CEO
- Courtney Hollett Executive Director
- Joy Aldrich Advocacy Director
- Estela Lugo Program Development Manager
- Bernadette Scarduzio Social Media Coordinator
- Robert Moore Registry Data Manager
- Cherie Gouaux Accounting Manager
- Kenneth Raymond GRIN Data Curator





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Movement  
is Medicine™



inspire™  
together we're better®

## MOVEMENT IS MEDICINE™

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Movement is Medicine™ mission is to promote the safe adoption of a more active lifestyle through exercise and nutrition programs specifically created for those with disabilities.

Our Movement is Medicine™ program offers adaptive fitness free online classes for everyone!

## INSPIRE™ COMMUNITY

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In 2009, HNF partnered with Inspire™, a social network for health, to launch a CMT online support community. The community has grown to more than 9,300 patient and caregiver members and generated 100,000+ posts — real-world data that reveal important trends, themes, and gaps.





## PATIENT RESOURCES

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Successful patient care for those living with Charcot-Marie-Tooth takes a multi-modal approach, from bracing to surgery to physical therapy.

HNF is committed to providing patient care resources and information to help improve the lives of CMT patients.

## TOPICS

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- [Accessible Travel](#)
- [Adaptive Driving](#)
- [Bracing](#)
- [Breathing](#)
- [Canine Companions](#)
- [Cannabis](#)
- [CMT en Español](#)
- [CMT Support Community](#)
- [Dating and Relationships](#)
- [Emotional and Mental Health](#)
- [Family Planning](#)
- [Fashion and Products](#)
- [Genetic Testing](#)
- [Home Accessibility](#)
- [Inclusive Employment](#)
- [Legal Rights and Benefits](#)
- [Neurotoxic Drugs](#)
- [Newly Diagnosed](#)
- [Nutrition](#)
- [Occupational Therapy](#)
- [Pain](#)
- [Podcasts](#)
- [Podiatry](#)
- [PT and Exercise](#)
- [Research and Clinical Trials](#)
- [School and College](#)
- [Surgery](#)
- [Symptom Checklist](#)
- [Tips and Hacks](#)





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## JULY 2021 - JUNE 2022

### CURRENT ASSETS

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Cash and cash equivalents \$1,143,213

Investments \$108,840

Accounts Receivable \$75,000

**Total Current Assets: \$1,627,053**

#### Liabilities and Net Assets

##### Liabilities

Credit Cards \$5,381

Accounts payable &  
accrued expenses \$271

**Total Liabilities \$5,589**

##### Net Assets

With Donor Restrictions \$1,059,629

Without Donor Restrictions \$561,835

**Total Net Assets \$1,621,464**

**Total Liabilities and \$1,627,053**

Net Assets

### REVENUE

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Individuals \$788,508

Foundations and Corporations \$265,906

In-kind \$170,777

Legacies & Bequests \$104,672

Realized gain on investments \$142,799

Book Sales \$1424

Individual and dividends \$1,418

Unrealized gain (loss) on investments (\$146,841)

**Total Revenue: \$1,328,663**

##### Expenses:

Program Services \$858,726

Management & general \$44,932

Fundraising \$71,341

**Total Expenses: \$974,999**