



# cmtupdate



## HNF Announces Patient-Centered CMT/HNPP Pain Summit

BY ALLISON MOORE, CEO/FOUNDER, HNF

The Hereditary Neuropathy Foundation is proud to announce that this year our annual Patient-Centered CMT Summit will include the Hereditary Neuropathy Pressure Palsy (HNPP) community to bring these stakeholders together in a focused manner to address a glaringly under-appreciated patient challenge: dealing with chronic pain. HNPP is one of the most common inherited neuropathies that suffers with chronic pain. This year's Summit will take place on **Friday, November 3, 2017**, on MIT's campus in Cambridge, Massachusetts.

For decades, the Charcot-Marie-Tooth (CMT) and inherited neuropathies (IN) patient community has expressed concerns regarding the impact that pain (neuropathic as well as musculoskeletal) is having on their daily lives. This was evident in our first hosted Patient-Centered CMT Summit in 2016. People with CMT and IN have chronic pain stemming from the disease state itself, as well as pain caused by the limited treatments currently available (i.e. surgery, improper use of braces and/or AFOs). Not to mention the emotional pain of living with chronic illness, especially for children and young adults navigating living with their disease. However, there is little evidence of work being done to address this important and debilitating symptom of CMT/IN, neither in the clinic nor in the laboratory.

HNF has decided to focus this year's Summit on pain to give CMT/IN patient's tools to help manage their pain. HNF also hopes the Summit will encourage more research and greater understanding of CMT/HNPP patients' needs when designing clinical trials

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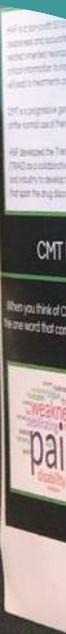
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**1-855-HELPCMT (435-7268)**

[www.hnf-cure.org](http://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.

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## HNF ANNOUNCES: PATIENT-CENTERED CMT/HNPP PAIN SUMMIT

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as well as developing standards of care. Below are some of the topics that will be addressed at the Patient-Centered CMT/HNPP Pain Summit:

- Scientific overview of types of pain and pain mechanisms involved.
- A review of scientific understandings of pain specific to CMT/HNPP.
- Assessment of current CMT/HNPP pain treatment options and discussion of available pain therapies for treatment and coping.
- Partnering with Your HCPs to Ask for Help with Pain Management.
- Communicating with Loved Ones About Your Pain—Getting the Help You Need.
- Panel Presentation: Powering Through—Keeping Active and Living Your Life at Home/at Work Despite the Pain.

**Please join us November 3rd in Cambridge, Massachusetts to join in the conversation on this critical topic.**

Patients, loved ones, caregivers, health care practitioners, researchers, industry, payors, and policymakers are all invited to ensure a comprehensive discussion on this greatly underserved community need.

**FOR MORE INFORMATION:** [CLICK HERE](#)

**WE THANK OUR SPONSORS:**



With partial support from Patient-Centered Outcomes Research Institute Eugene Washington PCORI Engagement Award.

## WE CARE ABOUT RESEARCH FOR HEREDITARY NEUROPATHY WITH LIABILITY TO PRESSURE PALSIES (HNPP)!

BY TINA TOCKARSHEWSKY, DIRECTOR, MEDICAL AND PUBLIC AFFAIRS, HNF

### What is HNPP?

Hereditary neuropathy with liability to pressure palsies (HNPP) is the second most common form of CMT/IN and may affect ~15,000 in the USA. It also affects the peripheral nervous system (those nerves connecting the brain and the spinal column to the rest/peripheral areas of the body); however, as the name suggests, it involves short periods of pressure that can result in tingling, numbness, weakness, pain and sometimes paralysis in the affected areas.

HNPP is also known as:

- Compression Neuropathy
- Entrapment Neuropathy
- Familial Pressure Sensitive Neuropathy
- Hereditary Pressure Sensitive Neuropathy

The peripheral nerves of people affected with HNPP are highly sensitive to pressure and patients with HNPP can experience:

- Recurrent episodes of numbness, tingling, and/or loss of muscle function.
- Pain in the limbs, especially the hands.
- Carpal tunnel syndrome.
- Permanent muscle weakness or loss of sensation.
- Difficulty writing, opening jars, and fastening buttons.
- Difficulty walking, climbing stairs, and driving.

### Help Us Bring Treatments Closer for HNPP!

If you have HNPP, you can help yourself and others with HNPP get closer to finding treatments by joining HNF's **HNPP Natural History Research Study**: [Click Here](#)

This important natural history research study will help us gain a better understanding of this disease and, ultimately, accelerate therapy development. HNPP is often not recognized as being one

of the CMT variants. However, research shows that it is caused by the same mutations as CMT1A, but is the result of a deletion rather than a duplication in the protein PMP22 gene.

This natural history study is part of the **Charcot-Marie-Tooth Research Network (CMTRN)**. The CMTRN supports various natural history studies via electronic surveys that collect patient experience and disease progression information. The data is made anonymous and stored securely in an on-line portal. HNF can share the data with individuals or institutions conducting research or clinical trials but cannot share any personally identifying information. As a CMTRN participant, you can elect to be informed about your eligibility to participate in additional upcoming clinical research studies and trials.

HNF worked closely in collaboration with the National Organization for Rare Diseases (NORD)—an independent charity that built a natural history study platform for rare diseases in conjunction with a cooperative agreement with the U.S. Food and Drug Administration (FDA)—to build this robust natural history study specifically to support of hereditary neuropathy pressure palsies (HNPP). When you complete your HNPP profile, your information will be utilized to advance research and clinical trials that could potentially lead to future treatments and cures for HNPP.

**HAVE HNPP? JOIN THE NATURAL HISTORY STUDY TODAY!** [CLICK HERE](#)

*“HNPP every day takes away a part of my life that I use to enjoy doing due to constant pain and fatigue. It is the silent, unaware and untreatable condition that you have to adjust living with. There is hope with HNF focusing efforts on HNPP.”*

— Lorraine G – HNPP Patient



HNF developed the Therapeutic Research in Accelerated Discovery (TRIAD) as a collaborative effort with academia, government and industry, to develop treatments for CMT. Currently, TRIAD involves many groups that span the drug discovery, drug development, and diagnostics continuum.

## ACTIVELY ENROLLING PHASE 2 CLINICAL TRIAL

Acceleron Pharma, a clinical stage biopharmaceutical company located in Cambridge MA, has initiated a Phase 2 clinical study of ACE-083, an investigational drug, in patients with Charcot-Marie-Tooth (CMT) disease. The Phase 2 clinical study is designed to evaluate ACE-083, a locally acting protein therapeutic, in up to 42 adult CMT patients with muscle weakness affecting ankle dorsiflexion (the ability to raise the foot at the ankle).

ACE-083 is an investigational drug that 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. Acceleron is developing ACE-083 for neuromuscular diseases in which patients experience weakness and atrophy in specific muscles, such as CMT patients with foot drop.

Acceleron has studied ACE-083 in both animals and healthy human subjects prior to initiating this Phase 2 study in CMT. In disease-specific animal studies, including a CMT mouse model, ACE-083 increased muscle mass and force in the specific muscles targeted. In a Phase 1 clinical study in healthy volunteers, ACE-

083 treatment resulted in significant increases in muscle size, with an average increase of 8.9% in the tibialis anterior (lower leg) and 14.5% in the rectus femoris (thigh) muscle volume at the highest dose levels. No serious side effects or treatment-limiting toxicities were observed in the study.

The Acceleron study in CMT will assess whether ACE-083 can safely increase muscle size and strength of the tibialis anterior muscle. The study is designed to determine whether ACE-083 can improve ankle dorsiflexion strength and alleviate foot drop, which in turn may improve measures of function and quality of life in these patients. This study is actively enrolling and will be conducted across 10 sites in the United States.

**LEARN MORE ABOUT THE PHASE 2 STUDY IN CMT: [CLICK HERE](#)**

**SPONSORED BY:**



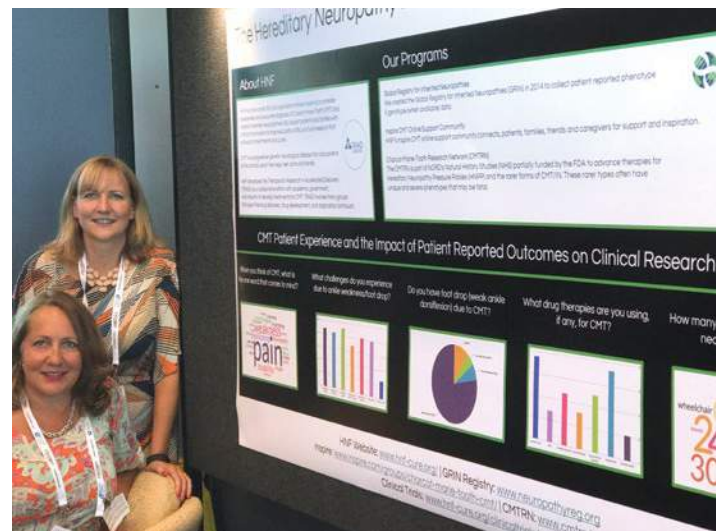
## HNF Attends the BIO International Convention, the Global Event for Biotechnology

BY COURTNEY HOLLETT, DIRECTOR OF DEVELOPMENT, HNF

What a thrilling experience to again be a part of this year's BIO International Convention hosted by the Biotechnology Innovation Organization (BIO) in San Diego, June 19-22! BIO represents more than 1,100 biotechnology companies, academic institutions, state biotechnology centers and related organizations across the U.S. and in 30+ other countries. BIO members are involved in the research and development of innovative healthcare, agricultural, industrial and environmental biotechnology products. BIO attracts 16,000+ biotechnology and pharma leaders who come together for one week to network to develop new opportunities and partnerships.

BIO gives HNF the opportunity to make connections and foster relationships that can help HNF find partners for research and therapy development, sustain projects and secure funding. You never know who you'll meet while you are waiting for the morning keynote speaker to begin, standing in line for coffee, or walking the halls of the Convention Center. Any moment can turn into a networking opportunity!

While in California for BIO, HNF was also invited to Pfizer's local offices to present as part of an interactive discussion on Research and Development, Clinical Trials, and Regulatory Challenges hosted at Pfizer's Research Facility in La Jolla, California. After the presentation, there was an interactive poster session



with reception where we met with Pfizer scientists and reviewed HNF's poster discussing the "CMT Patient Experience and the Impact of Patient Reported Outcomes on Clinical Research and Trial Design."



# HNF attends Peripheral Nerve Society Meeting: Barcelona, Spain

BY COURTNEY HOLLETT, DIRECTOR OF DEVELOPMENT, HNF

The Hereditary Neuropathy Foundation (HNF) was honored to be a sponsor at the Peripheral Nerve Society (PNS) meeting in Barcelona, Spain over July 8-12, 2017. This major research meeting, which happens every other year, brings together the leading peripheral nerve researchers and specialists from around the globe to discuss the latest findings for peripheral neuropathies. As one of the conference sponsors, HNF had an information table where we were able to bring more attention to our TRIAD research program, which emphasize collaboration and support of clinical trials.

The 2017 PNS Annual Meeting provided a mixture of informative lectures, oral platforms, oral posters, and poster sessions by experts in the Charcot-Marie-Tooth Community and

related neuropathies, the Inflammatory Neuropathy Consortium (INC) and diabetic peripheral neuropathy experts.

The HNF was proud to be invited to showcase our recent work in front of these global experts. Allison Moore, HNF's founder/CEO, gave an overview of an HNF study on the impact of patient-reported outcomes (PRO) on clinical trials. This study was done in collaboration with Acceleron and in conjunction with their Phase 2 ACE-083 clinical trial for CMT. Dr. James Nussbaum, PT, PhD, SCS, EMT introduced PNS members to a clinical trial study for CMT featuring the AlterG anti-gravity treadmill. HNF was grateful for this unique opportunity to inform these specialists about all of the exciting things that are happening as a result of HNF's efforts.



## Collaboration is at the heart of what we do at HNF.

We aim to collect data on everyone in the Charcot-Marie-Tooth (CMT)/Inherited Neuropathy (IN) community so we can accelerate research and therapy development. A collective voice will give our research partners a better understanding of the complexities of these diseases and help to design clinical trials.

By joining the Global Registry for Inherited Neuropathies (GRIN), you are participating in the future of potential therapies for you and your loved ones living with CMT and other IN's.

Join today! It only takes 30 minutes! [CLICK HERE](#)



It starts in infancy and lays dormant in the body until one day... the symptoms start to appear.

*Everything seems okay until your...*

<p><b>Feet</b> Start to Look Different</p> 	 <p><b>Balance</b> Becomes Unstable</p>	<p><b>Toes</b> Start to Curl</p>	<p>Neuropathic <b>Pain</b></p> 
<p>Ability to Hold, Grasp &amp; Turn Things is Lost</p> 	<p><b>Muscles</b> are Wasting</p>	 <p><b>Shoes</b> Don't Fit Well</p>	

Even if you are lucky enough to get a proper diagnosis of this genetic disease—Charcot-Marie-Tooth—there is no cure, and it is progressive.

But the Hereditary Neuropathy Foundation is on track to finding treatments and cures! Learn more at [www.hnf-cure.org](http://www.hnf-cure.org)

# HNF AND AANEM DEVELOP CMT KNOWLEDGE ASSESSMENT TEST FOR HCPS

HNF is pleased to be working with the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) to jointly develop and offer a first-ever Charcot Marie Tooth (CMT) knowledge assessment test module. HNF strongly believes CMT patient care and prognosis could be significantly improved if health care practitioners (HCPs) could demonstrate and enhance their proficiency in managing CMT patient care. Offering CMT knowledge testing—and then enabling participating HCPs to document their proficiency levels with CMT patients—can only enhance doctor-patient interactions. It would also greatly help to improve care levels and consistency of care offered across the US. Since there is no cure for CMT and its variants, symptom management is the current treatment plan for CMT patients. Patients therefore depend on working in partnership with their HCPs to develop a comprehensive treatment plan that can enable them to lead an active life—and this plan is dependent on the HCPs familiarity with CMT.

Currently, there are no standards of care for diagnosing and treating CMT. Many CMT symptoms are similar to other types of neuropathy. Compounding the issue, not all doctors are familiar with CMT. In addition, HCPs who are familiar with CMT may not be up to date on recent strides made in diagnostic testing, therapy interventions to improve quality of life (optimal

bracing, exercise regimens, etc.), and clinical research and trials. Due to the variability of the disease—many HCPs are not familiar with the many ways in which CMT can affect a patient systemically, how it can vary from patient to patient, and how it can vary progressively over a patient's lifespan. There is also a significant need for education regarding drugs that are neurotoxic and contraindicated for CMT patients. HNF and AANEM believe that these CMT care issues can be improved upon by encouraging on-going CMT education!

HNF intends to designate those HNF HCP online directory-listed professionals who have passed this knowledge assessment test so patients can readily identify them. While the test is initially designed for neuromuscular specialists, HNF wants the knowledge assessment's design to serve for future use with other fields/specializations that also interact with CMT patients.

HNF and AANEM will be sharing news of this new CMT Knowledge Assessment Test at the AANEM's annual convention, held September 13-16 in Phoenix, Arizona. HNF will be exhibiting, encouraging clinicians to learn more about CMT. We are very pleased to have AANEM's support and partnership to make this critical initiative a reality for our community!

*We thank Pharnext for their support of HNF to help improve the care of CMT patients.*

## CALLING ALL PEDIATRIC NEUROLOGISTS!

### Take Our Quick Survey To Improve Clinical Trials For CMT Kids!

New clinical trials are underway to treat Charcot-Marie-Tooth (CMT) disease. Your input is needed to gain a better understanding of clinical endpoints and outcome measures for children living with CMT.

The Hereditary Neuropathy Foundation (HNF) is committed to improving endpoints and functional outcomes in the pediatric patient population with CMT. Until recently, there was little hope for a treatment to help the thousands of children living today with CMT...nor for the thousands more being born each year. That is changing, however, as possible therapeutics are moving rapidly from the laboratory to the clinic!

HNF has launched an on-line pediatric neurology survey to gain

a better understanding of pediatric neurologists' evaluation techniques in assessing young patients with CMT and pediatric neurologists' perspective of the impact of CMT on their patients' quality of life.

Just a few minutes of time can strengthen our mission to improve the lives of the many children and families affected by CMT!

**If you are a pediatric neurologist, please share your valuable time with us and take our survey.**

Your input is invaluable to us—and to the lives of CMT kids.  
**Thank you!**

[TO TAKE THE SURVEY CLICK HERE](#)

# CMT DEBUTS ON MEDICAL SCREENS IN OFFICES NATIONWIDE!

What if patients and medical professionals could learn about CMT symptoms and diagnosis while sitting in a waiting room? What if our doctors could communicate more effectively and simplify the complexities of explaining a CMT/IN prognosis to a patient by using interactive anatomical renderings in their exam rooms?

The future of patient and health care practitioner (HCP) interactions is here, using technology to support relationships, enhance patient education, and improve health outcomes. HNF is taking a huge leap into this new digitized medical world by announcing a partnership with Outcome Health, a company which provides actionable health intelligence at the moment of care, impacting 585 million patient visits annually.

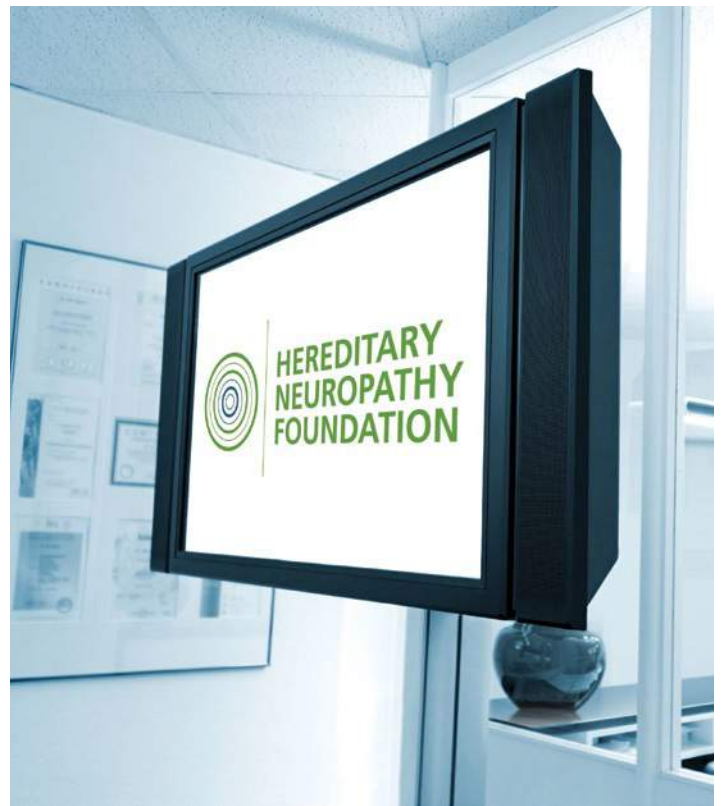
The partnership will empower patients living with the disease, those yet to be diagnosed, and caregivers to make more informed health decisions by bringing CMT-related information from HNF into critical moments of care across Outcome Health's extensive membership of hospitals, health systems and practices.

***“Because CMT is a devastating neurological disease with limited awareness and disease name recognition, these kinds of educational tools are an important way to help people recognize symptoms, obtain early diagnosis, and better understand treatment and clinical trial options to help manage their disease”***

— Allison Moore, founder and CEO of the Hereditary Neuropathy Foundation.

***“CMT affects around 2.6 million people worldwide, and we now have powerful educational information to share with patients and caregivers regarding causes, signs, symptoms and treatment options from a leading expert on the disease. Outcome Health is proud to increase awareness and education around CMT and related conditions through the quality information provided by HNF, so that those affected by the disease can make more informed health decisions.”***

— Matt Garms, director of Associations Partnerships at Outcome Health



Outcome Health's mission is to activate the best health outcome possible for every person in the world through technologies that change behavior to positively shape the human condition. The company serves health information and health intelligence during critical moments of care to enable patients and physicians to make the best healthcare decision possible.

HNF will provide CMT-related content that can be delivered via these devices to facilitate more constructive interactions between patients and health care providers to better manage their care.

HNF encourages the health care professionals in our community—and those in our online Health Care Provider directory—to learn more about the Outcome Health platform for use in their own clinics.

**FOR PROFESSIONALS SIGN UP: [CLICK HERE](#)**





meet  
**Michael Liebowitz**  
**CMT Patient**



BY: ESTELA LUGO, CREATIVE DIRECTOR, HNF

There is a growing body of clinical and scientific evidence that exercise and activity—when not contraindicated—is safe and effective for children and adults with a chronic disease like CMT.

**But it is difficult to not only know where to start, but to find an exercise professional who understands the specific needs and unique challenges of the CMT patient.**

HNF is excited to introduce Michael Liebowitz to the CMT/IN community. He is a certified personal trainer through the American College of Sports Medicine (ACSM), a Certified Sports Nutritionist from the International Society of Sports Nutrition (CISSN) Sports Nutritionist, and holds a MS in Sports Science/Exercise Science.

He is also a CMT patient.

Mike was diagnosed with CMT at ten years old. He had three reconstructive surgeries on each foot, and several smaller follow-up surgical procedures. Each surgery took over six months to recover.

But that has not stopped Mike from pursuing a career he is passionate about and living an active lifestyle as a CMT patient.

**Q: Why did you decide to pursue a degree in Exercise Science?**

**A:** I originally went away to school at the age of twenty-three after years of working as an IT guy for New York State working on Meteorology. That did not last long. I took exercise physiology 101, and I was a natural at it. It came easy to me, so I switched my major over to Exercise Science and never looked back. I have been a hockey player since I was young; physical activity came natural to me as an athlete, even with my surgeries, which started at the age of ten and ended at the age of twenty. I surely slowed down, but I never stopped. Once in college, I started my formal education in anatomy, chemistry, biology, etc. I found exercise to just be natural, there never was really a moment that made me realize I was a fitness professional or a clinical exercise specialist.

**Q: How has CMT influenced your training philosophy?**

**A:** Honestly, after years of practice (where sometimes you make mistakes), years of great teachers and mentors, I have just assimilated all this knowledge into a unique view of movement through the eyes of an individual with specific limitations due to CMT.

I prefer not to see this situation as something that "holds me back," but rather as a situation that requires me to be "smarter" than the average individual.

Everyone adapts to the situation placed on them. My unique adaptation is to be able to make complex information simple for

anyone to understand. My training philosophy is simple: "the right tool for the right job." No one form of exercise is "best." Everything serves a purpose, we just need to define the purpose and pick the right tool.

My experiences and education are not just limited to the CMT Community. Helping all populations is of importance to me. Helping the CMT community just seems right as I am greatly affected by CMT with numerous surgeries and constant pain. If anything, the community will feel connected to me as I am one of them and also someone to look to for guidance. There is no aspect of fitness/exercise that does not hold true to every population.

Exercise and physical activity is good for everyone: it just happens to be that individuals with CMT need specific guidance to flourish, just as an athlete does.

**Q: Can you tell us about your training regimen?**

**A:** My own training is quite complicated to explain. I currently have a four day training cycle. Two days are dedicated to classic strength work while two days are dedicated to decompressive work (myofascial slings). I have previously herniated discs in my back (L4, L5, S1), I have a former separated left AC joint in my shoulder, six total reconstructive surgeries on both feet (three on each - screws/pins/wires/tendon transfers/fused joints).

My own training revolves around keeping me mobile, yet strong; in control of my body, yet always pushing my limits and staying injury free.

Sometimes all of those goals criss-cross and leave me broken, but the only other option is to stop—and that is not an option. Recently, I have been into concepts that our medical world has "forgotten" about. Fascial anatomy is how the body really works; so few people really train using these concepts, and even fewer even understand it.

Part of my job is to educate anyone who wants to learn about these concepts and teach how it can help them.

**Q: What do you want CMT patients to know about exercise and physical activity?**

**A:** I would want fellow CMT-affected individuals to know that they must stay active in order to stay alive.

The day that you stop doing something is the day you lose the ability to do that thing. Meaning that the day you stop using your legs because they hurt—or they are weak or they cause you psychological despair—is the day that you lose your legs. Every day that you wake up in pain is another day that you are alive. If you did not feel pain, I'd bet that you are no longer alive. Stay strong, and have fun doing it!



# SEPTEMBER IS CMT AWARENESS MONTH!



BY: COURTNEY HOLLETT, DIRECTOR OF DEVELOPMENT, HNF

The Hereditary Neuropathy Foundation (HNF) is determined to keep pushing boundaries for CMT awareness—and we especially need your help during CMT Awareness Month! Join us throughout the entire month of September so, together, we continue our mission to increase awareness, raise research funds, and find a cure for CMT!

HNF has planned some exciting events and initiatives to observe CMT Awareness Month. We encourage you to do your part as well by either joining our activities or create your own campaigns!

**Here's a few ways you can get involved TODAY!**

## 1. "Band Together For CMT"

With and without CMT, exercise is a great way to stay in shape, to keep active, and to help attain and maintain a healthy lifestyle. Exercise helps people with CMT improve strength, function, and quality of life. For everyone—and especially for those with CMT, exercise regimens should be approached carefully, best started under the guidance of a trained professional, and with clearance from your physician. Begin slowly, working initially at a very comfortable level. You should NEVER have any pain when exercising and STOP immediately if you do experience pain. Maintain good form throughout, and listen to your body as you progress. Consider using resistance bands to help put together a great exercise routine. To help jumpstart your efforts, with a \$25 donation in recognition of September awareness month, HNF will send you a guided book of exercises with three resistance bands for your use!

**ORDER YOUR BOOK TODAY: [CLICK HERE](#)**

## 2. Social Media #Bandtogether4CMT #CMTAwareness

We all know the power of social media to spread the word and connect our community! During September, please share our posts on your social media platforms and engage with us on how we can better support you and others with CMT/IN. We will be featuring an interactive "**Question of the Week**" to encourage online conversations and discussions.

## 3. Zumbia Live Weekly

To get free access to watch and interact on our weekly updates with Bernadette Scarduzio, please [Click Here](#), quickly register and either download the iPhone app or watch the broadcasts on your computer by searching "CMT".

## 4. Kids Coloring Contest

Any young Picassos out there? We're calling all kids to show us their creativity during September by having kids participate in HNF's "Kids Coloring Contest". Download the PDF template and **draw yourself as a superhero with one superpower to overcome Charcot-Marie-Tooth**. Email the picture back to us at [kidscoloringcontest@hnf-cure.org](mailto:kidscoloringcontest@hnf-cure.org) by September 30th. The winning drawing will be featured in our quarterly *CMT Update* and will become HNF's wallpaper on Facebook—plus, the winner will receive a super-special prize of Beat earphones! (Please note we will use winner's first name and last initial only to respect their privacy)

**DOWNLOAD TEMPLATE TODAY: [CLICK HERE](#)**

## 5. Increase Awareness

Print out our special "**Diagnosis Chart**" and post them wherever you can to help increase awareness. At work, the coffee shop, your doctor's office, the post office, schools, churches, and anywhere else you might think of—share them broadly to help promote improved diagnosis and recognition of CMT!

**DOWNLOAD: [CLICK HERE](#)**

## 5. Neurotoxic Drug Card

Individuals affected with neuropathic diseases, such as CMT, may be more vulnerable to the effects of certain medical conditions, stresses, and medications. HNF has created a neurotoxic drug fact card that alerts CMT patients about medications that may worsen their neuropathy. With just a minimum donation of \$10, you can receive one of these special wallet cards.

**LINK: [CLICK HERE](#)**

We are thrilled with the strides being made by our community—people with CMT, family members, healthcare professionals, researchers, and industry together—let's use this important month to continue our efforts to forge ahead!

# THE RELATIONSHIP BETWEEN CMT AND RESTLESS LEG SYNDROME

BY DIA SU, HNF INTERN AND NEUROSCIENCE/SOCIOLOGY MAJOR AT BOWDOIN COLLEGE

Charcot-Marie-Tooth (CMT) hereditary neuropathy is characterized under a group of disorders described as chronic motor and sensory polyneuropathy (Bird, 2016). Restless legs syndrome (RLS) is classified as a sleep disorder, movement disorder, as well as neurological sensory disorder. People with RLS are forced to move their legs to relieve their symptoms of unpleasant or uncomfortable sensations in the legs (NINDS Restless Legs Syndrome Fact Sheet: [Click Here](#)).

Research has shown that there are different peripheral neuropathies, including CMT, that are associated with RLS. Neuropathies such as CMT2 are especially prone to developing RLS even in the early stages of the neuropathy (Gemignani and Marbini, 2002). Patients with CMT exhibit a threefold increase in RLS, which may result in increased fatigue, daytime sleepiness, and poorer sleep (McCorquodale et. al, 2016).

If you suffer from RLS, there are various treatments that may help relieve your symptoms. One at-home remedy may be the application of warm and cool packs to the muscles. Alternating hot and cold can alleviate some of the pain that is associated with RLS. Massaging the lower leg muscles may also help relax muscles. Moderate exercise can benefit your legs as well as your overall health. Leg stretches, meditation, tai chi, and yoga are examples of ways to relax the mind and body to reduce tension associated with RLS. To assist the way in which RLS interferes with sleep and causes fatigue, sticking to a regular sleep schedule may help the body's rhythm of relaxation before going to bed. Consider removing electronics that glow and anything work-related to make bedtime as comfortable and relaxing as possible (Pietrangelo, 2017).

As you begin to work with a doctor, he/she might consider adding vitamin and mineral supplements because RLS may be caused by deficiencies in certain vitamins and minerals, such as iron, folic acid, magnesium, and vitamin B. Blood tests can determine precisely what vitamins or minerals you are lacking, so be sure to consult your doctor. Over-the-counter medications may be an option if you are someone who is experiencing mild to moderate pain. These pain relievers and nonsteroidal anti-inflammatory drugs (NSAIDs) may include ibuprofen, naproxen, ketoprofen, and acetaminophen. Remember, prolonged usage of NSAIDs can cause stomach upset, ulcers, bleeding, and increased

potential for heart problems. Always talk to your doctor if the pain persists and if NSAIDs are being used long-term. There is also the option of prescription medications that may include anticonvulsant medication is used to treat seizures caused by epilepsy. Anti-seizure medicine has been shown to be effective in treatment of severe RLS by potentially lowering excitatory activity in the brain. However, potential side effects of this drug may include fatigue, headache, nausea, weight gain, difficulty swallowing or breathing, and swelling in the face and throat. Your doctor may also prescribe medication other than anti-seizure medicine. For instance, medicine for Parkinson's disease has shown to be helpful in people with RLS (Pietrangelo, 2017).

If you are a person who is suffering with RLS, you should avoid potential triggers that evoke RLS symptoms. For instance, avoid sitting in one position for too long and avoid foods and drinks with caffeine. Tobacco and alcoholic beverages can worsen symptoms of RLS, so see how your symptoms are affected by changing your diet patterns. Always remember to consult and work with a doctor to try and alleviate your specific symptoms associated with RLS to find the best treatment plan for you (Pietrangelo, 2017).

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**Join us on November 3, 2017 in Cambridge, MA for HNF's Patient-Centered CMT/HNPP Pain Summit.**

**REGISTER TODAY: [CLICK HERE](#)**

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# HNF'S CMT CENTERS OF EXCELLENCE

The national network of HNF-designated Centers of Excellence (COE) provides patients with resources to find hubs of expertise in caring for and treating CMT, as well as locations where CMT research is being conducted. Our primary goal for the program is to ensure that access to care results in positive outcomes for each individual patient's clinical experience. We are honored to have these premier Centers and their leading experts in partnership with us to improve the future for people with inherited neuropathies.

## CALIFORNIA

### **Cedars-Sinai Medical Center**

127 S. San Vicente Blvd.  
Advanced Health Sciences Pavilion,  
A6600

Los Angeles, CA 90048

**Contact:** Dana Fine

Phone: 310-423-8497

Email: Dana.Fine@cshs.org

### **Stanford Neuroscience Health Center Neuromuscular Clinic**

213 Quarry Road, 1st Floor  
Palo Alto, CA 94304

Phone: 650-723-6469.

**Contact:** Jennifer Fisher

Email: jnfisher@stanford.edu

## CONNECTICUT

### **Hospital for Special Care**

Charles H. Kaman Neuromuscular Center  
2150 Corbin Avenue  
New Britain, CT 06053

**Contact:** Boguslawa Koczon-Jaremko

Phone: 860-612-6356

Email: Bkoczon-Jaremko@hfsc.org

## FLORIDA

### **University of Florida Health**

2004 Mowry Road  
PO Box 100332  
Gainesville, FL 32610

**Contact:** Tracie Kurtz, RN, CCRP

Phone: 352-273-8517

Email: tlkurtz@ufl.edu

### **University of Miami**

Professional Arts Center (PAC)  
1150 NW 14th Street, 6th Floor  
Miami, FL 33136

**Contact:** Meri Jaime (for appointments)

Phone: 305-243-7400

Email: MJaime@med.miami.edu

## KANSAS

### **University of Kansas Medical Center\***

Landon Center on Aging  
3599 Rainbow Boulevard, MS 2012  
Kansas City, KS 66160

**Contact:** Nicole Jenci

Phone: 913-945-9934

Email: njenci@kumc.edu

## MASSACHUSETTS

### **Brigham and Women's Hospital**

Department of Neurology  
75 Francis St, Tower 5th Floor  
Boston, MA 02116

**Contact:** Kristen Roe

Phone: 617-525-6763

Email: kroe@partners.org

## MICHIGAN

### **University Of Michigan**

Pediatric Rehabilitation Center  
2205 Commonwealth Blvd.  
Ann Arbor MI 48105

**Contact:** Jen Thomas

Phone: 734-763-2554

Email: jennifkt@med.umich@edu

## MINNESOTA

### **University of Minnesota Health**

Department of Neurology  
420 Delaware Street SE, MMC 295  
Minneapolis, MN 55455

**Contact:** Valerie Ferment

Phone: 612-301-1535

Email: ferm0016@umn.edu

## MISSOURI

### **St. Louis University Medical Center**

Department of Neurology  
1438 South Grand Boulevard  
St. Louis, MO 63104

**Contact:** Susan Eller

Phone: 314-977-4867

Email: ellersc@slu.edu

## NEW JERSEY

### **Hackensack University Medical Center\***

30 Prospect Avenue  
Hackensack, NJ 07601

**Contact:** Eugenia Ndiaye

Phone: 551-996-8100

Email:

Eugenia.Ndiaye@hackensackmeridian.org

## NEW YORK

### **Columbia University**

Department of Neurology  
710 West 168th Street  
New York, NY 10032

**Contact:**

For clinical appointments: Allan Paras

Phone: 212-305-0405

For research studies:

Phone: 212-305-6035

Email: ap3476@cumc.columbia.edu

## WASHINGTON

### **St. Luke's Rehabilitation Institute**

715 South Cowley Street, Suite 210  
Spokane, WA 99202

**Contact:** Ann Cooper

Phone: 509-939-8079

Email: coopera@st-lukes.org

*\*Acceleron Pharma has initiated a Phase 2 clinical study of ACE-083, an investigational drug, in patients with Charcot-Marie-Tooth (CMT) disease. They are currently accepting patients at the centers above **highlighted in red**. For other locations accepting patients please visit: [CLICK HERE](#)*



## UPCOMING 2017 EVENTS

Save the date!

9/9/17

Scavenger Hunt  
Victor, NY

9/23/17

Summer Send-Off  
Celebration  
Charlestown, RI

11/3/17

HNF Patient-Centered  
CMT/HNPP Pain Summit  
Cambridge, MA

## TEAM CMT FOUNDER TO COMPETE IN MIAMI

On November 12th, Team CMT founder Chris Wodke will be racing at the USA Triathlon Long Distance National Championship in Miami. The race comprises a 1.2 mile swim, 56 mile bike and 13.1 mile run. Chris did the long distance aqua bike race last year, finishing 1st in the Physically-Challenged Open Division. Her performance also qualified her for Team USA and the World Championship in Canada.

“It was an honor to make the team,” shares Chris. My busy training and racing schedule kept me from going to Canada, but I hope to go next year when the World Championship race will be in Denmark.” Chris has competed in long distance aqua bike three times; she decided to add the full event this year. “I was energized by presenting at the HNF Patient Summit last year in NYC. It reminded me of why I founded Team CMT and the importance of the work we do with the HNF,” reflects Chris.

“I’ve been looking for a race like the Boston Marathon, to raise funds and awareness for CMT. “I haven’t done much long distance running since my last Boston Marathon, so it will be a challenge to stay healthy while training. I must push myself to be consistent in putting the time and miles in so it will pay off on race day. I feel fortunate to be able to even consider an event like this with my CMT. I am motivated by those who can’t do this, and I train and race for them. A national championship event draws a large field of athletes and spectators and is perfect for raising CMT awareness and research dollars.”

“When I finish this race, I will start training for the Winter Triathlon World Championship in Romania in January,” explains Wodke. “I qualified at the Winter Triathlon National Championship in St. Paul, MN last January. I am not a good skier so I have lots of work to prepare for the race. I like a challenge and look forward to representing Team CMT and my country.”

SUPPORT CHRIS: [CLICK HERE](#)



## SUMMER SEND-OFF CELEBRATION

On September 23, 2017, HNF is proud to support Grace’s Courage Crusade’s Summer Send-Off Celebration in Charlestown, RI. This annual event is being held at the Charlestown Rathskeller Tavern, where participants will enjoy games, tournaments, raffles, a signature drink, great food, fire pit Smore’s and a rockin’ after party!

GCC is a passionate mission of the Sidoti/Caldarone family to support those living with Charcot-Marie-Tooth disease, which affects Marybeth Caldarone and her daughter Grace. They dedicate their efforts towards funding cure-driven research and raising awareness of CMT worldwide. Please join us for this amazing event!

JOIN US: [CLICK HERE](#)



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NEUROPATHY  
FOUNDATION

[hnf-cure.org](http://hnf-cure.org)

401 Park Avenue South, 10th Floor  
New York, NY 10016

[f](#) Hereditary Neuropathy Foundation

[t](#) @CMTNeuropathy



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