HEREDITARY NEUROPATHY FOUNDATION

WINTER 2021

cmtupdate

HNF Celebrates 20 Years!

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Movement is Medicine™ Summit Goes Virtual!

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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.

www.hnf-cure.org

CMT UPDATE
WINTER 2021

Allison T. Moore
Founder and CEO
Hereditary Neuropathy Foundation

Reflecting on HNF's 20 Years:

Dear Friends:

It's hard to believe it's been 20 years since fate determined that I would start a foundation to support our patient community and find a cure for CMT. It certainly has been an experience with trials and tribulations, and I ask myself today, "has it all been worth it?" My inner self screams, without doubt, "YES!" There were times throughout my 20 years that I wanted to walk away. It has taken a toll on my CMT and health at times - the pressure of fundraising, managing a team and multiple projects, and the many, many absent days, weeks and sometimes months when I would not be with my husband and my two sons while I was nestled away at my office on the Upper East Side of Manhattan, and then later, Midtown Manhattan. There were countless days missing ladys' lunches, traveling to conferences and speaking engagements, meetings after meetings with researchers, donors, biotech and pharma companies as HNF grew. There were delays in the Delta lounge or back at the hotel for another night due to bad weather. But that's the investment — **the rewards have been immeasurable**.

This *CMT Update* issue is dedicated to sharing HNF's accomplishments and celebrating how close we are to treatments and cures for various subtypes of CMT.

As they say, it takes a village. So much goes into developing therapies for a rare disease, like CMT.

The HNF team is resilient, innovative, and passionate about betterment of lives for those living with CMT (as most of the team is). We have implemented a well thought out plan and strategy from the very beginning, addressing all the milestones that will enable success. From increasing awareness (a critically acclaimed documentary, a children's book series, a monumental meeting with the FDA), developing research tools (animal and cellular models), research collaborations and industry partnerships (setting up Centers of Excellence, identifying clinical trial sites for drug trials and providing seed funding for a startup biotech company), developing a patient registry (GRIN), and so much more! HNF is patient powered, patient centered and patient driven.

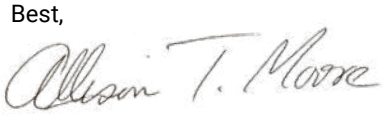
I hope you are as proud as we are and enjoy our four page spread of the successes and recognize the importance of each and every task. Without our members, board of directors, TRIAD counsel, sponsors and many others, we wouldn't be here to celebrate.

Let's continue to fight the fight, and together raise the funds needed to bring many of these treatments over the finish line!

Remember, we fight to cure CMT for YOU and we need help!

Please **DONATE TODAY**!

Best,



Allison T. Moore

HNF CELEBRATES 20 YEARS OF PATIENT-DRIVEN ACCOMPLISHMENTS

On January, 1, 2021 HNF celebrated its 20th year. We are so grateful for our friends, family and the CMT community for supporting us along the way. It all started with Allison's vision to find a treatment for her CMT, and now 20 years later, we have made tremendous strides in advocacy and research. Below is a highlight of the achievements that the HNF team has made through the years to educate, spread awareness and find treatments for CMT.

ADVOCACY

2001 HNF Was Founded

2007 Launched CMT Awareness Month – September

2008 Congressional Proclamations for CMT Awareness Month

2009 Established the Inspire® Online Support & Discussion Community

2010 CMT Continuing Medical Education (CME) Course with AANEM

2010 Established HNF's 1st Center of Excellence

2010 Published "*Arlene*" Children's Book Series

2011 Launched the National CMT Resource Center

2011 Launched "Advocacy On the Hill"

2012 Formed Team CMT

2013 Released & Screened the *Bernadette Documentary*

2015 Developed HealthCare Provider Directory

2015 Launched CMT-Connect

2016 Formed Neurology Reviews Collaboration

2016 Hosted Inaugural Patient-Centered CMT Summit, New York, NY

2017 Developed *Band Together for CMT* Exercise Booklet

2017 Hosted Patient-Centered CMT/HNPP Pain Summit, Cambridge, MA

2017 Launched Pediatric HealthCare Provider Survey

2018 Formed Strategic Alliance with Athena Diagnostics

2018 Hosted Externally-led Patient-focused Drug Development Meeting for FDA

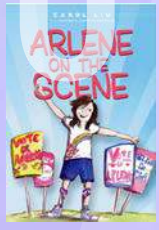
2018 Released Mini Documentary, *The Warren Family*

2018 Released *Voice of the Patient* True Reply Video

2018 Released *Voices of CMT* Video

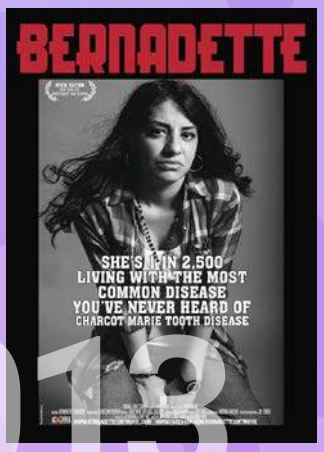
CMT Center of Excellence | HEREDITARY NEUROPATHY FOUNDATION

2010



2011

2012



2013

GLOBAL REGISTRY FOR INHERITED NEUROPATHIES

2018 Partnered with Child Neuropathy Foundation by leading a Collaborative Peer Support Work Group

2018 Screening of *Take a Look at This Heart*

2018 Screening of Mini Film *Date-able*

2019 Hosted Pediatric Neurologists Roundtable Meeting

2019 Hosted Movement is Medicine™ Summit at Ability360, Phoenix, AZ

2019 Presented TedX Talk

2019 Launched the "EmBrace It" Podcast

2019 Developed "ABC's of AFO's" Guide

2020 Launched Teen Survey

2020 Cast CMT Patient in Hallmark Movie

2021 Launched Movement is Medicine™ Ambassador Program

2021 Hosted Virtual Movement is Medicine™ Summit with Advent Health

RESEARCH

2007 Formed Therapeutic Research In Accelerated Discovery (TRIAD)

2008 Developed PRO Study: What It's Like To Live With CMT; Those Who Know It Best

2010 Developed CMT1A Assay

2010 Developed CMT2A Mouse Model

2010 Received $750,000 CDC Grant

2012 Partnership with Pharnext Pharma for the First Potential Treatment for CMT1A

2013 Funded CMT1A Rat Exercise Study

2013 Formed Global Registry for Inherited Neuropathies (GRIN)

2013 Funded CMT1A High Throughput Drug Screens

2013 Awarded TRIAD Video Grant

2014 Funded AFO Mechanics and Gait Patterns Study

2014 Awarded BeHEARD Grants (developed additional CMT1A research tools)

2015 Provided CMT2A Mouse Model to Jackson Labs Repository

2015 Tested HDAC6 in CMT2A & CMT6 ZebraFish

2015 Developed CMT1A Cellular Assay to conduct HTS (proprietary compounds)

2016 PCORI Certification Training & Patient Focused Research

2016 Awarded 1st Eugene Washington PCORI Engagement Award

2016 Developed PRO Study with Acceleron Pharma

2016 Developed CMT6 Vector

2017 Awarded 2nd Eugene Washington PCORI Engagement Award

2017 Funded AlterG Exercise Clinical Study

2017 Awarded by NORD & FDA: Natural History Studies (Ultra-Rare CMTs)

2017 Began Presenting Research Results at Scientific Meetings

2018 Relaunched Patient Registry – GRIN Proprietary Platform

2018 Hosted Externally-Led Patient Focused Drug Development Meeting for FDA

2018 Hosted 3rd Patient-Centered Summit

2018 Collaboration with The Genesis Project at University of Miami

2018 Collaboration with CMT&Me App (Real World Data Studies)

2018 Launched Core Natural History Study for CMT & IN

2018 Launched Medical Cannabis Patient Study for CMT & HNPP

2018 Launched Respiratory Dysfunction Study for CMT & IN

2018 Launched Voice Activated Study for CMT & IN

2019 Hosted the Movement is Medicine™ Summit

2019 Conducted Crowd Design Workshop for Exercise Clinical Trial Design

2019 Developed ASU Digital Assessment of Balance & Gait Clinical Study

2019 Hosted a Critical Path Innovation Meeting with FDA – Voice Activation Technology

2019 Tested HDAC6 in CMT2A mouse model

2019 Genetic & Functional Characterization of CNTNAP1 Mouse

2019 Funded the Evaluation of Changes on Gait in Children & Youth with CMT

2020 Published Paper on HDAC6 for CMT2A in Experimental Neurology

2020 Developed IP from Research Study at Fashion Institute of Technology

2020 Funded CaptureProof Virtual Natural History Studies & Foot Calculator

2020 Funded iPSCs for CMT6/Leigh's Syndrome & CMT4A

2020 Developed CMT4A & SORD Rat

2020 Formed HDAC6 Biotech Partnership for CMT

2021 Characterization of CMT4A & SORD Rat

2021 Developed Retrospective Natural History Studies (CMT4A, CMT6/Leigh's Syndrome, and CNTNAP1)

2021 Potential "Role of Cannabinoids for Managing Pain in Patients with Hereditary Neuropathies" Scientific Meeting

2021 Co-Funded GRIN Natural History Study Assessment of CMT Patients to Support Virtual Clinical Studies with Penn Medicine Orphan Disease Center

2019

Movement is Medicine™ **Summit Goes Virtual!**

Update:
Due to Covid-19, the Hereditary Neuropathy Foundation had to postpone our in-person Movement is Medicine™ Orlando Summit last March. We have decided to take our program virtual and we are thankful for AdventHealth and their support!

The Hereditary Neuropathy Foundation (HNF) is thrilled to announce the expansion of our Movement is Medicine™ program with a new 1-day Virtual Summit in partnership with AdventHealth on Sunday, March 7th from 9am-2:30pm ET. Charcot-Marie-Tooth (CMT) neurologist & expert, Dr. Nivedita Jerath and her AdventHealth team at the new, HNF Center of Excellence will offer patient focused workshops and exercise classes.

> **The Neuromuscular Medicine Program at the AdventHealth Neuroscience Institute is overjoyed to partner with the Hereditary Neuropathy Foundation as a Center of Excellence. The HNF has established itself as an organization in which individuals with hereditary neuropathies-also known as CMT-come first. Our division echoes this goal of patients coming first. We are excited to host the *Movement is Medicine*™ program here in Orlando; this program will demonstrate not only how much exercise is necessary in hereditary neuropathies, but also how much fun exercise can be by forming new friendships and creating positive energy that can be healing in every way."**
>
> **– Nivedita Jerath MD, MS**
> Medical Director of Neuromuscular Medicine, AdventHealth Neuroscience Institute

THE DAY'S EVENTS WILL INCLUDE CMT-FRIENDLY SESSIONS:

The Brain-Changing Benefits of Exercise & Mindful Meditation

This session will start with a discussion regarding cardiovascular benefits for the body and mind. Attendees will participate in cardiovascular exercise followed by breathing and meditation exercises for well being.

Therapy across the lifespan of the disease

This lecture will discuss when is the best time to begin therapy and check in with your therapist across the lifespan of the disease. Attendees will hear from a Physical Therapist, Occupational Therapist and a Speech Language Pathologist about what to expect in therapy and will leave with some takeaway exercises for each stage of the disease.

Strength Training

This 30-minute class utilizes resistance bands and weights for functional strength training moves to inform participants about the importance of strength training for CMT. Class will be modified to support all participants.

Core & Balance

This 30-minute class will be a mix of core strengthening exercises with yoga style balance poses. Class will be modified to support all participants. Core strength is an important piece to maintain balance.

Nutritional Workshop

Many neurological diseases have been shown to have a major impact on an individual's nutrition status. Because of this, these individuals are at an increased risk for malnutrition, micronutrient deficiencies and dehydration. Join Sherri Flynt, MPH, RD, LD, as she talks about the concerns with malnutrition and dehydration and which micronutrients are of special concern. She will also provide practical tips for ensuring proper nutrition and how to incorporate these tips into everyday life.

REGISTRATION IS FREE!
And since it's virtual, it'll be easy to join from anywhere! Children of all ages are welcome. Hope you can join us!
Click Here!

*Be on the lookout for Future Movement is Medicine™ events in your city!

TRIAD
THERAPEUTIC RESEARCH IN ACCELERATED DISCOVERY

Natural History Study Assessment of CMT patients to Support Virtual Clinical Studies

HNF is excited to announce that the Orphan Disease Center awards Florian P. Thomas, MD, MA, PhD, MSc, Director, Hereditary Neuropathy Center, Hackensack University Medical Center, Founding Chair & Professor, Department of Neurology, Hackensack Meridian School of Medicine and his team at Hackensack Meridian Health the Million Dollar Bike Ride (MDBR) 2020 CMT grant. This is HNFs second year participating in the annual MDBR to advance research for Rare Diseases. The 2020 event was virtual and HNF exceeded its goal of $25,000 and raised $27,545 which was matched by the ODC, with the total award in the amount of $55,090.

The grant title:
Global Registry for Inherited Neuropathies (GRIN) - Natural History Study Data Assessment of Charcot-Marie-Tooth (CMT) Patients to Support Virtual Clinical Studies

The goal of the project is to evaluate years of collected patient reported data and to correlate the findings to specific cohorts to include genotype, phenotype and clinical features. The findings will support the foundation's enhanced virtual natural history studies and validate outcome measures, identify potential biomarkers and support therapeutic research and trials.

SPECIFICALLY, THE AIMS ARE TO:

1. Evaluate GRIN data to uncover previously unknown genotype/ phenotype correlations among patients.
2. Determine if there are additional early signs of CMT in patients that should be targets for further research and therapeutic development.
3. Improve diagnostic accuracy and timing (i.e. catch it when they are young and interventions can be more impactful).
4. Disseminate findings through peer review publications.

COMING THIS SUMMER:

Virtual Million Dollar Bike Ride 2021

This will be the 3rd year HNF will partner with the Penn Medicine Orphan Disease Center for the Million Dollar Bike Ride .

On **June 12, 2021**, participants can participate virtually by riding on their own and logging 12, 42 or 72 miles. Pick a route, recruit some friends and have fun!

Register today: Click here!
Questions? courtney@hnf-cure.org

TRPV4 Hereditary Neuropathy Patients **Connect with Johns Hopkins Experts to Push Research Efforts Forward**

BY STEPHANIE CARMODY, TRPV4 RELATED HEREDITARY NEUROPATHY (CHARCOT MARIE TOOTH TYPE 2C) PATIENT

When you are diagnosed with an ultra-rare type of hereditary neuropathy, it is invaluable to be able to connect with others who share your diagnosis and join together to raise awareness and advocate for research into treatments and standard of care guidelines to optimize health. When I finally received my true diagnosis of CMT2C (one of the TRPV4 related hereditary neuropathies) six years ago after searching my entire life, I was thrilled to be able to come together with others who share my diagnosis through a Facebook group I developed that has turned into an amazing community of individuals affected by TRPV4 HN from around the world. The group has grown greatly over the past five years, and has become a wonderfully supportive and active community dedicated to sharing experiences and helping each other navigate our challenging disorder. Several of us were even able to meet in person in 2018 and testify about the burden of this disease at the HNF-hosted Externally-led Patient Focused Drug Development meeting for the FDA in Silver Springs, MD.

I soon realized that we represented a powerful advocacy force, and started to explore ways to connect with leading research experts looking to understand our disorder and find treatments. I was fortunate to be able to connect with the TRPV4 HN team at Johns Hopkins, which led to the incredible opportunity to host a virtual meeting between our Facebook group members and leading experts Dr. Brett McCray and Dr. Charlotte Sumner on December 4th, 2020. The purpose of this meeting was for both parties to learn from each other; the meeting included a research update and detailed Q&A session.

The importance of patient advocacy and involvement in the research process cannot be overstated. Patients play a critical role with researchers to advance understanding of hereditary neuropathies and bring about human trials. The team at Johns Hopkins has made incredible research advancements and is now launching a TRPV4 Hereditary Neuropathy registry that will serve as a natural history study in preparation for future clinical trials. In their breakthrough study published in May 2020, the Johns Hopkins team further identified the underlying mechanisms of our disorder and tested a potential TRPV4 antagonist in fruit flies and cultured primary mouse neurons. The ultimate goal is to investigate whether a TRPV4 antagonist may be a viable treatment option for TRPV4 HN patients, which will require engagement, participation, and advocacy within the TRPV4 HN patient community.

If you have been diagnosed with TRPV4 related hereditary neuropathy (Charcot Marie Tooth type 2C, Scapuloperoneal Spinal Muscular Atrophy, or Congenital Distal Spinal Muscular Atrophy), please email Dr. Brett McCray at bmccray3@jhmi.edu to participate in the Johns Hopkins TRPV4 Hereditary Neuropathy Registry. If you would like to join the TRPV4 HN community on Facebook, please search for TRPV4 Related Hereditary Neuropathies (CMT2C, SPSMA & CDSMA) and request to join, or email Stephanie at trpv4hngroup@gmail.com. You can read Dr. McCray and Dr. Sumner's May 2020 research publication at https://bit.ly/3tUr0nW

Thank you Stephanie for your dedication to the CMT community. Your representation at HNF's Externally-led Patient Focused Drug Development Meeting on September 28, 2018 was amazing!

CLICK HERE to watch Stephanie's testimony to the FDA.

If you haven't already created a profile and completed the natural history study in HNF's patient registry, GRIN, **please do so TODAY**! www.neuropathyreg.org

TRIAD
THERAPEUTIC RESEARCH IN ACCELERATED DISCOVERY

SORD:
A Lesson in Repurposing Drugs to Treat Hereditary Neuropathy

GUEST AUTHOR: **DAN KNAUSS**

SORD is a gene that has received a lot of attention lately. International research on SORD has increased greatly since the discovery in 2020 that its mutation causes the most common autosomal recessive form of CMT2 and the overlapping category of distal hereditary motor neuropathy (dHMN). CMT2 and dHMN are under-diagnosed rare disease categories, and up to nearly 10% of the cases that fall within them may be SORD-related.

The onset of symptoms occurs around age 17 on average, but symptoms may present themselves in the first years of life or as late as one's forties. The symptoms common to all cases are muscle weakness and wasting in the arms and/or legs. Leg muscles are affected in 98% of known cases.

Stephan Züchner, MD, PhD, is the Chairman of the genetics department at University of Miami's Miller School of Medicine and leads the CMT genetics effort for the Inherited Neuropathy Consortium. His group led an international team to the discovery of the role of the SORD gene in CMT. Dr. Züchner predicts that "SORD neuropathy will represent one of the few examples of a treatable hereditary neuropathy" because the mechanism of its harm is likely manageable with existing medication for diabetes.

SORD and the Harm Done by Sorbitol

SORD stands for sorbitol dehydrogenase (SDH), which is the protein the gene encodes. SDH's role is to convert sorbitol into fructose. Sorbitol is a carbohydrate and the sugar alcohol form of glucose; it is found in fruit and is used as an artificial sweetener in processed foods.

Since sorbitol is unable to cross cell membranes, it can accumulate quickly if there is no SDH available to break it down. Normally, blood sugar (glucose) is converted to sorbitol by an enzyme called aldose reductase and further converted to fructose by SDH, but this last step may not happen quickly enough to cope with the overproduction of sorbitol in uncontrolled diabetes. Sorbitol accumulation in the eyes, kidneys, liver, and nerves can do significant damage in those locations.

Thankfully, organ damage is not the typical result of SORD deficiency, but it does create sorbitol concentrations high enough to destroy the axons in nerves. Dr. Zuchner says a diabetic person may have twice the normal level of sorbitol in their system, but someone with a SORD deficiency will have 10-100 times the normal levels of sorbitol.

Excess sorbitol causes the tissue it is in to absorb water from osmotic pressure to the point that cells are severally stressed or destroyed. Taking in too much sorbitol in food, for example, can cause diarrhea in many healthy people, but a diabetic person who is hyperglycemic faces much greater risks as sorbitol builds up in the eyes or kidneys. For someone with SORD neuropathy, the damage is done mainly to the axons in motor nerves.

Inhibiting Sorbitol Production to Prevent Nerve Damage

The Miami team has also created and studied SORD deficient fruit flies (Cortese et al., 2020). These flies showed CMT-like symptoms that were reversed by drugs known as aldose reductase inhibitors (ARI). These drugs are currently not

available in North America or Europe. However, clinical trials are soon planned with a new type of ARI developed by Applied Therapeutics.

Aldose reductase inhibitors reduce sorbitol levels by inhibiting aldose reductase, the enzyme that creates sorbitol from glucose. If your body can't break down sorbitol, aldose reductase inhibitors will help reduce the amount of sorbitol being produced in your body from glucose. That is why aldose reductase inhibitors are anticipated to be a viable treatment for people experiencing neuromuscular damage due to a SORD mutation.

Diagnosing SORD Deficiency and Future Treatments

Dr. Zuchner and his colleagues are enrolling CMT patients for fast SORD screening into a research study, which will also reveal the full phenotypic (symptoms) spectrum of SORD neuropathy. Thus far nearly 100 patients have been identified with these efforts. Participants might qualify for upcoming clinical trials. Patients with a CMT2 diagnosis, negative genetic tests in the past, and where both parents did NOT show signs of CMT do qualify and should **contact Allison Moore** at allison@hnf-cure.org.

Finally, Dr. Züchner is currently working on a rat model with support from the Hereditary Neuropathy Foundation to confirm the impact of SORD mutations on sorbitol levels along with treatments to suppress sorbitol production. With all these projects in motion, it's likely we'll soon see the first significant therapeutic treatment able to prevent a type of hereditary neuropathy from progressing.

HNF has put together a full overview of the latest CMT research, including our own self-funded projects & partnerships.

To View: Click Here!

TRIAD
THERAPEUTIC RESEARCH IN ACCELERATED DISCOVERY

PREMIER

CMT1A Clinical Trial Update:
Pharnext PREMIER trial of PXT3003

The **PREMIER Trial**, which is being conducted in patients with mild-to-moderate CMT1A, is expected to enroll approximately 350 subjects ages 16-65 with a confirmed genetic diagnosis of CMT1A. This International multi-centered pivotal Phase III study will enroll patients at 50 sites worldwide (**20 in the US and 5 in Canada**) and is set to begin by the end of March 2021.

The **PREMIER Trial** is a randomized, double-blind, two-arm placebo controlled study designed to confirm PXT3003 safety and efficacy in patients with CMT1A. Patients enrolled will be treated for 15 months.

As agreed with regulatory agencies, the primary efficacy endpoint is the Overall Neuropathy Limitation Score (ONLS) scale, which measures functional disability. The secondary endpoints will include the following outcome measures:

1. 10-Meter Walk Test (10mWT),
2. Quantified Muscular Testing (bilateral foot dorsiflexion dynamometry),
3. Patient Global Impression of Severity (PGI-S),
4. Patient Global Impression of Change (PGI-C),
5. Charcot-Marie-Tooth Neuropathy Score, version 2 (CMTNS-v2), and
6. Quantified Muscular Testing (hand grip). Safety and tolerability will be monitored throughout the study.

For those interested in participation, the US sites will be listed and updated regularly at the clinicaltrials.gov website as they are activated and ready to screen and enroll patients. US sites, but also sites in Canada, Europe and Israel, will also be available and listed on a web portal dedicated to patients. This resource will also include interesting information about the trial. It will be live by the end of March 2021.

****Pharnext is also continuing to conduct its ongoing Phase III Extension Study, CLN-PXT3003-03, an open label study that has enrolled 187 patients out of the 323 with mild-to-moderate CMT1A patients that were enrolled in the first double-blind Phase III Trial (PLEO-CMT). As of today, 130 CMT1A patients are still being treated with high-dose PXT3003 and have been followed for more than 2 years in order to assess not only the safety and tolerability of PXT3003, but also its long-term efficacy. Pharnext will be reporting top-line interim data on the safety and efficacy of PXT3003 from this extension study during Q2 2021.*

More information about the **PREMIER Trial** can be found at: Click here!

You can also join HNFs patient-registry, GRIN for clinical trials updates. www.neuropathyreg.org

HNF Officially Launches Retrospective Natural History Studies for Rare Types of CMT: CMT4A (GDAP1), CMT6 (C12orf65) and CNTNAP1

HNF has received Internal Review Board (IRB) approval for the patient registry, Global Registry for Inherited Neuropathies (GRIN), to conduct Retrospective Natural History Studies for Rare Subtypes of CMT. HNF will collaborate with Dr. Mario Saporta at University of Miami for CMT4A and CMT6, and Dr. Jahannaz Dastgir at Goryeb Children's Hospital for CNTNAP1. Other CMT experts will be included to support patients from all over the world.

These studies will include a patient-reported natural history survey and an opportunity for patients and families to participate by providing their electronic health records for extensive review and analysis. It is imperative for therapy development to conduct natural history studies for regulatory agencies such as the FDA, EMA and other countries' agencies to understand specific CMT subtype symptoms, characteristics and the course of disease progression. This enables stakeholders to design clinical trial protocols for approval by the agencies, to conduct the actual clinical trials, and ultimately follow the path to commercialization.

By providing health records from the day of diagnosis to present, including surgeries, lab tests, injuries, etc. in pdf format uploaded into our HIPAA-compliant platform, you will enable our team to better understand how your subtype affects you and your family.

We are in this together and we're on our way!

TO JOIN GRIN: www.neuropathyreg.org

HNF Launches **NEW Virtual CMT Fitness Platform with Ambassador Instructors**

The Hereditary Neuropathy Foundation believes that activity plays an essential role in physical and mental well being, especially for people affected by debilitating diseases like Charcot-Marie-Tooth. The Movement is Medicine™ mission is to promote the safe adoption of an active lifestyle through exercise and nutrition programs specifically created for those with disabilities.

Movement is Medicine™ has assembled a stellar team of Fitness Ambassadors who have expertise in Yoga, Pilates, strength and resistance training and more! Each Fitness Ambassador will offer at least one live class per month. Classes are free of charge!

MEET THE FITNESS AMBASSADORS

Marc Daigle

My name is Marc Daigle and I'm a trainer, coach, and motivator. I was born and raised in St. Charles, Missouri and currently live in New York City. I was diagnosed with CMT in 2017, but still don't know the specific type.

I believe fitness should be fun and for everyone. I've trained young children, active older adults and friends with CMT, and have worked with athletes at the highest level. No matter who you are, movement is key and I want to help you move better and achieve your goals.

Movement is Medicine™ is something I practice everyday. Since being diagnosed I have completed an Ironman (2.4 mile swim, 112 mile bike, 26.2 mile run). Anything is possible if you keep a positive attitude, stay consistent, and surround yourself with good people. I'm here to help!

Christine Panico

I've been practicing yoga for over 15 years and it is part of my daily routine. When my youngest went to college in September of 2019, I decided to further my practice by enrolling in a 200 hour Teacher Training program at Mandala Healing and Arts Center in Amagansett, NY. I really love to teach restorative yoga, which offers pose modifications as well as the use of props. This type of yoga is accommodating to those who would like to further their practice regardless of their limitations, whether it be due to an injury or physical limitation.

I have been friends with Allison Moore, Founder of HNF, for over 28 years, and have been a supporter of HNF since its inception in 2001. I am thrilled to be able to provide instruction to the HNF & CMT community via their Movement is Medicine™ initiative!

Julie Stone

CMTer (type 2A), adaptive fitness coach, and owner of All Bodies Community. I strive to provide fitness for all mobility types. In my classes, I want you to learn to listen to your body and do what is best for it. I believe growth should be measured on a personal level, not compared to others – I want you to strive to be the best version of you!

I was thrilled to be a part of the first Movement is Medicine™ Summit in 2019. I am excited to have the opportunity to use my CMT-centric exercise technique with the HNF community!

Learn More: Click here!

"We believe, now more than ever, that adaptive fitness should be fun, interactive and virtually accessible to all regardless of where they live."

– Robert Moore, MiM™ Coordinator

The Hereditary Neuropathy Foundation is excited to announce the Movement is Medicine™ Fitness Ambassador program!

Introduced at the first Movement is Medicine™ Summit in November, 2019, HNF's Movement is Medicine™ initiative was created to promote and support safe exercise, healthy nutrition and overall wellness within our CMT community.

We are excited to announce the launch of the Movement is Medicine™ Fitness Ambassador program, which will provide members weekly live classes that help increase your strength, balance and overall fitness level. All the classes are adaptive and can be enjoyed regardless of your fitness or skill level!

Getting started is easy, just follow these three steps:

1. Join **Movement is Medicine**™ — membership is FREE! **CLICK HERE!**
2. After you join, just scroll down the page and **meet your ambassadors**.
3. Scroll down further and use our calendar to **sign up for a class**!

It's that easy!

Here's to being healthy and safe in 2021 – See you in class!

Participate today!

HNF Teams up with AdventHealth for Movement is Medicine™ Video Series

Allyson Spivey, PT, DPT
Board Certified Clinical Specialist in Neurologic Physical Therapy

HNF is proud to expand our Movement is Medicine™ virtual platform with partner AdventHealth for a new collaborative video series. Classes will highlight adaptive exercises that address common CMT-related impairments.

Exercise has been shown to improve quality of life and function for individuals with CMT Disease when appropriately prescribed. Physical therapists focus on strengthening muscles not heavily affected by CMT, balance and fall prevention, flexibility, and aerobic conditioning. Research has shown that initiating an exercise program early in the disease process may slow the progression and help to maintain function. In addition, mixed programs addressing multiple impairments are superior to focusing on one single mode of exercise.

Remember, exercise should be fun and something you enjoy doing! For an individualized program, please consult your local physical therapist with experience treating neuromuscular conditions.

To view our class calendar and growing video library, Click here!

Learn more about the *Neuromuscular Medicine Program at the AdventHealth Neuroscience Institute*: Click here!

New Feature In The CMT&Me App
Falls Tracker

Did You Know?

First results from the Falls Efficacy Scale — International Survey (which measures individuals' level of concern about falling) in the CMT&Me study show that CMT patients have high levels of concern about falling during social and physical activities inside and outside the home (median score 38, where a score of 28-64 indicates high levels of concern).

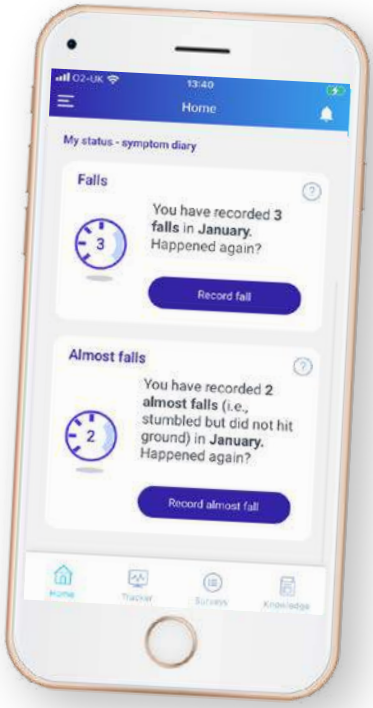
Is that true for you?

Let us know either way by completing the **'Falls Efficacy Scale – International'** survey within the Surveys section of the CMT&Me app!

The CMT&Me app study was designed and co-created with patient advocacy groups and patients around the world.

The new Falls Trackers were developed because participants asked for a tool to record the times they fall or almost fall (i.e., stumble but do not hit the ground). With approval from the Scientific Advisory Board (SAB), the CMT&Me team and Pharnext set to work and are delighted to announce that the Falls Trackers are now available on the CMT&Me app homepage.

Each time you press the Falls Counter or the Almost Falls Counter, the fall or almost fall will be time stamped and will then appear in the Symptoms Diary (Tracker > Symptoms diary). Falls and almost falls will be recorded during the month and the counter will reset to zero at the beginning of each month. You will be able to download your number of falls and almost falls per month in your symptoms diary in PDF format so you can share it with your healthcare professional or save it for your records.



Click here to sign up for the CMT&Me app today!

	Almost falls per day (month)	Falls per day (month)	Legs weakness	Ankles weakness	Hand weakness	Arms weakness	Breathing	Tiredness	Feet feeling	Lower legs feeling	Hands feeling	Forearms feeling	Fine control of hands	Pain	Sore skin on feet	Emotional problems
7/11 Sat	1 (Nov.: 4)	1 (Nov.: 4)	-	-	-	-	-	-	-	-	-	-	-	-	-	-
8/11 Sun	2 (Nov.: 4)	2 (Nov.: 4)	-	-	-	-	-	-	-	-	-	-	-	-	-	-
9/11 Mon	1 (Nov.: 4)	1 (Nov.: 4)	-	Very severe	Mild	-	-	-	-	None exp.	Severe	Moderate	None exp.	-	-	-

Pain Series: Part 2 Nutrition

"There is a belief that our food and lifestyle choices have little or no effect on CMT due to the fact that it is genetically based. In fact, I have noticed that food and lifestyle as therapy is rarely given much more than lip service in this community. Unfortunately, this mindset is a disempowering one that gives all our power to the "experts" in white coats and leaves us feeling like victims sitting around, waiting for a scientific miracle. I hope this comes and I believe it probably will. But in the meantime, the question is, what can we do now?

Hippocrates famously said, "Let food be thy medicine and let medicine by thy food". This is as true today as it ever was. Our food and lifestyle choices can have a huge impact on our overall sense of well-being, physical, mental, and emotional, no matter where we are in the disease state. Through my own experience, as well as seeing how others with CMT and other challenging conditions have used nutrition therapy and behavioral changes to blunt the impact of their disease, I would like to share not only the basics of eating for our condition, but also some ways we can use well-researched behavior change techniques to make the changes necessary to have a powerful impact on our overall health and well-being."

– Paul Fowler, FMCHC

WATCH THE WEBINAR HERE!

We are happy to announce that Paul has joined HNF's Movement is Medicine™ Ambassador Program and will offer monthly classes. **Click to sign up for classes.**

About Paul Fowler

From his middle school teaching days in the 90's to his yearly trips to Thailand to study Thai massage, traditional self-care and meditation to his training at the Functional Medicine Coaching Academy, Paul has been working with people to help them improve their health and well-being for most of his life.

In 2017, when Paul was diagnosed with CMT, he spent a year completely transforming his diet and lifestyle. In that year, much of the nerve pain in his hands and feet receded and though he still has some numbness in his feet, many of the most challenging aspects of the condition have gone away.

After this success, he saw that it was possible to make an impact on CMT through diet and exercise and he wanted to help others who also faced scary and debilitating health challenges, especially people with CMT. That was when he dove into the year-long Functional Medicine Coaching Program. It was the best decision he ever made. He loves working with people using the "coach approach", where they lead and he supports. He has found it endlessly gratifying to see people realize their own power to overcome things that they never before thought possible.

Meet Corinne Weinstein
New Pharmacist Contributor

Clinical Oncology Pharmacist at Cancer Centers of Colorado-Good Samaritan, Denver, Colorado

Q: TELL US ABOUT YOURSELF:

I was born and raised in Colorado where I attended Regis University. I completed my undergraduate course work there and also received my Pharm.D. I currently work as an oncology pharmacist at an infusion center in Lafayette, Colorado. Outside of work, I love spending time with my sisters/family, my husband, my 2-year-old son and my two dogs. I recently invested in a Peloton, which has helped keep me active.

Q: WHEN WERE YOU DIAGNOSED WITH CMT? WHAT TYPE DO YOU HAVE?

I wasn't officially diagnosed until ~June 2020, where I had a rapid progression in symptoms, causing difficulty walking. Prior to this I was running/hiking/playing volleyball etc. so it was especially challenging.

However, other signs/symptoms of CMT have been present since I was a kid (high arches, hammertoes, overall "clumsiness" along with a couple cases of osteomyelitis due to lack of sensation in my feet). In fact, I saw a neurologist when I was about 11 or 12 who suspected I had a form of CMT that had yet to be discovered (all the genetic testing for CMT was negative). I have since repeated the genetic testing in lieu of the numerous new genes that can cause CMT, but it was also negative. So my official diagnosis is an "unknown type of CMT2."

Q: DO OTHER MEMBERS OF YOUR FAMILY HAVE CMT?

Nope! (Lucky me).

Q: WHAT ARE THE CHALLENGES YOU FACE WITH CMT?

Walking and balancing have become increasingly difficult, especially with the new progression in symptoms. I now wear AFOs, which provide some degree of support, but I still struggle with pain and fatigue if I am forced to stand or walk for long periods. "Running" after a 2 year old, and being limited in the activities I can do with him, has also been extremely challenging (both mentally and physically), as anyone with a toddler could attest to! I've just started having more weakness and lack of sensation in my hands, which has posed its own set of challenges with multiple activities (writing, cooking, changing diapers etc.)

I have also struggled with anxiety and depression. Being the only person in my family with CMT there can be a sense of isolation that goes along with the physical struggles of CMT. Since my diagnosis, I now regularly see a therapist and take medication which has been instrumental in helping me face these challenges. I encourage anyone struggling with their mental health to do the same.

Q: HOW HAS CMT CHANGED YOUR LIFE?

It's limited my ability to do many of the things I used to get enjoyment out of. Running, playing volleyball, going on long walks with my son- but it's also forced me to be appreciative of what I still have. It forces you to look for the good, encourages you to be grateful for things that so many people take for granted.

It's easy to focus on all the things I can't do anymore, but I'm actively trying to focus more on what I can do. It's taught me to be present, to be more empathetic. It's shown me how lucky I am to have such a supportive circle of friends and family. It makes all the difference.

Q: HOW DO YOU INCORPORATE CMT INTO YOUR PROFESSION?

As an oncology pharmacist I am in a unique position to help educate my colleagues not only about CMT but about the detrimental effects neurotoxic chemo can have in a CMT patient. I am actively trying to help educate providers and incorporate a process, which screens for CMT prior to the initiation of chemotherapy.

Corinne Weinstein
Clinical Oncology
Pharmacist

Thank you to Corinne for contributing quarterly to HNF's CMT Update.

CAUTION

Question: Other than weighing the risk/benefit, and changing diet/exercise, is there a treatment for high cholesterol that is not neurotoxic?

Answer: There was a study from 2002 showing that statins had an increased risk of neuropathy, but studies since have been inconclusive. Other medications are available for high cholesterol that have little to no risk (I listed them below). It is important to note, however, that statins are by far the most effective at reducing cholesterol. They have great data in reducing the risk of heart attack, stroke and even death- so you should absolutely discuss this with your doctor.

That being said, there are a few options. You could try reducing the dose of the statin and adding on an additional agent (such as ezetimibe). You could try a different statin (atorvastatin and fluvastatin were **more** likely to cause neuropathy). You could also try adding niacin to the statin. There was a study from September 2020 showing that niacin combined with statins could potentially lower the risk of neuropathy (although more studies are needed).

Otherwise other agents are available which include:

1. Cholesterol Absorption Inhibitors: Ezetimibe (Zetia)
2. PCSK9 inhibitors: Alirocumab (Praluent), Evolocumab (Repatha)....These are often reserved for patients with genetic conditions causing high LDL. They are also injectables and can be very costly. Additionally, there have been a few post marketing case reports of neuropathy with these agents, but more data is needed.
3. Bile Acid Sequestrants: Cholestyramine, Colesevelam (Welchol)
4. Fibrates: Fenofibrate, Gemfibrozil (Lopid)
5. Niacin
6. Omega 3 fatty acid: Comes in prescription strength (Lovaza)

ASK THE EXPERT

Do you ever wish you could have direct access to a neurologist for your CMT questions? Now you can! HNF continues to feature real questions from CMT patients across many topics. Submit your questions from our site to the Directors of the HNF Centers of Excellence, Dr. Jafar Kafaie for St. Louis University School of Medicine, St. Louis, MO, and Dr. Florian Thomas for Hackensack University Medical Center & Hackensack Meridian School of Medicine, Hackensack, NJ

Q: I have severe pain in my neck and have swallowing and speech issues. I have been diagnosed with exaggerated thoracic kyphosis with multilevel acquired thoracic fusion and degenerative thoracic spondylitis. Additionally, my lower back has exaggerated lumbar lordosis with superimposed mild spondylosis degenerative disc disease along with right sided foraminal stenosis. My surgeon wants to perform surgery on my neck called ACDF. Is this a common condition as well as a procedure for individuals with CMT?

A: Dr. Florian Thomas:
Degenerative changes of the spine are not uncommon and become more frequent the older a person is. While leg weakness due to CMT can affect posture and thus the spine, I am not aware of a strong link between both conditions, but of course they can co-exist merely by chance.

It is often a good idea to seek a second opinion before agreeing to an expensive spine surgery. Variations in deciding on the best course are significant between different surgeons.

Some surgeons are more aggressive than others. It can be a good idea to seek a salaried academic spine surgeon (orthopedist or neurosurgeon) since they do not directly and personally bill for a procedure.

For a good background read you may want to look up two books written by a spine neurosurgeon I work with, Dr. Patrick Roth: *The Me in Medicine* and *The End of Back Pain*.

HAVE A QUESTION?
www.hnf-cure.org/ask-the-expert

Brace Yourself **For Another Day**

My name is Ginnell McDonald. I live in Madison, Wisconsin where I grew up. I am a wife, mom, retired teacher and now an author/illustrator. In my spare time I love learning new things, traveling, drawing, going on picnics and eating cherry pie!

There are several reasons why I wanted to write *Brace Yourself For Another Day*. I read a quote that said, "Writing is painting with your voice." I thought I can do that! As an elementary school teacher I knew I could impact children in a positive way by writing a children's book. I wanted to give children with disabilities a voice. This book is written through the eyes of Peaches, a spunky little girl who wears leg braces. She gives you a glimpse of what her life is like with braces and eventually views her braces in a positive light. Through my writing I can plant seeds of compassion and encourage children to be the best they can be. Everyone has a story and if we share our stories my hope is that there will be a better understanding and acceptance of each other. It has been quite a journey that has allowed me to meet some amazing people and give back to the community by donating the proceeds of each book.

I have CMT1A and currently wear leg braces. I also have atrophy in my hands, which makes fine motor activities a challenge, and my balance has been affected. That said, I feel these physical limitations have made me a better person. They have taught me to embrace what you have, celebrate it and surround yourself with people that feel like sunshine!

The reaction from my readers has been overwhelming. The support and kind words have been very encouraging. Readers thought it was heartwarming and inspirational. Others highly recommended it and loved the positive message. Some comments include:

"This book will open minds and hearts. It conveys a message of positivity in overcoming obstacles."

"This book boosts confidence, increases self esteem and encourages kids to be who they are."

"As a former special education teacher, this is the type of book that would be helpful in every elementary classroom."

"Loved it so much I bought extra copies to donate to a few local schools."

I decided to accept my braces when I knew they would make it possible for me to continue to do things I wanted to do. I love staying active and want to experience everything that life has to offer.

There are many things I hope my readers take away. I hope it will bring awareness, understanding, acceptance and compassion for those who may live with any kind of visible or invisible disability. My wish is that this book will initiate conversations about dealing and overcoming challenges in our lives. I want everyone to realize that everyday you have the opportunity to be the best version of yourself and to take time to be grateful and joyful for those things that you can do. Everyone has a gift to give to the world, what is yours?

I have been thinking about future books with Peaches. There is nothing started yet, but my pen and paper are ready to go!

TO PURCHASE THE BOOK:
Click Here!

Have you considered legacy planning?

Legacy planning allows you to efficiently pass assets to others upon your passing. While end-of-life issues are never easy to think about, legacy planning is a key part to ensuring your family's resources. It's also a way to pass along your values and support the causes you care about.

The Hereditary Neuropathy Foundation offers you the opportunity to plan a gift through your estate, life insurance, will, or retirement plans to help achieve your philanthropic goals and ensure that our mission at HNF continues. Legacy planning does not require an immediate change to your current spending or savings.

You can support HNF with legacy planning through the following ways:

Will & Living Trust: HNF will receive the bequest you specify in your will or trust. For retirement accounts (e.g., IRA's, Annuities, 401K), naming HNF as the beneficiary of your plan passes the assets in those plans directly to our foundation.

Life Insurance: As a beneficiary (or partial beneficiary) of your existing life insurance policy, the policy amount will pass directly to HNF.

Personal Property: You can transfer personal property such as valuable paintings, automobiles or collectibles for an immediate tax deduction of the appraised value of the gift(s).

Real Estate Gifts: You can deed a home or vacation property to HNF. You can continue to use the property rent-free, then ownership passes to the foundation when you no longer need it.

Income Producing Gifts: Multiple types of trusts can be designed to provide income to you now, with the balance directed to the Hereditary Neuropathy Foundation. Consider choices such as Charitable Gift Annuities, Charitable Remainder Trusts, Charitable Lead Trusts, Deferred-payment Gift Annuities, and other estate planning options.

We have included examples of the language and terms that you can use for legacy planning: Click Here!

If you would like more information or have questions on how you can get involved in legacy planning with HNF, please contact:
courtney@hnf-cure.org

HNF Center of Excellence and Telemedicine

HNF is diligently working with our designated CMT Centers of Excellence to increase the use of telemedicine to improve care during these difficult times of COVID-19. Our goal is to highlight on our website the Centers actively engaged in telemedicine, rules for in and out of state visits, and designating which centers are conducting research. Anyone who is in our patient registry, GRIN, and the CaptureProof Clinical Study (see the featured article in the Fall addition of the CMT Update for more details) will be offered the opportunity to share their visual medical journal with one of our leading CMT Experts.

To Join GRIN: Click here!

For more information on the CaptureProof Study, contact joyaldrich@hnf-cure.org

Dr. Jerath was very thorough and understanding during our visit. She was reassuring even though I was not in person and I felt at ease. She helped me with genetic testing and confirming my CMT type. My visit was covered by insurance even though I was in NJ and she practices in Florida.

–Lori M, CMT Patient

Click to view telemedicine directory

** The Health Insurance Portability & Accountability Act of 1996 was passed to protect patient privacy and the restriction from the Centers for Medicare & Medicaid and most other insurers to reimburse for telemedicine visits. It's important to note that HIPAA compliance is met utilizing special teleconferencing features with a dedicated virtual exam room protecting privacy.

What is GRIN?

The Global Registry for Inherited Neuropathies (GRIN) is a patient registry that collects and stores patient medical information, family history and other relevant information for de-identified use in medical research and therapy development. You are invited to participate in online questionnaires in a survey format by answering surveys and uploading medical information, when applicable.

What is CaptureProof?

CaptureProof is a mobile application that uses software to document and analyze precise gait, structural foot measurements and other functional measures that can be used to evaluate patients and diagnose CMT virtually and may add value for future CMT clinical trials.

HNF's New Center of Excellence: Barrow Neurological Institute Phoenix, AZ

SHAFEEQ S. LADHA, M.D.

Q: TELL US ABOUT YOURSELF:

I am a neuromuscular neurologist at the Gregory W. Fulton ALS and Neuromuscular Disease Center at Barrow Neurological Institute. It was during my residency training at Barrow Neurological Institute that I developed a fascination with neuromuscular diseases. The field allows me to use my neurological exam skills to make diagnoses that have often been missed and to treat patients with a wide array of diseases. This led me to undertake fellowships at the Mayo Clinic in peripheral nerve diseases and clinical neurophysiology, after which I returned to Barrow.

Q: WHY IS CMT YOUR PASSION?

I am passionate about CMT for a few reasons. First, I think there is a lot that can be done to improve quality of life in people with CMT. Educating them about good foot care, walking safety, and the sometimes confusing genetics of CMT is gratifying. Second, the clinical research world is beginning to understand that CMT is a disease state that desperately needs treatments and affects individuals who are motivated and determined to be part of the solution for their disease.

Q: TELL US WHAT PATIENTS WILL EXPERIENCE WHEN THEY COME TO YOUR CENTER?

At the Fulton ALS Center at Barrow Neurological Institute, patients will experience a "one stop shop" for all their CMT care. Our physicians and multidisciplinary care team are extremely experienced at taking care of people with CMT, many having treated the disease for 20+ years. Our center is organized, efficient, and delivers compassionate care to our patients.

Q: WHAT DO YOU LOVE MOST ABOUT YOUR PRACTICE?

I love that I get to spend the time I need with my patients. Neuromuscular diseases are complicated, and complicated diseases require more time and discussion if one is to deliver high quality care. Barrow recognizes that and allows our providers the time they need to give our patients the best care possible.

Q: HOW CAN PATIENTS MAKE AN APPOINTMENT AT YOUR CENTER?

Arranging an appointment is easy. Rose Anaya is our amazing clinic coordinator and makes our clinic hum. To make an appointment, CMT patients can call her at 602-406-2704. It is always helpful to have prior medical records faxed to us ahead of your appointment or you can bring them with you. In particular, any genetic testing or EMG testing reports you can provide will allow us to spend more time discussing a plan of care and reduce repeat testing. For more information, visit www.barrowneuro.org.

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 is to ensure care results in positive outcomes for each individual patient's clinical experience. We are honored to partner with these premier Centers and their leading experts to improve the future for patients and families with inherited neuropathies.

ARIZONA

Barrow Neurological Institute
350 West Thomas Road
Phoenix, Arizona 85013
Contact: Rose Anaya
602-406-2704

ARKANSAS

Arkansas Children's*
Little Rock, AR 72202-3591
Contact: Dr. Aravindhan Veerapandiyan
Primary Care Appointments: 501-213-1883
Specialty Care Appointments: 501-819-3520
Hospital *Pediatric Center of Excellence

CALIFORNIA

Cedars-Sinai Medical Center
Los Angeles, CA
Contact: Tara Jones
tara.jones@cshs.org
CMT Clinic line 310-423-4268

Stanford Neuroscience Health Center
Neuromuscular Clinic
Palo Alto, CA
Contact: Jennifer Fisher
jnfisher@stanford.edu

UCLA Department of Neurology
300 Medical Plaza, Suite B200
Los Angeles, CA 90095
Contact: Dr. Halabi Anasheh Office Telephone: 310-794-1195
(note: request to be scheduled with Dr. Halabi)

COLORADO

Children's Hospital Colorado*
Contact: Alison Ballard at 720-777-8723 or call the clinic schedulers at 720-777-2806

CONNECTICUT

Hospital for Special Care
New Britain, CT
Contact: Sharon McDermott
860-612-6305

FLORIDA

AdventHealth Neurology at Winter Park
1573 W Fairbanks, Ste 210
Winter Park, FL 32789
Contact: Nivedita Jerath MD, MS
407- 303-6729
Orl.neuromuscular.medicine@adventhealth.com

University of Florida Health
3009 Williston Road
Gainesville, FL 32608
Contact: Melissa Hines
352-294-5000 mhines@ufl.edu

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

ILLINOIS

Ann and Robert H. Lurie Children's Hospital of Chicago*
225 East Chicago Avenue
Chicago, IL 60611
Contact: 312-227-4471

KANSAS

University of Kansas Medical Center
Kansas City, KS
Contact: Nicole Jenci 913-945-9934
njenci@kumc.edu

MASSACHUSETTS

Brigham and Women's Hospital
Boston, MA
Contact: Kristen Roe 617-525-6763
kroe@partners.org

MICHIGAN

University Of Michigan
Ann Arbor MI
Contact: Keianna Banbury
734-763-2554
kbanbury@med.umich.edu

MINNESOTA

University of Minnesota Health
Maple Grove, MN
For Research Studies: 612-624-7745
CNRU@umn.edu
For Clinic Appointments: 763-898-1080

MISSOURI

St. Louis University Medical Center
St. Louis, MO
Contact: Mrs. Molly Labrier
314-977-6177
molly.labrier@health.slu.edu

MU Health Care
Columbia, MO
Contact: Dr. Raghav Govindarajan
573-882-1515 govindarajanr@health.missouri.edu

NEW JERSEY

Hackensack University Medical Center
Hackensack, NJ
Contact: Florian Thomas, MD, PhD
551-996-8100
Annerys.Santos@HMHN.org

Atlantic Health System*
Morristown, NJ
Contact: Dr. Jahannaz Dastgir
973-971-5700
jahannaz.dastgir@atlantichealth.org

NEW YORK

Columbia University
New York, NY
Contact: For clinical appointments
Allan Paras 212-305-0405
For research studies 212-305-6035
ap3476@cumc.columbia.edu

NORTH CAROLINA

Dr. Rebecca Traub
University of North Carolina
194 Finley Golf Course Road, Suite 200
Chapel Hill, NC 27517
Contact: For clinical appointments
984-974-4401
Referral Fax: 984-974-2285

Atrium Health Neurosciences Institute-Charlotte
1010 Edgehill Road North
Charlotte, NC 28207
Contact: The phone number for appointments is 704-446-1900. Ashley Clyburn is our incoming referrals coordinator and referrals can be faxed to 704-355-5650

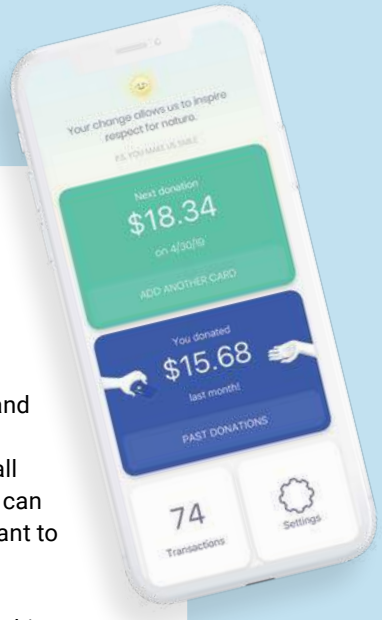
TEXAS

Austin Neuromuscular Center
3901 Medical Parkway, Ste. 300
Austin, TX 78756
Contact: Yessar Hussain, MD
512-920-0140
Website: austinneuromuscle.com/contact

WASHINGTON

St. Luke's Rehabilitation Institute
Spokane, WA
Contact: Ann Cooper 509-939-8079
coopera@st-lukes.org

*Pediatric Center of Excellence



Help Support HNF with the RoundUp app!

HNF has partnered with an app called RoundUp that allows you to round up and donate the change from your credit or debit card purchases to support us – all automatically and without hassle. You can even cap the maximum amount you want to donate in a given month. CLICK HERE.

If you would be willing to support us in this way, simply download the app or use the web version at roundupapp.com. You will be able to create an account and choose us when prompted to select the organization you will support. Also, we would love for you to spread the word to other individuals who may be interested!

Please let us know if I can answer any questions
courtney@hnf-cure.org

Thanks,
Courtney

HEREDITARY NEUROPATHY FOUNDATION

401 Park Avenue South
10th Floor
New York, NY 10016
hnf-cure.org

HNF
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New York, NY 10016
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Events

Get Involved and Join us at an Upcoming HNF Event

Movement is Medicine™

Virtual Movement is Medicine™
March 7, 2021
Sign up here: cmtsummit.org

Million Dollar Bike Ride Virtual
June 12, 2021

Link Up for Team Zach
September 20, 2021
Sign up here: TeamZach.givesmart.com

Jaxson Crusaders Clay Shoot
October 2021

TCS New York City Marathon
November 7, 2021

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