



**HEREDITARY
NEUROPATHY
FOUNDATION**

July 1, 2015 - June 30, 2016

Year End Review



Hereditary Neuropathy Foundation Incorporated January, 2001



On behalf of the Board of Directors of the Hereditary Neuropathy Foundation, I would like to extend a warm and heartfelt thanks to each of you for supporting the Hereditary Neuropathy Foundation in 2016. Every year, hundreds of lives are positively impacted by the programs the Foundation offers. Your financial support, participation and advocacy make all of this possible.

2016 has been such a momentous year for HNF and the CMT community! Just look at what we've accomplished together thanks to your support:

Therapeutic Research In Accelerated Discovery (TRIAD): HNF has been actively partnering with industry to help facilitate clinical trials with focus groups, expert meetings, and trial site selection. In addition, we have been actively translating HNF's drug and gene therapy assets into potential treatments for various forms of CMT. HNF continues to collaborate with Pharnext on the Phase 3 clinical trial for PXT-3003 and CMT1A. This is an unprecedented and exciting time for our community! Stay tuned as we will shortly announce new clinical trials for additional forms of CMT.

Inaugural Patient-Centered Charcot-Marie-Tooth Summit: On October 6th, 2016, HNF hosted the first-ever Patient-Centered Charcot-Marie-Tooth Summit at the 3 West Club in New York City. Over 160 attendees, including CMT patients, caregivers, and top leaders in healthcare, industry, and research, joined us to encourage improvements in caring for CMT patients and in developing critically needed treatments. This landmark event provided a unique opportunity for our community to voice their needs and concerns, learn about the latest in research and clinical trials, and connect with other CMT families.

CMT/Inherited Neuropathies Natural History Study: Over the Summer, the National Organization for Rare Diseases (NORD) announced the selection of twenty rare disease patient groups to partner with NORD to develop natural history studies, a grant award supported in part by a cooperative agreement with the U.S. Food and Drug Administration (FDA). HNF was proud to be included among the leading rare disease groups chosen for this major project. The effort will address the research gaps currently challenging our understanding of our disease's progression over time.

HNF-Designated CMT Centers of Excellence Network: In Spring 2016, we announced our new national initiative designating medical Centers of Excellence (COE) for the CMT patient community. The initial network of 10 centers has now been increased to 12 Centers thanks to the addition of Hackensack University Medical Center in Hackensack, NJ and the University of Michigan in Ann Arbor, Michigan. The designated COEs provide hubs of CMT expertise and excellence in offering CMT clinical care and dedicated research, as well as serve as a collaborative network for partnership with HNF to continuously improve clinical care, encourage community engagement, run clinical trials, pursue research opportunities, and provide training/education.

CMT-Connect: In 2016, HNF also proudly launched the CMT-Connect program, a holistic educational workshop series held in New York metropolitan area. These on-going workshops offer a safe environment to talk about the emotional dynamics of dealing with a chronic illness while encouraging and empowering participants to be proactive advocates for their own care, quality of life, and wellness needs. These innovative patient-centered workshops will soon be offered in other states both "live" and via webinars.

Inspire Community Growth: Since its inception in 2010, Inspire's on-line Charcot-Marie-Tooth (CMT) support group and discussion community has grown to almost 4,500 members! Inspire connects patients, families, friends, and caregivers with one another for support and inspiration, hosting impactful discussions on CMT diagnosis, managing symptoms, and treatment options such as bracing, orthotics, and exercise.

As a non-profit organization, HNF depends on your donations to support our programs and to enable our initiatives to increase CMT awareness and accelerate research to find treatments and cures.

On behalf of all of us at HNF, we thank you for your generous support and commitment to helping us realize a better future for those impacted by CMT.

Allison Moore, Founder, CEO

Hereditary Neuropathy Foundation



Mission Statement

Hereditary Neuropathy Foundation is a non-profit 501(c) 3 organization whose mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related inherited neuropathies, support patients and families with critical information to improve quality of life, and support research that will lead to treatments and cures.

Hereditary Neuropathy Foundation Program



Team CMT



Hereditary Neuropathy Foundation

www.hnf-cure.org

www.run4cmt.com



Patients. Caregivers. Doctors. Nutritionists. Researchers. Physical Therapists. Pharma. Together.

brought to you by



HEREDITARY
NEUROPATHY
FOUNDATION

HNF'S CMT CENTERS OF EXCELLENCE

The national network of HNF-designated Centers of Excellence (COE) provides patients with resources to find hubs of expertise in caring for and treating CMT, as well as locations where CMT research is being conducted.

Our primary goal for the program is to ensure that access to care results in positive outcomes for each individual patient's clinical experience. We are honored to have these premier Centers and their leading experts in partnership with us to improve the future for people with inherited neuropathies.

CALIFORNIA

Cedars-Sinai Medical Center

127 S. San Vicente Blvd.
Advanced Health Sciences Pavilion,
A6600
Los Angeles, CA 90048
Contact: Dana Fine
Phone: 310-423-8497
Email: Dana.Fine@cshs.org

Stanford Neuroscience Health Center Neuromuscular Clinic

213 Quarry Road, 1st Floor
Palo Alto, CA 94304
Phone: 650-723-6469.
Contact: Jennifer Fisher
Email: jnfisher@stanford.edu

CONNECTICUT

Hospital for Special Care

Charles H. Kaman Neuromuscular
Center
2150 Corbin Avenue
New Britain, CT 06053
Contact: Boguslaw Koczon-Jaremko
Phone: 860-612-6356
Email: Bkoczon-Jaremko@hfsc.org

FLORIDA

University of Florida (UF) Health

2004 Mowry Road
PO Box 100332
Contact: Tracie Kurtz, RN, CCRP
Phone: 352-273-8517
Email: tlkurtz@ufl.edu

University of Miami

Professional Arts Center (PAC)
1150 NW 14th Street, 6th Floor
Miami, FL 33136
Contact: Meri Jaime (for appointments)
Phone: 305-243-7400
Email: MJaime@med.miami.ed

KANSAS

University of Kansas Medical Center

Landon Center on Aging
3599 Rainbow Boulevard, MS 2012
Kansas City, KS 66160
Contact: Nicole Jenci
Phone: 913-945-9934
Email: njenci@kumc.edu

MASSACHUSETTS

Brigham and Women's Hospital

Department of Neurology
75 Francis St, Tower 5th Floor
Boston, MA 02116
Contact: Kristen Roe
Phone: 617-525-6763
Email: kroe@partners.org

MICHIGAN

University Of Michigan

Pediatric Rehabilitation Center
2205 Commonwealth Blvd.
Ann Arbor MI 48105
Contact: Jen Thomas
Phone: 734-763-2554
Email: jennifkt@med.umich@edu

MINNESOTA

University of Minnesota Health

Department of Neurology
420 Delaware Street SE, MMC 295
Minneapolis, MN 55455
Contact: Valerie Ferment
Phone: 612-301-1535
Email: ferm0016@umn.edu

MISSOURI

St. Louis University Medical Center

Department of Neurology
1438 South Grand Boulevard
St. Louis, MO 63104
Contact: Susan Eller
Phone: 314-977-4867
Email: ellersc@slu.edu

NEW JERSEY

Hackensack University Medical Center

30 Prospect Avenue
Hackensack, NJ 07601
Contact: Eugenia Ndiaye
Phone: 551-996-8100
Email: Eugenia.Ndiaye@hackensackmeridian.org

NEW YORK

Columbia University

Department of Neurology
710 West 168th Street
New York, NY 10032
Contact: For clinical appointments: Allan Paras
Phone: 212-305-0405
For research studies:
Phone: 212-305-6035
Email: ap3476@cumc.columbia.edu

WASHINGTON

St. Luke's Rehabilitation Institute

715 South Cowley Street, Suite 210
Spokane, WA 99202
Contact: Ann Cooper
Phone: 509-939-8079
Email: coopera@st-lukes.org

July 1, 2015 - June 30, 2016

Year-End Financial Summary

ASSETS

Cash and cash equivalents	\$965,574
Prepaid expense	\$7,005
Security Deposit	\$2,100
Property and equipment (net)	\$3,689

TOTAL ASSETS: **\$978,368**

LIABILITIES AD NET ASSETS

Liabilities

Credit Cards	\$10,539
Accounts payable and accrued expenses	\$4,618

TOTAL LIABILITIES **\$15,158**

NET ASSETS

<u>Unrestricted</u>	\$733,809
Temporarily restricted	\$229,402
TOTAL NET ASSETS	\$963,211

TOTAL LIABILITES AND **\$978,368**
NET ASSETS

REVENUE:

Foundations and Corporations	\$293,519
Individual	\$143,877
In-kind	\$109,293
Legacies & Bequests	\$162,690
Allowance for doubtful accounts	(\$2,815)
Contract Services	\$19,393
Interest Income	\$43
Special Events	\$35,196
Miscellaneous	\$1,045
Unrealized / realized gain	\$5,846

TOTAL REVENUE: **\$768,087**

EXPENSES:

Program Services	\$366,975
Management & general	\$45,321
Fundraising	\$45,255

TOTAL EXPENSES: **\$457,551**



Hereditary Neuropathy Foundation Team

The Hereditary Neuropathy Foundation Staff

Founder.CEO

Allison Moore

Email: allison@hnf-cure.org

Fundraising Coordinator

Courtney Hollett

Email: courtney@hnf-cure.org

Chief Science Officer

Sean Ekins

Accounting Manager

Cherie Gouaux

Email: cherie@hnf-cure.org

Social Media Manager

Bernadette Scarduzio

Email: bernadette@hnf-cure.org

**Advocacy Director**

Joy Aldrich

Email: joyaldrich@hnf-cure.org

Writer

Jessica Roberts

Email: jessica@hnf-cure.org

Creative Director

Estela Lugo

Email: estela@hnf-cure.org

Director, Medical & PublicAffairs

Tina Tockarshewsky

Email: tina@hnf-cure.org

Board of Directors

Allison Moore, Founder/CEO

Joy Andal Kaye, Chairman

Matthew Downing, Secretary

Donna Cusimano, Treasurer

Iris Adler, Board Member

Marybeth Calderone, Board Member

Debi Houliares, Board Member

Carol Liu, Board Member

Gerald Lynch, Board Member

Kerin Reilly, Board Member

Kathleen Zappola, Board Member

Scientific Advisory Board

Renee JG Arnold, PharmaD, Rph

Dr. Robert Burgess, Ph.D

Sean Ekins, Ph.D

Dr. Joel Freundlich, Ph.D

Dr. Steven J. Gray, Ph.D

Joseph J. Higgins, MD, FAAN

Dr. Lucia Notterpek, Ph.D

David Pleasure, MD

Dr. Michael Sereda, MD., Ph.D

Dr. Scott Stromatt

Dianna E. Willis, Ph.D