HEREDITARY NEUROPATHY FOUNDATION

2018 HIGHLIGHTS

cmtupdate

IN THIS ISSUE

1-855-HELPCMT (435-7268)

www.hnf-cure.org

The Hereditary Neuropathy Foundation's 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 fund research that will lead to treatments and cures.

pg. 6

The Externally-led Patient-Focused Drug Development (PFDD) Meeting was a Huge Success!

HNF's Vision Comes to Fruition on September 28

HNF successfully executed the Externally-led PFDD Meeting for the FDA, one of 14 to-date. Its purpose was to accelerate therapy development, support our industry sponsors - Pharnext and Acceleron Pharma – and others to help facilitate a better understanding by the FDA and stakeholders of what matters most to patients and families living with Charcot-Marie-Tooth (CMT) and Inherited Neuropathies (IN). Also important was developing an understanding of the benefit-risk that patients are willing to consider or tolerate when thinking about a biologic and/or gene therapy.

HNF is an innovative patient advocacy and research organization with a history of success, but there is still much work to do, as HNF leads the way to bring new treatments and therapies to our patient community. Your donations are imperative to fund our accelerated strategy as HNF continues to build partnerships with industry leaders and stakeholders in the community through the Therapeutic Research In Accelerated Discovery (TRIAD) Program.

(Continued on page 2)

HNF'S VISION COMES TO FRUITION

(Continued from page 1)

- **There were 698 in attendance (155 in person and 543 on the webcast)**
- **FDA officials attendance exceeded our expectations with 24 participants**
- **14 patients and their families showed bravery as they provided snapshots of their lives with CMT, five of them were kids and adolescents**
- **Stakeholders stepped up and sponsored HNF to host this groundbreaking event. Thank you to our sponsors: Pharnext, Acceleron Pharma, Cydan, FlexPharma, Athena Diagnostics, Ionis, Ceres, Champlain Valley Dispensary, Cresco Labs, Everylife Foundation for Rare Diseases, CMTA, MDA**
- **The debut of the HNF mini-documentary, "The Warren Family" captured the daily physical struggles and the emotional impact of living with CMT**
- **HNF used innovative Voice Activation Technology (VAT) to capture 27 additional testimonies for the FDA in the patient's own voice**
- **Leading CMT experts gave an overview on the importance of diagnosis, genetics, treatment options, therapy pipeline and clinical trials to educate the FDA and stakeholders on various aspects of CMT**

"Although the day was emotional and at times hard to listen to the heart-wrenching testimonies, the empathy and love shared throughout the room came through."

– Allison Moore, CEO/Founder HNF

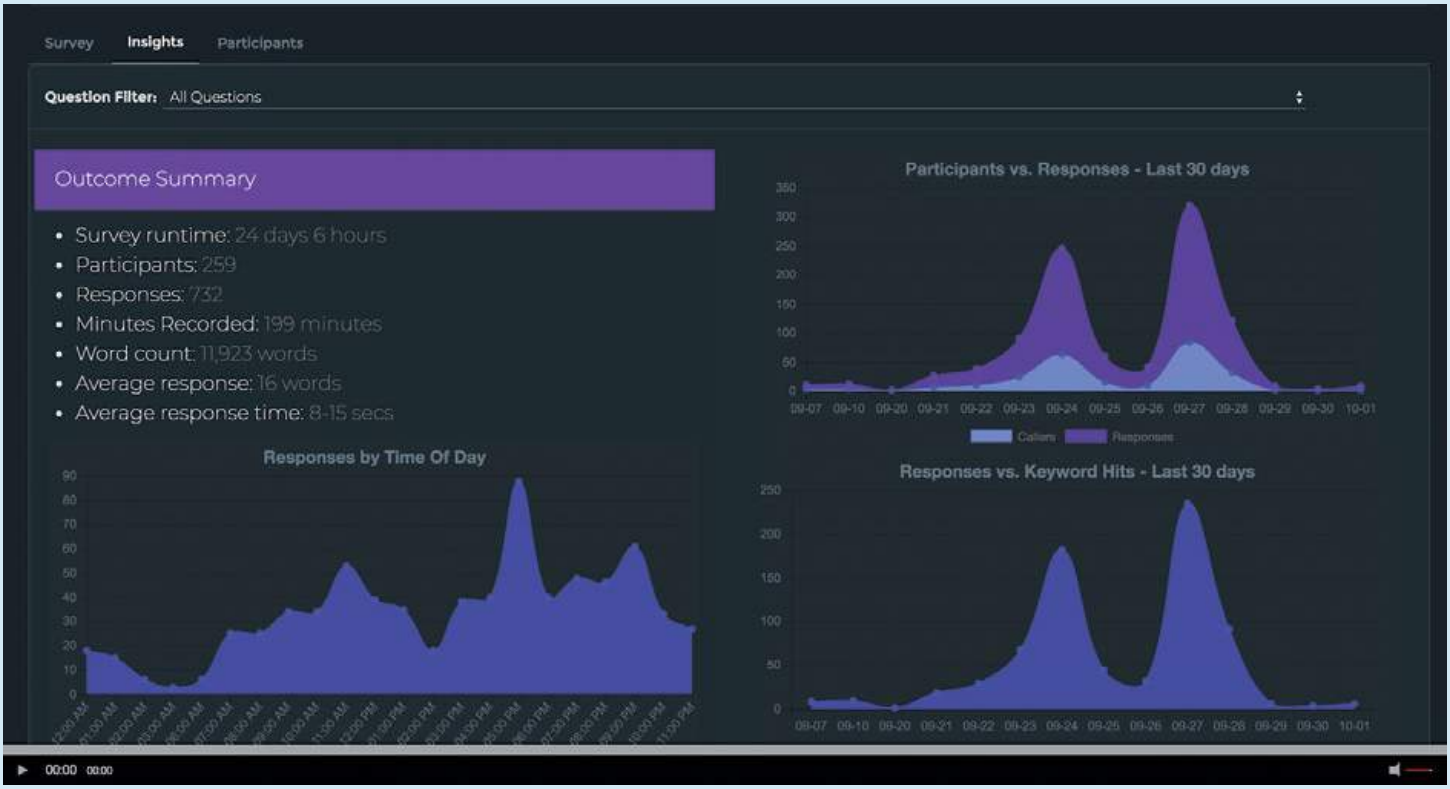
FEEDBACK FROM THE FDA INCLUDED:

"What I was impressed with from the beginning is that this is a very organized community. I'd like to recognize the fact that your board has been so forward-thinking about how they've been approaching positioning this community for drug development and therapeutic development in general. It sounds like you've been very diligent about developing a very good understanding of the natural history of the illness. You have characterized the variability and then done all the hard basic science research of characterizing the genetics that help understand all that variability, so that when it comes time for therapeutics to come into your community, it's going to be very targeted and very easy to do. It's those sort of things that will come out of your analysis of the survey work that you did today that will really make a difference for helping drug developers, or device developers or biologics or gene therapy developers understand what they should be measuring and how to address this population, meet you where you are for what you want in the future. So, at least from the FDA, I appreciate this meeting. I think it was very successful. You should all be very proud of the work you did today."

– Lucas Kempf, MD, PLLC, Acting Associate Director, Rare Disease Program at FDA, Office of New Drugs, CDER, FDA

Thank you FDA and all who participated in this groundbreaking meeting! HNF looks forward to continuing to work closely with you on the accelerated path of therapy development for our patient community.

Stay-tuned for more news in early 2019!
YOUR VOICES WERE HEARD! WATCH THE PFDD MEETING
click: cmt-pfdd.org



HNF Partners with True Reply, the Future of Data Collection: Voice Activated Technology (VAT)

- Accessible and innovative new platform allows for HNF to capture the patient's experience with CMT in their own words
- Respondents call into a toll free number where they are asked a series of questions
- Data is then processed with Artificial Intelligence powered analytics to reveal telling insights
- Pilot study was launched in 2017 at HNF's Patient-Centered CMT/HNPP Pain Summit (funded by PCORI's Eugene Washington Engagement Award #EAIN-7238) where patients were asked to use one word to describe their disease. PAIN was the #1 response
- Internal Review Board (IRB) approved study through HNF's patient registry, GRIN, captured 292 patient testimonies in their own voice and 27 of these testimonies were presented to the FDA during the Externally-led PFDD Meeting

So go ahead and speak up.
YOUR VOICE HAS NEVER BEEN MORE POWERFUL THAN NOW!
click: www.neuropathyreg.org

GLOBAL REGISTRY FOR INHERITED NEUROPATHIES

HNF Launches Online Clinical Study

GRIN Captures Robust Patient Data to Accelerate Therapy Development

HNF launches GRIN with four studies that are important as we continue with our therapy development pipeline and to support our biotech, pharma and other stakeholder collaborations.

RESEARCH STUDY SURVEYS:

Natural History Study (NHS)

Why: By participating, you will be helping HNF and its collaborators to identify important trends, comorbidities (presence of another condition that may occur due to primary disease, CMT/IN) within the CMT/IN patient experience that will provide direction for future research and therapeutic development.

How: The NHS Study is designed to document a CMT/IN patient's experience from diagnosis and throughout their disease. Patients create a profile that captures in-depth information on their disease type, diagnosis, functional challenges, experience with pain, quality of life and other issues associated with CMT/IN.

Respiratory Dysfunction

Why: Respiratory dysfunction has become a recognized and more common symptom of CMT/IN that needs attention. HNF continues to shed light on one of the most devastating symptoms of CMT/IN.

How: With this study, HNF will gather data to inform healthcare providers to better understand, diagnose and develop standard treatment options for patients suffering from respiratory dysfunction. The TRIAD program is targeting a research initiative for this urgent symptom that must be addressed immediately.

Voice Activation Technology (VAT) Research Study

Why: For CMT/IN patients living in pain and dealing with emotional challenges, VAT recognizes more robust and meaningful data to capture the symptom impacts that may be harder to express through traditional survey, especially pain and the impact on behavioral health.

How: With this VAT research survey, HNF has taken the first steps to the development of a modernized instrument for potential use in clinical trials for CMT/IN and other rare and common diseases. By calling into a toll free number provided, this automated system will ask brief questions and allow for opt-in consent.

"By using the patient's own voice we are able to collect added texture and emotion to responses that forms can simply not deliver."

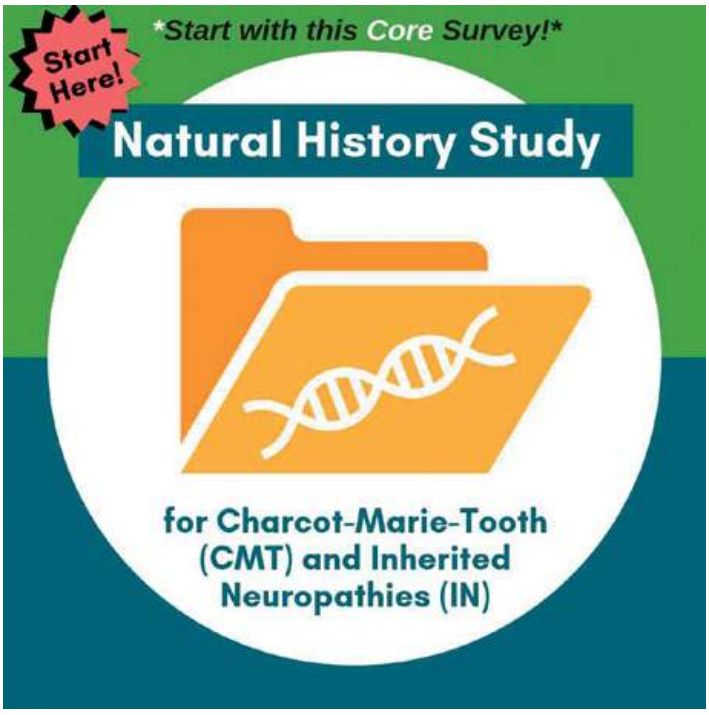
– Allison Moore, CEO/Founder, HNF

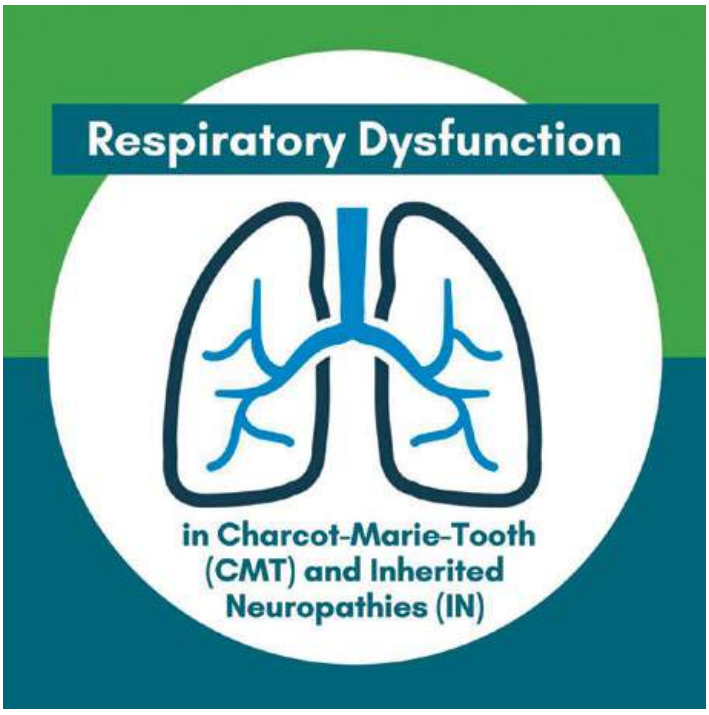
IMPORTANT NOTE:

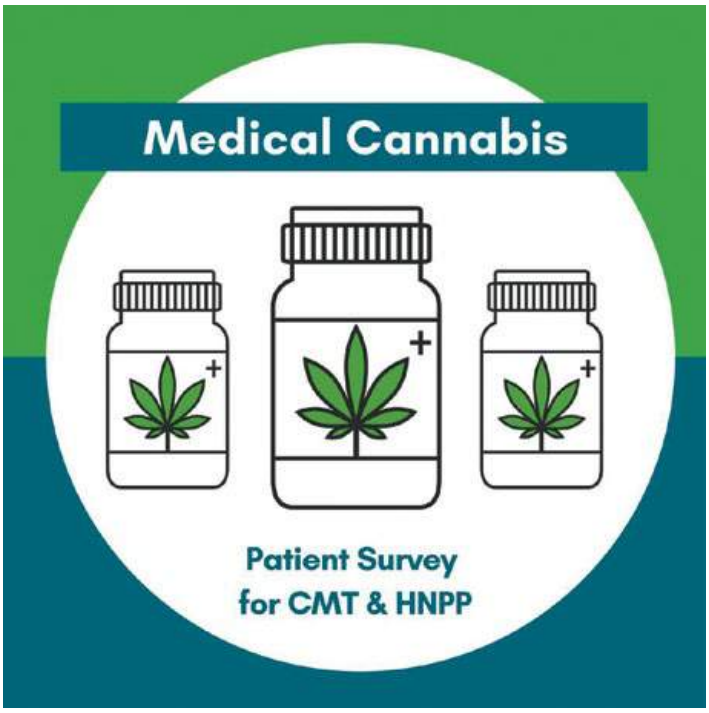
One of the most common treatment errors for people with CMT/IN respiratory dysfunction is oxygen therapy, which John R. Bach MD, Rutgers, Professor of Neurology; Medical Director, Center for Non-Invasive Mechanical Ventilation likens it to "putting a Band-Aid on a cancer." Bach says that oxygen should never be used for people with neuromuscular conditions unless pneumonia has resulted in the need for intubation and intensive care.

Oxygen turns off the brain's drive to breathe and greatly increases the likelihood of ventilatory failure, basically allowing the blood's carbon dioxide to increase to levels that render a person unconscious and cause the person to stop breathing entirely (respiratory arrest).

Learn more: www.hnf-cure.org/breathing-and-cmt/







Medical Cannabis

Why: We understand that medical cannabis is being used to treat CMT/HNPP symptoms within the community and is being adopted into mainstream medicine. Whether or not you use cannabis to help provide relief from your CMT/HNPP symptoms, please participate in this survey to help us better understand if and how it plays a part in your treatment regimen.

How: HNF, in partnership with Champlain Valley Dispensary, is conducting this medical cannabis survey for CMT/HNPP patients to determine if its use is beneficial.

Questions concerning types, amounts, methods of consumption and utilization of cannabis will help inform researchers.

Join GRIN Today!

www.neuropathyreg.org

A completed Study profile may also make you eligible to participate in patient studies and clinical trials that could result in treatments for CMT/IN diseases. Your participation in these groundbreaking studies will help us in our mission to find treatments and a cure!

A LETTER FROM HNF'S CEO/FOUNDER

2018 was a pivotal year for the Hereditary Neuropathy Foundation (HNF) and the entire Charcot-Marie-Tooth (CMT) Community. Our team at HNF has worked tirelessly to ensure that we help to bring the first drug to market ASAP. As we wrap up 2018, we are challenging all of our generous HNF members, new and old friends, and others in the community to please consider supporting our work. We are 100% dedicated to developing and supporting treatments in 2019 and beyond. In fact, we are on the cutting-edge of more human trials within the next 12 months and our pre-clinical research is also looking promising for many types of CMT.

Our proudest accomplishment and most important initiative to accelerating therapies and early access to treatments was the successful execution of the Externally-led Patient-Focused Drug Development (PFDD) Meeting for the FDA for all types of CMT!

We could not have been successful without our donors' support. HNF is transparent, collaborative and results driven. We will continue to work for you, bridge the gaps and partner only with leaders that will deliver more treatments in the near future.

Let's continue the momentum toward our research goals to deliver more results for hundreds and thousands of families living with CMT.

I ask you, from the bottom of my heart, to please make a donation (no amount is too small) as we wrap up 2018.

Allison T. Morse

click to Donate

HNF and Athena Diagnostics Form Strategic Alliance

They will Collaborate on Research and Provide Access to Genetic Testing for CMT

We understand that genetic testing can be a daunting journey, especially for patients concerned over high costs, access to testing and the worry that results may have an impact for future insurance. This exciting new partnership aims to relieve the stigma around genetic testing, provide the patient with empowering information regarding a CMT diagnosis, and outline next steps, including information on how a patient may be eligible to participate in research and clinical trials.

The strategic alliance will focus on five key areas:

- Providing diagnostic insights via quality genetic testing for participants in HNF's patient registry, GRIN
- Facilitating research discoveries
- Developing educational material to assist healthcare providers in identifying patients with CMT
- Generating publications that provide insights into the diagnosis, management, and treatment of CMT, and
- Encouraging patient enrollment in GRIN to facilitate participation in research and clinical trials

"With a significant pipeline of CMT research initiatives, current clinical trials and the near future of potential treatments, it's critical that patients know their genotype in order to participate in research and clinical trials. By collaborating with Athena Diagnostics, we will ensure patients have access to affordable testing along with continued education on the importance of genomic testing."

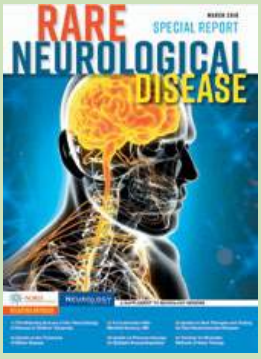
– Allison Moore, Founder and CEO of the Hereditary Neuropathy Foundation

"Our strategic alliance with the Hereditary Neuropathy Foundation marks a milestone for Athena Diagnostics as we continue to provide diagnostic insights for patients living with Charcot-Marie-Tooth disease (CMT). Providing high quality genetic test information is crucial to improving outcomes by identifying appropriate clinical trials and emerging therapies for patients with CMT."

– Shalabh Chandra, Vice President and General Manager, Neurology, Athena

The Hereditary Neuropathy Foundation and Athena Diagnostics are available to help you navigate the complexities of determining what genetic tests to order, decide on the right time for genetic testing, and minimize out-of-pocket costs.

Questions? info@hnf-cure.org



HNF continues to make strides in educating neurologists on CMT – awareness continues to rise for the fourth consecutive year. CMT is front and center in the Rare Neurological Disease Special Report.

- Most read article by respondents (84%) Peripheral Neuropathy: Navigating Diagnosis and Treatment, HNF Center of Excellence Chair Jafar Kafaie, MD, PhD, Assistant Professor of Neuromuscular Diseases at Saint Louis University School of Medicine
- Voice Activation Technology (VAT) continues to engage stakeholders, respondents (46%) read article on Patient-Centered CMT/HNPP Summit Utilizes VAT to capture pain
- CMT makes top 5 rare diseases that respondents want to learn more about

We value our many **TRIAD partnerships** that span the drug discovery, drug development, and diagnostics continuum

The Genesis Project
Connecting Science for Genomic Medicine

PHARNEXT

ACCELERON

InFlectis BioScience

Boston Children's Hospital
Until every child is well™

ProHealth & Fitness

University of North Carolina Vector Core

CDC Workplace Safety and Health
NIOSH

University of Miami

ACADEMIA
GOVERNMENT
TRIAD
THERAPEUTIC RESEARCH IN ACCELERATED DISCOVERY
INDUSTRY

AANEM
American Association of Neuromuscular & Electrodiagnostic Medicine

Inherited Neuropathies Consortium

The University Of Sheffield.

The Jackson Laboratory
Leading the search for tomorrow's cures

Cydan

athena diagnostics

Max Planck Institute

Inspire
together we're better™

ceres

NEUROLOGY REVIEWS

systasy BIOSCIENCE

UFHealth
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TRUE REPLY
& be heard

StarWise

SOUTHERN VERMONT WELLNESS
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ADVOCACY

Child Neurology FOUNDATION
Creating a Community of Support

NORD
National Organization for Rare Disorders

Global Genes®
Allies in Rare Disease

CANNABIS COMMUNITY CARE AND RESEARCH NETWORK®

EXCITING NEWS FOR CMT PATIENT COMMUNITY:

THE FIRST POTENTIAL TREATMENT EVER!

HNF – Pharnext collaborative highlights:

- Collaborative relationship since 2013
- Identified the HNF Center of Excellence clinical sites for the Adult Phase III clinical trial for PXT3003 and HNF was essential in patient recruitment
- Created awareness and expanded knowledge in the medical professional communities on CMT (coordinated important conferences, dissemination of educational materials, and media outreach)

October 16, 2018: Pharnext Announced Positive Topline Results from Pivotal Phase 3 Trial of PXT3003 for CMT1A

- HNF is instrumental in setting up the pediatric clinical trial sites for PXT3003 (launch mid 2019)
- HNF's Externally-led PFDD Meeting for FDA helps inform and raise critical awareness on the impact CMT has on a patient's quality of life.
- HNF supports the CMT&ME App (sponsored by Pharnext), an international observational real-world data study to explore the impact of CMT on patients in the real-world setting

"Thank you to the Hereditary Neuropathy Foundation and their Centers of Excellence for assisting Pharnext with patient recruitment for PXT3003. We are thrilled with the outcome of the trial and with the clearly demonstrated efficacy of PXT3003 in addressing the debilitating disease progression of CMT1A."

– Professor Daniel Cohen, MD, PhD, Pharnext's Co-Founder and Chief Executive Officer.

HNF – ACCELERON PHARMA COLLABORATION HIGHLIGHTS

The Hereditary Neuropathy Foundation and Acceleron Pharma have been collaborating since January, 2016. Acceleron Pharma is a "clinical stage biopharmaceutical company" based in Boston, Massachusetts.

Their lead investigational drug is based on a naturally occurring protein and works to enhance the body's own promoters of muscle growth. ACE-083 can be customized to patients needs by administering the drug into target muscle(s) with the aim of increasing muscle size and strength. The drug was developed for neuromuscular diseases in which patients experience weakness and atrophy in specific muscles, such as CMT patients with foot drop.

- **August, 2016** conducted focus groups in Cambridge, MA at Acceleron Pharma headquarters to help with the clinical trial design of their ACE-083 phase II study
- **February, 2017** launched a collaborative Patient Reported Outcomes (PRO) study* to help Acceleron Pharma gain additional insight into the burden of the disease from the patient perspective
- **July, 2017** Allison Moore presented the "CMT Patient Experience and the Impact of Patient Reported Outcomes Study on Clinical Research and Trials" at the Peripheral Nerve Society Meeting in Barcelona, Spain
- **September, 2018** HNF sheds light on the impact foot drop has on CMT patients' quality of life at the Externally-led PFDD Meeting to inform the FDA on the importance of a drug that may mitigate this debilitating symptom

"People suffering from CMT currently have no drug therapy options to address the major consequences of this serious disease, such as foot drop leading to mobility impairment and frequent falls. We hope that ACE-083 will prove to be an important agent to increase lower leg function, improve the ability to walk, and reduce falls."

— Robert K. Zeldin, M.D., Chief Medical Officer of Acceleron.

For more information on the randomized, double-blind placebo controlled study using the optimal dose level selected from Phase II part 1 for CMT1 and CMTX of this study, can be found on clinicaltrials.gov, identifier NCT03124459.

*This study is being referenced globally by CMT researchers, clinicians, and industry at conferences accepted as poster abstracts, oral presentations and was highlighted at the groundbreaking Externally-led PFDD Meeting.

THE GENESIS PROJECT
Connecting Science for Genomic Medicine

CMT ON THE CLOUD

HNF takes Action and Joins Genomics Revolution for CMT and Rare Forms of IN

Stephan Züchner, Founder of The Genesis Project, a cloud-based database designed for storing and analyzing genomic data, joins HNF's TRIAD Gene Therapy Research Initiative. Also pictured Lori Sames.

"The partnership with HNF is a big step towards our mission of providing advanced genetics to even more CMT patients, ultimately guiding the way to new therapies."

– Dr. Stephen Züchner, MD, PhD
Professor for Human Genetics and Neurology Chair, Dr. John T. Macdonald Foundation Department of Human Genetics Co-Director, John P. Hussman Institute for Human Genomics University of Miami Miller School of Medicine and founder of The Genesis Project

"I love what I do and I'm eager to apply what I've learned to other debilitating forms of inherited neuropathies. The technologies exist to treat many of these horrific disorders, but what's absent is the attention and funding."

– Lori Sames
Co-Founder of Hannah's Hope Fund for Giant Axonal Neuropathy

"Fighter Mom" Lori Sames joins the Genesis Project, too! Lori from her kitchen table lead the development of the first-in-human gene therapy to the spinal cord, with Steven Gray, PhD UT Southwestern, as the principal investigator. Lori was able to translate to human trials in a fraction of time it typically takes industry.

A brighter future with more treatments and cures for all types of CMT.

- The Genesis Project collects, stores and analyzes patient registry, GRIN, CMT genomic data through their ongoing research study. This will empower GRIN to become the data hub of choice for clinical trials in CMT
- Support for patients that have not obtained a definitive diagnosis through genetic testing and for those interested in having personal Whole Genome Sequencing
- Gain more insight into the genes and experience of different symptoms and onsets associated with genomics and functionality
- Identify more secondary genes that may be CMT disease causing and modify the onset and severity of symptoms in families
- GRIN data will be made available to CMT stakeholders
- This is an opportunity for the best scientists globally to participate in solving the genetic diagnostic riddles of CMT and work towards therapies

Donate: http://weblink.donorperfect.com/GeneTherapy

GRIN connects with The Genesis Platform to accelerate a better understanding of patient's genomics to advance gene therapy research and for recruitment in clinical trials.

StarWise Therapeutics & HNF Form A Strategic Alliance to Bring a NextGen HDAC6 Drug Therapy to CMT2A (MFN2) Patients

StarWise Therapeutics:

- Founder Prof. Alan Kozikowski of Starwise has a successful track record of drug development and licensing of his first generation of HDAC to leading pharmaceutical companies
- In a 2011 published study in Nature Medicine, Prof. Kozikowski and one of the leading HDAC6 research experts, Ludo Van Den Bosch, PhD VIB-KU Leuven Center for Brain & Disease Research and others demonstrated that a selective HDAC6 inhibitors can be used to treat CMT*
- NextGen HDAC6 are novel, safe inhibitors for use in the treatment of various neurological disorders, specifically targeting CMT2A

* Nat Med. 2011 Jul 24;17(8):968-74. doi: 10.1038/nm.2396.

- Lead CMT2A researcher, Prof. Brett Langley from Waikato University in NZ has demonstrated that this key drug is able to restore sensory and motor function in the CMT2A mutant animals

Hereditary Neuropathy Foundation:

- Funding the drug optimization to accelerate the path to human clinical trials
- Prof Brett C. Langley and Prof. Dianna E. Willis, Burke Neurological Institute & Brain and Mind Research Institute, Weill Cornell Medicine, both served on the HNF Scientific Advisory Board for more than a decade and have published several papers on the impact of HDAC on mitrochondrial diseases such as CMT2A
- Expertise in clinical trial design, identifying patients for the trial and FDA regulatory filings

HNF has been committed to funding HDAC inhibitor research since 2014. Andrew Grierson, PhD of University of Sheffield study titled: Pre-clinical testing of HDAC6 inhibitors in a zebrafish model of CMT2A, showed promise as a potential treatment. Funding was made possible through the Help Elliot Live Proud (H.E.L.P.) Fund founded by Iris and Nathaniel Adler and Grace's Courage Crusade (GCC) founded by Marybeth and Christopher Calderone.

To support HNF's efforts and to help us get to phase 1 clinical trials, please consider making a donation to our CMT2A funds:

DONATE TODAY!

H.E.L.P. Fund www.hnf-cure.org/h-e-l-p-for-cmt/

GCC Fund www.hnf-cure.org/graces-courage-crusade-cmt2a/

HNF OUT AND ABOUT IN 2018

HNF ON THE ROAD 2018!

PRESENTING AND ATTENDING PRESTIGIOUS CONFERENCES WORLDWIDE

Rare Disease Week on Capitol Hill

February 2018, Washington, DC

- HNF team and 10 CMT patients/caregivers participated in meetings with 12 Congress officials to inform them about Charcot-Marie-Tooth

Learn more here:
http://rareadvocates.org/category/rare-disease-week/

American Academy of Neurology Annual Meeting

April 2018, Los Angeles, CA

- Conducted important meetings with leading CMT stakeholders to enhance HNF's programs
- Identified additional clinical sites to participate in the Pharnext PXT3003 Pediatric Trial to launch early 2019

Rare Patient Advocacy Symposium in Partnership with Penn Medicine Orphan Disease Center and Global Genes

May 2018, Philadelphia, PA

- Allison Moore, a Rare Disease thought leader presented on "Patients as Key Opinion Leaders and Partners In Research and Clinical Development." The presentation highlighted the vital role that patients play in the development of drugs and treatments for the CMT community.

BIO International Convention

June 2018, Boston, MA

- Hosted by the Biotechnology Innovation Organization (BIO). BIO represents more than 1,100 biotechnology companies, academic institutions, state biotechnology centers and related organizations globally
- For the fourth year, HNF was invited to participate in the Patient Advocacy Pavilion to explore new TRIAD partnerships

Peripheral Nerve Society (PNS) Annual Meeting

July 2018, Baltimore, MD

- HNF was an exhibitor and connected with attending CMT physicians, researchers and partners from all over the world
- James Nussbaum, PT, PhD, SCS, EMT, oral poster, "Functional Improvements in Patients with CMT participating in Skilled Physical Therapy: A Retrospective Analysis", in collaboration with HNF and the AlterG, was selected for display

HNF was honored to be chosen to present at two sessions at Global Genes Annual RARE Patient Advocacy Summit

October 2018, Irvine, California.

- **Session – Architecting Your Disease Community** HNF Advocacy Director Joy Aldrich moderated the session with Allison Moore, CEO of HNF and Jill Jarecki, PhD and CSO of Cure SMA, on challenges and benefits of engaging in the effort to help FDA and other stakeholders in understanding the patients' disease experience to accelerate therapy development.
- **Closing Session – Data and Technological Innovation** Allison Moore, CEO of HNF presented along with Scott Schliebner, VP Scientific Affairs, PRA Health Sciences, a leading CRO company, to close the meeting on the importance of utilizing innovative technology (Voice Activated Technology and conducting virtual clinical trials) and how these technologies will improve drug discovery, clinical trials design and the acceleration of patient screening and recruitment.

Peer Support Boot Camp hosted by Child Neurology Foundation (CNF)

October 2018, Irvine, CA.

- HNF continues our collaboration with the CNF and the Family Support & Empowerment Program (FSEP) to bring peer support to the CMT caregiver community. Stay-tuned!

HNF Hosted CMT Symposium at the annual American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) Conference

October 2018, National Harbor, MD

- A 90-minute educational session moderated by Estela Lugo, HNF Medical Outreach Director featured a panel of experts with insight on the importance of Patient Reported Outcomes in new technology, genetic testing, therapy development, patient care, and Healthcare Provider networks.
- Panelists included: Mark Larkin, PhD, Vitaccess Founder, Andrea Paal, MS, CGC, Athena Diagnostics, Florian Thomas, MD, MA, PhD, MS, Chair of the Neuroscience Institute and the Department of Neurology, and Director of the Hereditary Neuropathy Foundation Center of Excellence at Hackensack University Medical Center, Jahannaz Dastgir, DO – Pediatric Neurologist at Atlantic Health, James Nussbaum, PT, PhD, SCS, EMT, founder and director of ProHealth & Fitness.

Watch our AANEM full presentation click here: https://player.vimeo.com/video/296448087

We are proud to announce that HNF's AlterG Anti-gravity Clinical Study Principal Investigator Dr. Nussbaum received a President's Research Initiative Award at the AANEM.

HNF HEARS YOU!

We shed the light on Emotional and Behavioral Health

The HNF 2018 Patient-Centered Behavioral Health Summit was one-of-kind: HNF launched a new curriculum.

Keynote Speaker:
Fast-Forward CoFounder, Lisa McCarthy

- The two-hour workshop opened with an interactive empowerment session called, "Fuel Your Confidence" which was developed specifically for the CMT community by highly-accredited thought leader and co-founder of The Fast Forward Group, Lisa McCarthy in collaboration with the HNF team.
- The energetic discussion dove into the concept of an "inner critic"; the cynical voice we all carry in the back of our minds and the key strategies we can use to replace negative language with empowering self-talk.
- Attendees worked in groups and with partners to deconstruct their own critics, insecurities and self-judgments.
- A live demo was performed by Estela Lugo and Lainie Ishbia to showcase "Clearing Power-Outages" and the importance of creating supportive connections and friendships.
- Other themes explored throughout the morning included, "Writing A New Story" and "Running Your Own Race."

"We often hear so much in regards to the physical aspects of disease and disability, but very little on how it impacts our emotional well-being, which for many can be more devastating. Our goal with this summit was to provide strategic tools for attendees to incorporate into their daily lives for increased fulfillment and wellness across all avenues."

– Estela Lugo, HNF Medical Outreach Manager

"It felt very vulnerable sharing my critical inner thoughts with a stranger, but I'm so glad I did… it really helped me realize the power of identifying the ways in which I limit my own potential growth."

– Bernadette Scarduzio, HNF Social Media Coordinator

Breakout workshops; Assertiveness & CMT, and Nutrition & CMT, topped off the day with interactive discussions and exercises for improving nutrition and social interactions.

- Founder of Trend-Able.com (a lifestyle blog for people with disabilities) and social worker, Lainie Ishbia moderated her Assertiveness workshop with daughter, Zoe along with volunteers from the audience. The four types of communication were explained and role-played during an entertaining set of demonstrations with plenty of laughs and participation. Attendees learned the importance of assertiveness and healthy applications for improved social interactions.
- Alana Kessler, Registered Dietitian and Holistic Health Coach, began her workshop with a guided meditation and explanation of its medical benefits. Attendees were informed on the ways nutrition and lifestyle can affect the nervous system as well as CMT symptoms. A comprehensive list of nerve-healthy foods was presented along with their unique benefits on health. Attendees were then asked to divide into groups of 3-4 people and create a full day's menu using the foods discussed. Each group presented their creative dishes and guilt-free meals in a fun and mouth-watering finale.
- Bernadette Scarduzio presented on the holistic treatment of Cupping Therapy with a live demonstration and interactive discussion.

Orthopedic Surgeon and CMT Expert, Glenn B. Pfeffer, MD

- He led the room with an insightful talk and presentation on "How Surgery Outcomes Affect Behavioral Health."
- Dr Pfeffer identified what makes a patient a strong candidate for corrective surgery with some dramatic before-after cases.

ASSERTIVENESS

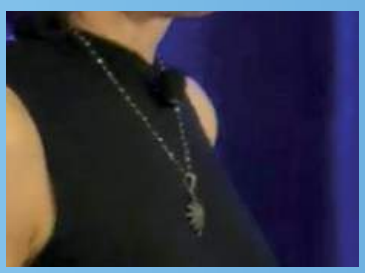
CUPPING THERAPY

NUTRITION

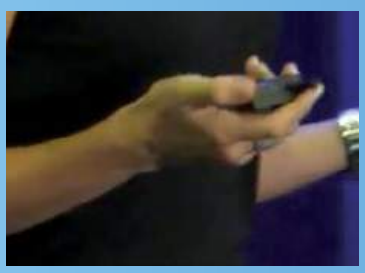
MAKE UP A NEW STORY

ACCEPTING COMPLIMENTS

FUEL YOUR CONFIDENCE



MANAGE YOUR INNER CRITIC



JOURNALING

CLEARING POWER OUTAGES

HEREDITARY NEUROPATHY FOUNDATION

401 Park Avenue South
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New York, NY 10016

2018 ACCOMPLISHMENTS

1 New Patient Registry, GRIN	3 Clinical Trial Recruitment Campaigns	4 Prestigious Speaking Engagements	4 New HNF Center of Excellence
1000+ New Inspire Community Members	4 New Board Members	1 New Chief Science Officer	1 Mini-Documentary "The Warren Family"
1 "Voices of CMT" Video	1 Award-Winning Exercise Study	5 CMT-Connect Workshops	23 New Team CMT Members
9 Fundraising Events	19 New Partnerships	7 Successful Initiatives for September Awareness Month	1 Developed Medical Professional CME Course
	1 Externally-led Patient-Focused Drug Development Meeting (PFDD)	1 Patient-Centered CMT Behavioral Health Summit	

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