



cmtupdate



GLOBAL REGISTRY
FOR INHERITED NEUROPATHIES

HNF LAUNCHES NEW REGISTRY PLATFORM, G.R.I.N.!

(Global Registry for Inherited Neuropathies)

How do CMT researchers and scientists develop therapies, clinical trials and drugs?

It starts with **VITAL patient data!** Without genetic, clinical and historical information, there is no platform to study or build on. This is where patient participation is crucial.

HNF has been hard at work customizing a new registry platform that will gather information about Charcot-Marie-Tooth (CMT) and other Inherited Neuropathies. Each registration requires only 25-35 minutes to complete, yet provides years of invaluable data.

This HNF-funded project ensures your private data remains confidential while providing essential information where it matters...at the fingertips of researchers. HNF's Global Registry for Inherited Neuropathies (GRIN) is one of many ongoing initiatives supporting our personal commitment and dedication to developing treatments and discovering cures for CMT and other Inherited Neuropathies.

“Our voices are a crucial piece of the treatment development puzzle, and I am incredibly grateful for the opportunity to come together with others who share my diagnosis and raise our collective voice.”

– Patient: **Stephanie Carmody**

“The patient registry will provide an invaluable resource for scientists engaged in research directed toward understanding and treating hereditary neuropathies. Furthermore, the GRIN platform will support our efforts in strengthening the bridge between patients and researchers, and will have a major positive impact on ongoing translational efforts.”

– Chief Science Officer, HNF: **Lucia Notterpek**

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1-855-HELPCMT (435-7268)

www.hnf-cure.org

The Hereditary Neuropathy Foundation's mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related Inherited Neuropathies, support patients and families with critical information to improve quality of life, and fund research that will lead to treatments and cures.



Top 5 Ways your CMT Data is Helpful

- 1. Your detailed clinical and genetic information will help researchers and industry develop drugs, gene therapy, and clinical trials.** *As a registrant, you will be informed when you may be eligible for a clinical trial.
- 2. Scientists can learn which genetic modifiers might mitigate the disease using your patient information.**
- 3. As our registry grows, we gain exponentially wider visibility for researchers into the CMT community and allow for more precise targeting of specific conditions.**
- 4. Researchers can study why individuals have different symptoms.**
- 5. It helps researchers learn how treatments work or don't work for a given patient population.**

Ready to Drive Progress & Register?

Anyone diagnosed with CMT or a Inherited Neuropathy can join our registry. Your information is always kept confidential. Researchers see de-identified information. Only approved Principal Investigators and registry personal can see your information.

If you are interested in joining our registry, there is no better time than right now. Join GRIN and be on the front lines to help find the treatments and cures for all inherited neuropathies, for your family and families across the globe.

Join the registry today! <http://neuropathyreg.org>

ALLISON MOORE SPEAKER AT 2018 RARE PATIENT ADVOCACY SYMPOSIUM

BY ESTELA LUGO, MEDICAL OUTREACH MANAGER, HNF

On May 19, the Hereditary Neuropathy Foundation (HNF) participated in the Rare Patient Advocacy Symposium in partnership with Penn Medicine Orphan Disease Center and Global Genes. HNF's CEO/Founder, Allison Moore, spoke on the importance of the "Patient's Voice" and "Patients as Key Opinion Leaders and Partners In Research and Clinical Development". The presentation highlighted the vital role the patients play in the development of drugs and treatments for the CMT community. Moore presented the key steps and processes used to acquire our upcoming Externally-led Patient-Focused Drug Development (PFDD) meeting with FDA officials and other stakeholders, as well as the tools HNF will use to inform the FDA on what matters most to patients and how they view the benefits and risks of potential treatments.

Attendees were also briefed on the wide spectrum of Charcot-Marie-Tooth (CMT) symptoms and severities, as well as on the urgency for collecting patient data and the importance of natural history studies. HNF's innovative proprietary patient registry — Global Registry for Inherited Neuropathies (GRIN), will help to improve drug discovery, clinical trials design and the acceleration of therapy development and regulatory approvals. HNF has been collecting patient data for close to 5 years, part of

the organization's continued commitment to making patients a key part of the research process and clinical development.

Moore has extensive experience in patient engagement methods, with an emphasis on identifying the gaps that have been hindering CMT patient care, standard of care guidelines, issues with patients having delayed and accurate diagnosis, and the need for improved clinical outcome measures and endpoints to support clinical trials.

The symposium was another valuable opportunity to network and partner with like-minded advocacy groups and key players to exchange valuable resources. HNF is dedicated to remaining on the cutting-edge of new pathways, technologies and collaborations like those displayed at the symposium. HNF is grateful to Global Genes for inviting us to participate!

We will continue to work tirelessly to provide the optimal treatment path for our CMT families, and look forward to meeting many of you at our "Voice of the Patient" Weekend, Sept 28-29. **Learn more:** www.cmt-pfdd.org

Donate here: <https://bit.ly/2t0u1UO>

Register here: <https://bit.ly/2siMVXy>

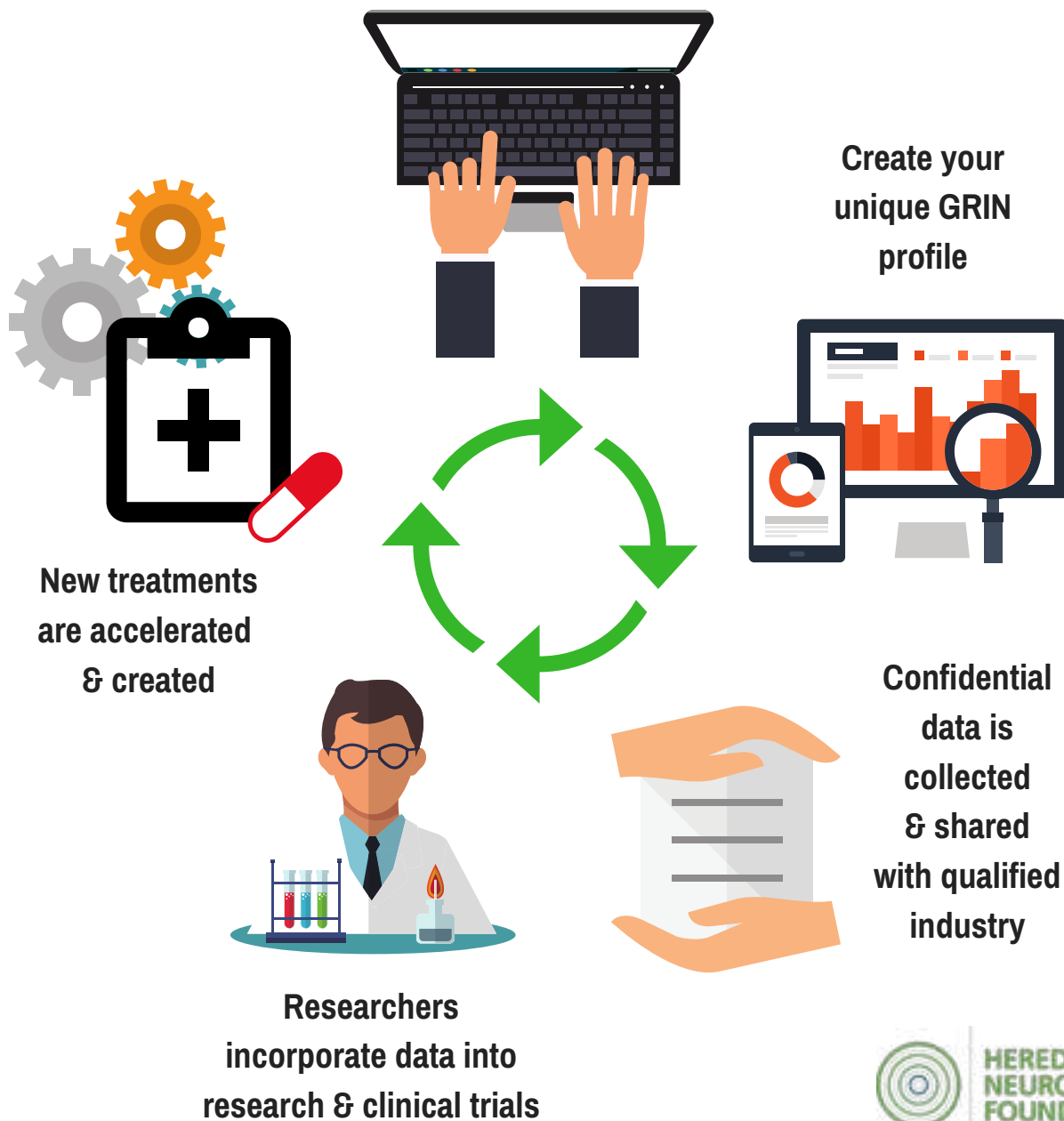
GRIN :)



GLOBAL REGISTRY
FOR INHERITED NEUROPATHIES

Progress begins with YOU...

www.neuropathyreg.org



HNF'S BOARD IS GROWING!

BY JOY ANDAL KAYE, CHAIRMAN, HNF

HNF is excited to announce the addition of four new board members to our team! They come to us with a wealth of knowledge and impressive backgrounds. We are excited to have them on board to further HNF's mission to increase awareness of Charcot-Marie-Tooth (CMT) and Inherited Neuropathies, support patients and families with critical information to improve quality of life, and fund research that will lead to treatments and cures.

Each of these individuals is touched by CMT on a personal level and is looking forward to assisting in HNF's efforts toward making a difference.



Gretchen Cappiello

Gretchen worked at the Federal Reserve Banks of New York and Chicago for just over 17 years (10 years in NY and 7 in Chicago) in the Bank Supervision Group, until she decided to stay home with her three children in late 2015. Her specialties included consumer protection and capital risk

management. She managed several teams of examiners, including a large bank supervision team in Chicago, which was responsible for oversight of the most complex bank holding companies in the district. She has a B.A. in Spanish from Washington University in St. Louis and an MBA from NYU.

Gretchen grew up quietly managing her CMT, and, now, two of her children have it. She plans to be an active advocate and part of the progress that HNF has been facilitating. She believes there can be a cure and thinks that the Chicago area is ripe for more involvement. She hopes to increase awareness and spearhead fundraising in the Chicago area!

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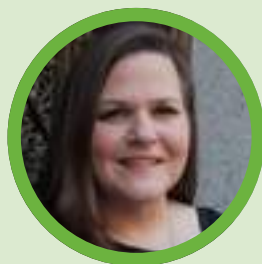


Deborah Newcomb

Deborah Newcomb recently retired from a successful career as a portfolio manager in New York. Her career included several small boutique firms on Wall Street, followed by ten years at Scudder Stevens & Clark, and 30-plus years as a Managing Director at US Trust/ Bank of America.

Deborah was born and raised in New England, and is a graduate of the University of Vermont. She currently lives on the Upper West Side with her husband, Jonathan. They raised two sons who went to school in New York and both now reside and work in the City. Deborah has been involved in a number of community activities, and was an active member of the CitiKids board for a number of years. She was a member of several residential boards and President of the Board in the last co-op in which she lived. She continues to raise funds for several local libraries.

Deborah has been involved in the Hereditary Neuropathy Foundation for the past two years, and was recently asked to join the board. Deborah's personal interest in the Hereditary Neuropathy Foundation stems from her many years of dealing with peripheral neuropathy.



Brooke Warren

Brooke is the proud mother of a smart, articulate and engaging third-grade daughter dealing with the challenges of CMT1A. Brooke has dedicated her life to finding the best care for her daughter and husband, and has been the primary medical advocate for the family through several surgeries. Brooke sought out

HNF five years ago as a way to be better prepared to deal with the challenges her daughter would face. Brooke is committed to finding a cure for all children, and hopes to share her knowledge about her experiences and any effective treatments with others.

Brooke earned a Bachelor of Science in Civil/Environmental Engineering from the University of Notre Dame, a Master of Engineering Management at Northwestern University, and a Master of Business Administration from the Kellogg School of Management at Northwestern University.

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Kara Sprague

Kara most recently spent 7 years as a Vice President for Barclays Investment Bank in New York in their internal audit function specializing in Finance, Compliance, and Financial Crime, as well as implementation of global strategic change initiatives. Prior to Barclays, she worked for 6 years as a

Manager with KPMG, LLP focused on financial statement audits for banks and other financial institutions in Chicago and New York. Kara is a Certified Public Accountant (CPA) and earned her Bachelor of Science in Accountancy at the University of Illinois.

Kara became involved with HNF after moving to New York in 2010. She is dedicated to raising awareness and supporting scientific research to find effective treatments and improve the lives of her family members and others impacted by CMT. Kara has recently relocated to Los Angeles where she is excited to raise CMT awareness and continue to expand the HNF network and support for our mission to the west coast.



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.

Sean Ekins to Focus on Collaborations Pharmaceuticals, Inc.

BY ALLISON MOORE, FOUNDER/CEO, HNF

The Hereditary Neuropathy Foundation (HNF) looks forward to working side by side with Collaborations Pharmaceuticals, Inc. as we pursue funding to bring a treatment for Hereditary Neuropathy with Liability to Pressure Palsies (HNPP) to the patient. We will be sure to highlight HNPP at our Externally-led Patient-Focused Drug Development (PFDD) Meeting for the FDA in September.

Sincere gratitude to Sean Ekins, PhD for your dedication and support to HNF. It's sure been a ride, Sean! I am grateful for all you have taught me about pre-clinical research, and for your many years and oversight of the Therapeutic Research in Accelerated Discovery (TRIAD) Program. We are so excited that you have stepped down so that you can pursue bringing a therapy for one of the most common types of Inherited Neuropathy to the clinic.

For all those who don't know Sean, he is a Clinical Pharmacologist by training and an entrepreneur at heart who co-founded Phoenix Nest Inc., a rare disease company in NY and Collaborations Pharmaceuticals, Inc., a drug discovery company in North Carolina. Sean has received dozens of NIH grants to study various infectious and rare diseases.

After working closely with HNF, Sean became passionate about helping to find therapies for our CMT Inherited Neuropathy

patient community. Working with a clinician at the University of Vanderbilt, Collaborations Pharmaceuticals, Inc. licensed his invention of a drug which showed activity in a mouse model for HNPP. HNPP is the second most common form of CMT and Inherited Neuropathies and may affect approximately 15,000 in the USA. It also affects the peripheral nervous system – nerves connecting the brain and the spinal column to the peripheral areas of the body. As the name suggests, it involves short periods of pressure that can result in tingling, weakness, periods of numbness, motor deficits, and, sometimes, paralysis in the affected areas.

HNF will continue to pursue funds to help identify the gaps in patient reported outcomes that are hindering HNPP patient care, standard of care guidelines, issues with diagnosis, therapy development, and the need for improved clinical outcome measures and endpoints to support clinical trials.

If you have HNPP and would like to participate in the Externally-led PFDD meeting, contact allison@hnf-cure.org

Donate to HNPP research:

<https://www.hnf-cure.org/cmt-hnpp/>

HNF is excited to announce that Dr. Lucia Notterpek will Take the Reins as HNF's New Chief Scientific Officer.

BY ALLISON MOORE, FOUNDER/CEO, HNF

Dr. Lucia Notterpek is Professor and Chair of the Department of Neuroscience at the University of Florida in Gainesville, Florida. She obtained her PhD in Neuroscience from UCLA and was a Postdoctoral Fellow in Neurobiology at Stanford University. Dr. Notterpek has spent more than two decades on Charcot-Marie-Tooth (CMT) research, and has been intimately involved as a Scientific Advisory Board Member with HNF for the past five years. In fact, Lucia was the first scientist to establish a relationship with HNF back in 2001.

Dr. Notterpek's primary research on hereditary neuropathies dates back to the mid 90's when under the direction of Dr. Eric Shooter at Stanford University she studied the PMP22 protein, which causes CMT1A. Dr. Shooter was one of the key scientists in elucidating the linkage of PMP22 to a host of hereditary neuropathies. Dr. Notterpek's laboratory at the University of Florida continues to investigate the normal function of PMP22 in peripheral nerves. Another major effort of her work is to facilitate the development of effective therapies for demyelinating hereditary neuropathies,

including CMT1A, HNPP and congenital hypomyelinating neuropathy, also known as Dejerine-Sottas syndrome (DSS). Dr. Notterpek's therapeutic approaches for CMT include small molecule enhancers of protein degradation and protein folding, and miRNA-mediated gene suppression. Her laboratory is also interested in understanding the influence of total caloric intake and dietary lipids on peripheral nerve function and neuropathy progression.

Dr. Notterpek will oversee HNF's Therapeutic Research in Accelerated Discovery (TRIAD) program and will work closely with HNF's CEO, Allison Moore, on existing and new industry stakeholder partnerships. Dr. Notterpek has been instrumental in connecting HNF to the University of Florida and the designation of University of Florida as an HNF Center of Excellence in 2016, as well as bringing the first CMT clinical trial (Pharnext pivotal PXT3003 Phase 3) to the University.

We welcome Dr. Notterpek as our new CSO and look forward to continuing to build robust research studies and accelerating therapy development to treat patients.



STARWISE THERAPEUTICS LLC & HNF JOIN FORCES FOR TREATMENT OF CMT2A

BY COURTNEY HOLLETT, EXECUTIVE DIRECTOR, HNF

StarWise Therapeutics LLC, based in Madison, WI has developed novel, safe HDAC6 inhibitors for use in the treatment of various neurological disorders. On the top of its list is the use of the new drugs in the potential treatment of the genetic disorder known as Charcot-Marie-Tooth disease, or CMT for short.

CMT is a progressive genetic disease of which there are many variants. CMT2A is a mutation in the sequence of the mitofusin 2 gene or MFN2. MFN2 is a protein that plays an essential role in the function of mitochondria which generate energy in the cells. In MFN2 patients, the energy produced by neuronal mitochondria is insufficient to sustain axons. As a consequence, axonal degeneration gradually occurs, causing muscle weakness, atrophy and deformities in the feet, legs, arms and hands. Those with CMT often lose the ability to walk, and may become dependent upon assistive devices to remain mobile. Severe, chronic pain is common, and there is no cure.

StarWise Therapeutics and Waikato University in NZ have demonstrated that their key drug is able to restore sensory and motor function in the CMT2A mutant animals to performance levels akin to those of the wild type animals.

The Hereditary Neuropathy Foundation (HNF) is a non-profit 501(c)3 global organization whose mission is to increase awareness and accurate diagnosis of CMT, support patients and families with critical information to improve quality of life, and support research. HNF has notably developed the Therapeutic Research in Accelerated Discovery (TRIAD) program, a collaborative effort with academia, government, and industry to support and develop treatments for CMT.

These two entities have now linked their expertise in order to advance the StarWise agents to the clinic. Key medicinal chemistry, biology, and clinical experts met in New York City in April to make plans for the filing of an Investigation New Drug (IND) application with the FDA for the treatment of CMT2A disorder. And this couldn't be more timely with the upcoming HNF-hosted Externally-led Patient-Focused Drug Development (PFDD) Meeting for the FDA on September 28 at the College Park Marriott Hotel & Conference Center in Hyattsville, Maryland. StarWise and HNF are forging the way to accelerating therapies to the clinic for many CMT sub-types and for the first time CMT2A will be added to that list. Stay-tuned as we will be reporting with research and clinical updates!

Donate to CMT2A Research: <https://bit.ly/2rtwvLJ>

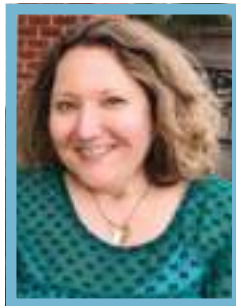
Why I'll be attending the "Voice of the Patient Weekend" A Patient's Perspective

BY STEPHANIE CARMODY, CMT2C PATIENT

When you live with an ultra-rare, severe form of hereditary neuropathy like I do, being able to have a voice in the treatment development process is invaluable. The genetic connection to my disorder was only discovered 9 years ago; because it is so rare and newly discovered, it is a struggle to raise awareness and interest in the need for accelerated research into treatments.

The opportunity to meet with the FDA, drug developers, and other stakeholders as the HNF holds its Externally-led Patient-Focused Drug Development Meeting for the FDA on September 28 at the College Park Marriott Hotel & Conference Center in Hyattsville, Maryland is invaluable. Being able to share with them how my disorder, TRPV4 Hereditary Neuropathy (also known as CMT 2C, Scapuloperoneal Spinal Muscular Atrophy, and Congenital Spinal Muscular Atrophy), impacts my life and the lives of the others I have met since my diagnosis will be game changing.

My disorder can cause a myriad of severe symptoms including respiratory insufficiency, which can be life threatening; there is an urgent need for translational research to improve function and save lives. Fortunately, there is great hope that a treatment could



be developed, but there remains a critical need to raise the awareness needed to speed up the process to get us there.

I am attending HNF's "Voice of the Patient" Weekend 2018 to tell the FDA and other stakeholders how TRPV4 HN impacts my life, and to give my perspective on how important it is to accelerate research so that the children who share my diagnosis don't have to grow up to experience some of the severe symptoms our disorder can cause in adulthood.

As patients, we are experts in how we experience our disorders, and experts in which symptoms should be priorities as treatment targets to improve our quality of life. Our voices are a crucial piece of the treatment development puzzle, and I am incredibly grateful for the opportunity to come together with others who share my diagnosis and raise our collective voice. I encourage others living with hereditary neuropathy to raise your voices at this groundbreaking, important meeting. We are sitting on the precipice of new treatments for many types of hereditary neuropathy. We need our perspectives to be heard, and I hope to see many of you there!

Donate to CMT2C Research: <https://www.hnf-cure.org/cmt-2c/>

It starts in infancy

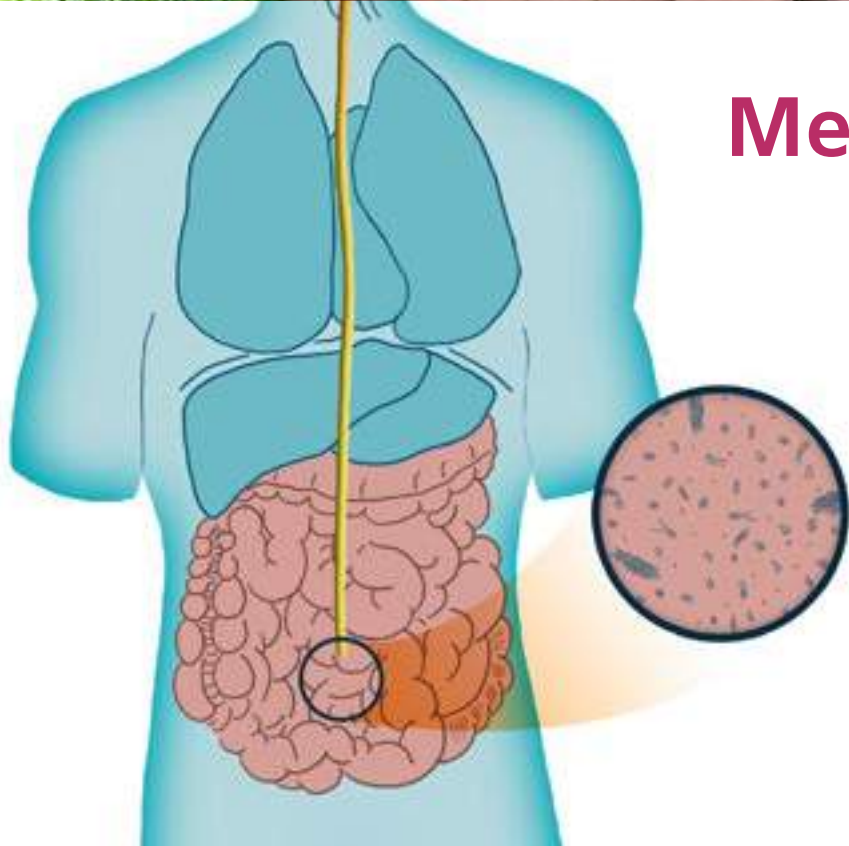
and lays dormant in the body until one day...
the symptoms start to appear.

Everything seems okay until your...

<p>Feet Start to Look Different</p> 	<p> Balance Becomes Unstable</p>	<p>Toes Start to Curl</p>	<p>Neuropathic Pain</p> 
<p>Ability to Hold, Grasp & Turn Things is Lost</p> 	<p>Muscles are Wasting</p>	<p> Shoes 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**



Meet Alana Kessler MS RDN E-RYT

Nutritionist, Dietitian & Wellness Expert

BY ALANA KESSLER

Are all of your CMT symptoms really CMT symptoms?

What is the gut-brain access/connection,
and how is it related to inflammation?

Hello, my name is Alana Kessler, and I am a Registered Dietitian with a Master's in Clinical Nutrition from NYU, and an expert guide in yoga, meditation, and alternative nutrition methods based in Chinese medicine and Ayurveda.

When we talk about inflammation, the first question we must ask is: How does our diet affect our nervous system?

Inflammation is a localized physical condition in which part of the body becomes reddened, swollen, hot, and often painful, especially as a reaction to injury or infection.

Inflammation is a pervasive and self-perpetuating condition affecting the optimal functioning of the body's natural processes. Unfortunately, only when significant symptoms arise, such as IBS, joint pain and neuromuscular issues, headaches, hormone issues, weight fluctuations, do we begin to address the underlying issues.

When we talk about the mind-gut connection, we can look to the **vagus nerve**, one of two extremely long cranial nerves that extend from the brain to the abdomen, to assess our mental and emotional states. This connection explains why the quality of food we choose has a direct impact on our state of mind and sense of well being.

Inflammation stems from many sources, and will most likely be experienced as the derailment of the hormones that act as messengers between the belly and the brain. These sources include—but are not limited to—sugars, chemicals, **pathogens**, and stress, which trigger the central nervous system to release insulin and cortisol as a means for survival. Problems arise because continuous low-grade stimulation of these hormones, especially **cortisol**, act as a systemic immune suppressant, lowering levels of secretory IgA, an important body guard of the gut **microbiome** and triggering **hypothyroidism** and adrenal fatigue.

When cortisol is high, high levels of insulin and sugar remain in the blood while the cells become deprived. Too much insulin inhibits the fat cells from being broken down as energy, and begin to secrete their own SOS signals, leading to hormone shifts resulting in estrogen dominance, increased **DHEA** and **androgens** to fuel the **aromatization** of testosterone to **estradiol**. Symptoms present as acne, hair growth and irritation.

Once triggered, inflammation causes a cascade response in the tissues, and especially the mitochondria, whose main role in the cell is management of energy or food intake. "Mitochondria are highly dynamic organelles that fuse and divide in response to environmental stimuli, developmental status, and energy requirements. These **organelles** act to supply the cell with **ATP** and to synthesise key molecules in the processes of inflammation, oxidation, and metabolism. Therefore, energy sensors and management effectors are determinants in the course and development of diseases." (Reference <https://www.hindawi.com/journals/mi/2013/135698/>).

A neurotransmitter is a chemical messenger that carries, boosts, and balances signals between neurons, or nerve cells, and other cells in the body. Billions of neurotransmitters work constantly to keep our brains functioning, managing everything from our breathing to our heartbeat to our learning and concentration levels. They fail to convert if the cells are not functioning properly.

The result is an unhappy brain expressing a collection of symptoms, including lethargy, sleep disturbance, decreased social

activity, mobility, libido, learning, and, on occasion, anorexia. An unhappy gut perpetuating the inflammatory response causes more and more mutations in the tissues, leading to many chronic and acute conditions.

In my work, I have found that treating inflammation through a careful low refined sugar diet, with a high level of natural fats, meditation, and strategic supplementation can help restore a natural homeostasis. When discussing the possibility of treatment for CMT, it is imperative that we explore nutrition, lifestyle, and stress (internal, inherited and environmental) as major influences in the causation of this condition, and begin to develop protocols to support a more holistic approach in the investigation.

To learn more about Alana Kessler and her practice, please visit: www.bewellbyak.com

Or follow on Instagram: [@bewellbyalanakessler](https://www.instagram.com/bewellbyalanakessler)

GLOSSARY:

Inflammation – a localized physical condition in which part of the body becomes reddened, swollen, hot, and often painful, especially as a reaction to injury or infection.

Pathogens – a bacterium, virus, or other microorganism that can cause disease.

Cortisol – a glucocorticoid C21H30O5 produced by the adrenal cortex upon stimulation by ACTH that mediates various metabolic processes (such as gluconeogenesis), has anti-inflammatory and immunosuppressive properties, and whose levels in the blood may become elevated in response to physical or psychological stress.

Microbiome – collective genomes of the microbes (composed of bacteria, bacteriophage, fungi, protozoa and viruses) that live inside and on the human body.

Hypothyroidism – abnormally low activity of the thyroid gland, resulting in retardation of growth and mental development in children and adults.

DHEA – a steroid hormone made by the adrenal glands, that acts on the body much like testosterone and is converted into testosterone and estrogen. The blood levels of DHEA decline with age.

Androgens – any steroid hormone that promotes male secondary sex characters. The two main androgens are androsterone and testosterone.

Aromatization – a chemical reaction in which an aromatic system is formed. It can also refer to the production of a new aromatic moiety in a molecule which is already aromatic.

Estradiol – Estradiol is a female sex hormone produced by the ovaries, adrenal gland and also the placenta during pregnancy. Estradiol is the most important hormone during a female's reproductive years, and is required for reproductive and sexual function as well as having an impact on the health of other organs and tissues.

Organelles – a specialized cellular part (such as a mitochondrion, chloroplast, or nucleus) that has a specific function and is considered analogous to an organ.

ATP – formed especially aerobically by the reaction of ADP and an orthophosphate during oxidation, or by the interaction of ADP and phosphocreatine or certain other substrates, and serving as a source of energy for physiological reactions, especially muscle contraction.

Catching up with Team CMT Member Katherine Crandall Symons



Q: Tell us about yourself?

A: I grew up in Upstate New York in a cookie-cutter house with a white picket fence and a dog in the front yard. I went to college in the Adirondacks, where I fell in love with hiking. I really wanted to be an “ADK 46er”, climbing all 46 high peaks of the Adirondacks before I turned 25, but that didn’t happen. I met my husband at an event at his college where I was volunteering. We both participated in his school’s juggling and unicycling club (aka circus club). He did parkour and acrobatics, and I did hula hoop, spin poi, and performed in sign language.

We moved fast. We met, dated, got engaged, got married, and got pregnant all within one year. Life brought us to southeast Texas, which was an extreme culture shock. After our daughter was born, I decided we needed to make friends, so we found a local running club. Turns out southeast Texas has a phenomenal running community. Neither of us were really “runners” before we joined the club, but the community was so welcoming, and we were hooked.

Q: When were you diagnosed with CMT? Briefly explain your journey arriving at that diagnosis.

A: Since CMT is genetic, my parents had been watching for signs. I made it until I was 12 before they spotted a curve in my spine. During my preteen growth spurt, I developed scoliosis. They brought me to a specialist who pointed out additional CMT symptoms they hadn’t caught—my hips were not square, my one leg was slightly longer, and I already showed signs of high arches. The doctor gave me shoe inserts and a list of daily exercises.

I was very high functioning, so I ignored his treatment. I didn’t wear my inserts. I didn’t want to admit I had the disease because I was a typical kid and didn’t want something that would make me a target. It wasn’t until college that I started to take care of my body. I joined a gym and started to strengthen my hips. I am very lucky my symptoms didn’t get out of hand in the years I ignored them.

Q: Do other members of your family have CMT?

A: CMT is rampant in my family. My father’s maternal grandmother had the disease, and most of her children and grandchildren have it. She was a huge advocate for “use it or lose it”. Her doctors weren’t always supportive or knowledgeable, so she used to keep a little book with all her symptoms and medications. She was a brilliant old woman. She passed away while I was in college, and her passing was part of the reason I decided to take control of my body.

She told me, “Katie, you need to learn everything about this disease, because the doctors don’t know nothing.” Her youngest son was severely impacted, to a point where (this was back in the day) the state tried to take him away. But she fought for him, and he was able to stay home. Even with his severe disability, he learned to play the piano beautifully. We actually have a few different types in our family tree, and some family members have had surgery (one cousin has metal rods in his ankle, two aunts had back surgery).

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Q: Why did you join Team CMT?

A: When I first started running, I knew I was slow and my form was really bad. Honestly, I was looking for a way to justify and show the other runners that I was “bad for a reason”. I was still embarrassed. But within a few months of running, I started doing well, despite CMT. It’s hard, but it’s possible. I do a lot of strength training.

I realized that I’m not a good runner with a disability. I’m actually a good runner. It hit me that I have this incredible power to inspire people, especially kids, who think that can’t run because of their body. My motto is: “You can’t choose your genetics, but you can choose your attitude”.

Q: What challenges will you face, if any, participating in a half marathon?

A: After I had my daughter, my disease rapidly progressed. “Use it or lose it” is no joke, and after 9 months with limited gym activity, I lost a lot of mobility and gained a lot of pain. Most of my issues when it comes to running are with my ankles and hips. If you see pictures, you’ll see my ankles don’t bend when I run. I lock them, so then my hips have to compensate. I work hard to engage them, but when I’m tired they fall back.

I can run a 5k pretty well. I’m working on the 10k without losing my form. I have gotten back to the gym to strengthen my ankles and hips for my first half marathon. I also have my husband take lots of photos. That is the only way I can see what my body is doing. Perhaps the most important thing I’ve learned is to not skimp on shoes. My first pair of shoes was

a clearance sneaker. No, no, no. I now go to a local running shop and let them pick my shoe. They are skilled, and I trust them 100%.

Q: How has CMT changed your life?

A: The biggest impact is mental. I still look fine. If someone sees me, they can’t see this disease. When I’m struggling, it’s really hard for me to show it. I can no longer pick up my daughter and take her out of her car seat. She begs me to hold her, but I can’t. I have to ask her if she’d like to sit on my lap instead. The comparison monster is so evil. I have cousins who “have it worse”, so I mentally downplay my own disease. Even though I know the pain I feel is real, I haven’t required surgery. I don’t need AFOs.

CMT leaves me in a mental struggle, seeking to validate if the pain I feel is real. It’s incredibly frustrating when people question me if I am tired, or want to sit down, or when I read the label on something because I might react. It’s so frustrating when people question my disease. I once mentioned CMT by name on a fact sheet for a performance, and one of the organization volunteers wrote on her public Facebook that “People who make up disabilities for attention are pathetic”. I was humiliated (and no, I didn’t participate after that). But now that I’m older and wiser, I know that I am in control of my own body. I can’t choose my genetics, but I can choose my attitude, and I spent the first half of my life with a rotten attitude. I’m not going to waste this half.

To join Team CMT visit: <https://www.hnf-cure.org/team-cmt/>

Be a Part of the Team CMT

BY JESSICA ROBERTS, DIGITAL ASSET MANAGER

Team CMT is a grassroots community fundraising program founded by Chris Wodke, a CMT athlete who partnered with the Hereditary Neuropathy Foundation (HNF) to raise awareness for Charcot-Marie-Tooth disease. Currently we have 213 athletes in 39 states. We also have members in Australia, Canada, England, Finland, Vietnam, Iran, Scotland, Ireland, France, Turkey, Poland, Norway and Sweden.

Building awareness about CMT is essential to increasing support, research, and helping to find a cure for the many forms of CMT. The members of Team CMT are at the front lines of raising CMT awareness in local communities around the world.

Be part of an international effort to change the future for those living with CMT! Join us today and register to become a Team CMT member. By joining the team and making a minimum donation of \$25, we will send you a Team CMT shirt that you can wear to help build CMT awareness. You can wear your Team CMT shirt to the gym, physical therapy, or athletic events.

Team CMT Members can also share their CMT story by creating a personal fundraising page on our Team CMT donor page. You can also host and represent Team CMT at various

events such as walks, bike races, and marathons. Just check out Team CMT founder Chris Wodke’s activities and her amazing contributions to generating CMT awareness.

There are so many exciting initiatives and new progress being made for the CMT community thanks to increased global awareness and the groundbreaking recent CMT research developments. Current scientific studies are bringing us closer to understanding and creating the technology needed for accurate disease diagnosis, effective genetic counseling, and targeted therapies.

**This summer,
become a Team CMT champion!**

Help us raise CMT awareness and the much-needed funds to finally find cures for CMT!

JOIN TEAM CMT TODAY

Visit: <http://www.hnf-cure.org/team-cmt>

TEAM CMT



THANK YOU AND CONGRATULATIONS TO TEAM CMT RIDERS

BY COURTNEY HOLLETT, EXECUTIVE DIRECTOR, HNF

On Sunday, May 6, 2018, Team CMT took to the New York City streets to conquer 42 miles of the TD Bank Five Boro Bike Tour through each of Manhattan's five boroughs! The team was made up of patients, caregivers, family members, friends, and even a neurologist who specializes in CMT.

“What an amazing, unique way to see the city! This was my fifth time riding with Team CMT to raise money for HNF. Each year is more inspiring and fun than the one prior. I just love the array of musicians and performers cheering us along the 42 miles up and down hills, bridges, ramps, around NYC’s famous potholes, weaving through a throng of 36,000 other riders. A pleasure and an honor to ride and raise money for treatment and research for this underrepresented condition.”

— Tess Quadrozzi – Bike Rider, Fundraiser, Friend

“The Five Boro Bike Tour was amazing! They did an amazing job coordinating and organizing such a huge crowd. The energy was felt from the moment I arrived and lasted until we cruised through the finish line! I specially loved that we were able to represent HNF and our fight to raise money and awareness for Charcot Marie Tooth disease. Can't wait to do it again next year!!!”

— Debi Houliares, CMT6 Caregiver

HNF has been fortunate to be included as a charity team in the event for the past six years. We are thrilled to report we raised over \$23,000 for HNF's Therapeutic Research in Accelerated Discovery (TRIAD) program—a collaborative effort with academia, government and industry—to develop treatments for CMT. It's not too late to make a donation!

FOR MORE INFORMATION VISIT:

[HTTPS://BIT.LY/2RFENOP](https://bit.ly/2RFENOP) TO SUPPORT AND CHEER TEAM CMT TODAY!



DESIGNING A BETTER GRIP

ACTIVE HANDS Q&A WITH ROB SMITH

We love coming across empowering products with inspiring people behind them. When we learned of Rob Smith's story, and how his line of gripping aids came to be, we knew it was one worth sharing.

Often, our bodies are set to push further but hand atrophy stops us in our tracks. Whether it's in the gym, kitchen, office or outdoors, it's vital to keep the sense of independence and well-being that these activities provide. Thankfully, there are forward-thinkers like Rob who pave the way for others to pursue their best selves.

(Make sure to check out Rob's impressive video tutorials on the Active Hands website and enjoy an exclusive HNF discount below!)

Q: What is Active Hands and who is it for?

A: Active Hands is a company that manufactures and sells a range of gripping aids for those with reduced hand function from a number of congenital and acquired disabilities and conditions. This includes those with spinal cord injuries, MS, CP, Stroke, limb difference, and many other lesser-known conditions affecting hand function.

Q: How were you inspired to create the company and product line?

A: I have a mechanical engineering degree. I had a cliff fall accident between my second and third year at university resulting in a C5/6 spinal cord injury and both hands being severely affected. I designed the products to help me get back into the gym, and others saw them and wanted some for themselves. The company developed from there.

Q: Are all of the products on your site designed by you?

A: Active Hands has an ever-expanding range of products we manufacture ourselves in the UK. We also now sell some other products made by others that are designed to work really well for those with reduced hand function.

Q: How can/do your products improve quality of life for people with disabilities?

A: At Active Hands, we are passionate about helping people move forward with life in whatever way that's important to them. The mental, physical and social benefits of being able to achieve goals, partake in activities and be included rather than excluded in life cannot be underestimated. We understand that sometimes the smallest catalyst of being able to hold a dumbbell, kayak paddle, kitchen knife, gardening trowel, or pull up your own socks, fasten shoelaces, carry a cup of tea, etc., can be the start to someone pushing their own boundaries, becoming more independent or just changing their attitude to life. At Active Hands, we want to be that catalyst.

Q: What/who inspires you to design? Mentors, role models?

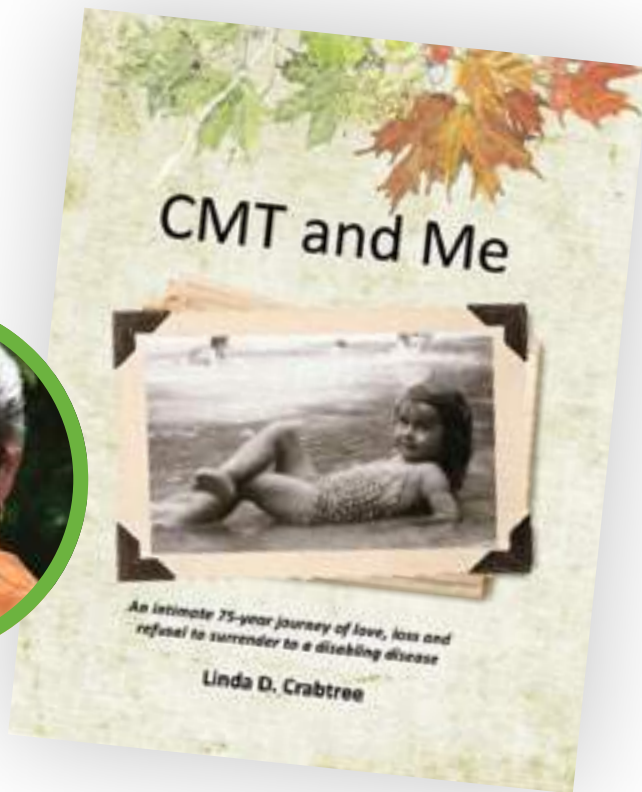
A: I think our own customers inspire us to design. The more we grow as a company, the more customers we come into contact with, and the more varied the conditions and disabilities we experience. If we can continue to learn about these new conditions and in some way assist our customers to make the small changes in life that make things a bit better, that inspires us to keep going.

10% discount code of "HNF10"

Valid June 1 – July 31st

www.activehands.com

FACEBOOK: ACTIVEHANDSCO TWITTER: @ACTIVEHANDSCO



Meet Linda Crabtree

Q: In your recently published autobiography, *CMT and Me: An intimate 75-year journey of love, loss and refusal to surrender to a disabling disease*, you talk about not giving in to CMT. Can you share a story about how you kept going?

A: When I was just a little kid, I wanted to do what all the other kids did, and my mother didn't stop me. I wore heavy metal braces as a child in the '40s, and slept in tendon stretchers that were hot and heavy, but I kept going. High school was horrendous because I kept falling down the stairs, but that didn't stop me from getting a good education, although I never did finish. I went back to school when I was older and had some clout to change things so that, finally, school worked for and not against me. I often had no difficulty finding work; however, getting to work and into the workplace was my biggest challenge. Stairs have always been a huge barrier for me. I worked outside of the house for approximately 15 years in photographic production and in a variety of newspaper editorial positions and then ran CMT International for 18 years from our home office. And, at 76, am still working, but for myself. I think that was the key: to be my own boss because it allows me to set my own pace and work from home. I've never been accused of thinking small or being lazy but, because of my CMT, I do have to do things my own way, and sometimes that doesn't fit with the way employers want things done. I've had very down periods in my life but have always found a way to turn things around so that I can use what I have left to make a difference.

Q: You were the pioneer in sharing information about living with CMT with people around the world from 1984 until 2002 — LONG before the internet and social media. How did that help you deal with your own CMT challenges?

A: I began looking for people with CMT back in 1984 because I couldn't find any information on CMT at all—anywhere—and I needed to know more about this condition that was changing my life. The many letters I wrote to newspaper editors all over North America brought in hundreds of letters from people telling me about their CMT and all wanting advice. I didn't have any advice to give them, so I designed the *CMT Newsletter* so we could all share what little each of us knew. Everyone helped everyone else and, eventually, we also included advice from doctors and professionals worldwide. We promoted research, gave out scholarships, and held conventions to bring people together. You can just imagine how my life changed when I had thousands of people with the same disease giving me a reason to move, to push, to work, to feel useful. I was working to find out about CMT, not just for myself, but for everyone else as well. I learned something new about CMT every day for 18 years, and most of that went into the *CMT Newsletter*. I had been a journalist and newspaper editor, so I knew how to put a newsletter together. You are right that it was long before the internet and social media, so mail was the only way to go and we used to it for 18 years to send out information to people all over the world. When we shut down *CMT International* in 2002, I put a great deal of that newsletter information on LindaCrabtree.com so it wouldn't be lost. It is still there, and much of it is still relevant today.

Q: In your book there are some exceptionally intimate passages concerning sex and sexuality, self-esteem, marital problems, and finding love. What prompted you to include this information?

A: I knew from the beginning that if I was going to write this book at all, I was going to be honest and forthright about everything. Why bother if you're going to cover up or exclude the things that changed your life? I believe that when any woman writes about her life, all women learn from it. What I've been through, millions of other women have been through as well, but it's always good to know that you're not alone. And, on top of everything, I was coping with the added stresses of CMT taking away my ability to walk and use my hands. Not all women find their second spouse through the personal ads in the newspaper, have an opportunity to design their own home, are given an honorary doctorate, or are awarded the highest honour their country can give: the Order of Canada and I also have the Order of Ontario.

We are entering a new age for women, and I may be 76, but I have believed all of my life that women should not be exploited but recognized as having sexual desires and needs just as men are. Women who profess to enjoy sex are often labeled as loose or sluts. Men who profess to enjoy sex and search it out are macho and virile. This double standard has been part of society forever. I'm hoping it will change now that women are speaking out.

Q: In your opinion, why has CMT not become as recognizable and researched as diseases like Multiple Sclerosis, ALS, or even Muscular Dystrophy?

A: I think part of the reason is that CMT is something that slides up on you. Because it is genetic, you were born with it. Some of us, like me, begin to see the signs when we are very young. For me, it was at 16 months. Others slowly see degeneration over the years, while some only notice their CMT in later years.

MS and ALS have been recognized for a long time. There are many types of Muscular Dystrophy, so I won't get into that. In the past, the literature on CMT, what little there was of it, reported that it is simply a nuisance. Since there is no cure or treatment, physicians simply ignored it. Now that we know what causes it, a great deal of research is being done, and because it can be diagnosed through blood tests, doctors are taking note.

Since 1984 there has been a great deal more literature pushed from the private sector to have CMT recognized as a condition with many secondary side-effects. These side-effects, such as vision and hearing problems, vocal cord and diaphragm paralysis, curvatures of the spine, hip dysplasia (there's a long list of symptoms in my book) can puzzle a physician if s/he doesn't recognize it as possibly (and I say possibly, because not everything should be chalked up to CMT) part of the CMT diagnosis, they can't properly treat a person with CMT.

Because the disease has been ignored for so long, it has taken years to interest researchers and to raise money for that research. Although it is estimated that there are three million people with CMT worldwide, there might only be one family in any given region and, because people with CMT can be few and far between, it is difficult to interest the public in

fundraising projects. It also seems that if a disease doesn't kill or totally incapacitate you, it doesn't get the respect or attention it deserves. Now that CMT is becoming more well-known and its ability to disable recognized, larger sums of money are being directed towards research, and that's what we need. In 1984, no one knew what caused CMT. Now we know and can go forward to learn to treat—and eventually—eradicate it.

Q: If you could give your younger, CMT self some advice, what would it be?

A: Back when I was a teenager, if I'd have known what CMT could do to me, I would have concentrated on getting an education in the sciences as either a psychologist, geneticist, or in one of the fields where I could use my brain 99% of the time and not have to stand, walk, or rely on my hands. As it was, I got my undergraduate degree in psychology but was unable to continue to get my masters/doctorate, simply because I was a mature student and didn't have the energy that I had when I was in my 20s. I would also value myself more. I didn't realize my potential back then. If you think smart about your future when you're young, you have a huge advantage when you're older. I think genetic and educational/career counseling is worth its weight in gold.

Q: You're quite the traveler! What tips would you offer to someone living with CMT who is anxious about traveling with a disability?

A: I really haven't traveled that much. I've been to the U.K. a couple of times and traveled across Canada and United States. I do run a website AccessibleNiagara.com for tourists with physical disabilities who want to visit the Niagara Falls, Ontario, Canada area, and have for the last 16 years. My advice is to do your homework before you go. Talk to other people who have CMT who have been where you are going. The way to do that is to get on the CMT Facebook pages. Some major cities and tourism venues have websites that tell you what is accessible, where to rent a scooter, wheelchair or other aids for daily living, and give you answers to basic questions before you leave home. Or, call ahead and ask if the venues you want to visit and the hotel you are thinking of using are accessible. The U.S. is pretty good, but other countries vary drastically.

Q: It is mentioned in your book that during the 18 years CMT International existed you worked with more than 10,000 people with CMT. Thank you for everything you've done for those with CMT you've touched over the years, Linda! How can people get your book?

A: *CMT and Me* is available on Amazon.com in 13 countries. The e-book is available for Kindle, Kobo, iBooks, Barnes & Noble and just about every other e-book distributor out there. The paperback is 328 pages (which includes a Resource section on CMT and symptoms often overlooked by the medical profession), plus 225 photos. The e-book has about one-third of the photos and identical text.

Working with my CMT peers for the past 34 years has truly been a life-changing pleasure, and I am still online almost every afternoon at linda@lindacrabtree.com.

TRAVELING *with* a DISABILITY

After a recent Facebook post by Bernadette got a lot of attention (and tons of questions), we thought we'd interview her and ask her to share her tips and tricks for traveling with a disability.

At the airport:

- ◆ Ask for a wheelchair if you don't have a scooter and you get to skip the lines
- ◆ If you're in a scooter, look for handicapped line
- ◆ There are usually ramps available — you just have to ask

Scooter tips:

- ◆ Bernadette uses a Gogo Elite Traveler (best advice: charge it every time it's not in use! Bring an extra charger, just in case.)
- ◆ See gate agent and let them know you need early boarding
- ◆ You can ride the scooter to door of the plane
- ◆ An airline employee will tag and store your scooter (they know what to do)
- ◆ It helps to know how heavy it is and the type of battery it uses
- ◆ To get to/from the airport or for sightseeing at your destination,
 - Request handicapped taxi
 - Uber offers handicapped rides in some places
 - Carry bungee cord in case you need to store the chair/scooter in a trunk that's a little too small

The concierge at your hotel can be helpful in so many ways

- ◆ They will request taxis or shuttles for you
- ◆ They can coordinate tours, shopping, reservations, etc. that take your special needs into consideration
- ◆ Request handicapped room (doors are wider, roll-in shower)
- ◆ Request shower chair (cover it with towel for comfort)
- ◆ They can provide information about getting around the property (ramps, elevators, courtesy shuttles/golf carts)

Many travel websites and apps are available to find accessible hotels, restaurants, pools, tours, etc.

- ◆ Expedia.com (Filter properties by Accessibility)
- ◆ Use Google Maps Street View to get the lay of the land before booking a hotel room
- ◆ Tripadvisor.com provides Search results for Wheelchair Accessible Restaurants, Hotels with Accessible Rooms
- ◆ There are some wonderful travel websites/blogs such as:
Paris in a Wheelchair
(<https://bit.ly/2wpXoow>)

Wheelchair Accessible Cities in Europe
(<https://bit.ly/2FWTDX8>)

Sage Traveling
(sagetraveling.com)

Rick Steves
(<https://bit.ly/20N6X9z>)



What are the Top Tips you have to share re:accessible traveling?

- ◆ Get a wheelchair at the airport!
- ◆ Carry 2 chargers for your scooter — just in case
- ◆ Use a lightweight manual wheelchair with pop-off tires — add a backpack that fits on the back of the chair
- ◆ Ask for elevators, or even a freight elevator
- ◆ If you haven't traveled with your wheelchair or scooter, you should!

Traveling with a CPAP or BiPap?

Things to do before you fly:

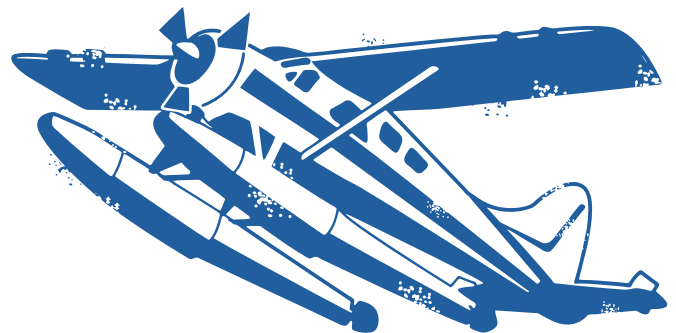
- ◆ Pack your CPAP prescription from your doctor in your CPAP case
- ◆ **Seat Guru (seatguru.com):** Pick a seat that has access to power if you need to use your CPAP machine on a long flight. Also, bring your airline's phone number and website with you to check their assisted device policy. The airline has the final approval for in-flight usage
- ◆ **FAA Compliance Letter:** Download from the manufacturer's website and keep with your CPAP machine
- ◆ **Transportation Security Administration (TSA):** Review the airport security page for medical conditions to confirm the process for CPAP machines (www.tsa.gov/travel/special-procedures)
- ◆ Review airline website for policies for using CPAP machine for in-flight use and restrictions for carry ons

Things to do when you fly:

- ◆ Bring your CPAP machine in its case as carry-on
- ◆ Prepare to show appropriate documentation (pack with your machine)
- ◆ Remove your CPAP from your luggage for security
- ◆ Turn humidifier off, and turn on airplane mode (if your CPAP machine has it)

Car Rental tips for traveling with a disability:

<https://bit.ly/2jLagfZ>
<https://bit.ly/2KPfkvT>



meet Dr. Raghav Govindarajan

MU Health Care

Raghav Govindarajan is a board certified neuromuscular physician at University of Missouri. He is the director of a neuromuscular clinic, as well the associate medical director of the neurology outpatient clinic. We caught up with Dr. Govindarajan to discuss his multifaceted approach to treating CMT.

Q. Why is CMT your passion?

A: Providing care to CMT patients is one of the most satisfying aspects of my job, and is one of the reasons why I became a neuromuscular expert. I am determined to find a treatment for CMT.

Q: Tell us what patients will experience when they come to the HNF Center of Excellence at MU Health Care and how they will benefit?

A: Patients will meet our CMT team, all of whom will provide expert and compassionate care. Patients will also have access to latest therapies and research. Patients will be evaluated by neuromuscular physicians who specialize in CMT care and a multidisciplinary team that can treat the patient from varied perspectives.

Q: What other doctors will patients be able to see when they visit the HNF Center of Excellence?

A: Patients will see physical therapists, occupational therapists, orthotists, wheelchair experts and social workers.

Q: What kind of success stories have you seen so far with CMT patients?

A: I have many success stories with CMT, but two instances come to mind. First, a patient who was misdiagnosed as alcoholic neuropathy and neglected came to us for a second opinion. We did electrodiagnostic testing, which pointed towards CMT, and gene testing confirmed it. Second, a patient who had CMT had developed ulcers on the foot due to ill-fitting orthotics. Our wound care experts helped with healing of the ulcers, and our orthotic expert fitted the perfect shoes!

Q: How can patients make an appointment at the HNF Center of Excellence?

A: Patients can make appointment by having their primary care physicians fax their records to us at 573-884-4199. Visit here to schedule and appointment: <https://bit.ly/2L28Hqk>
Patients can also email me directly at govindarajanr@health.missouri.edu

**Find an
HNF Center
of Excellence
near you:**

<https://www.hnf-cure.org/centersofexcellence/>

American Academy of Neurology
Annual Meeting, April 21-27.
Left to right: Courtney Hollett,
Dr. Govindarajan, Allison Moore



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 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

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University of Florida Health
2004 Mowry Road
PO Box 100332
Gainesville, FL 32610
Contact: Tracie Kurtz, RN, CCRP
Phone: 352-273-8517
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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
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Email: njenci@kumc.edu

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75 Francis St, Tower 5th Floor
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University Of Michigan
Pediatric Rehabilitation Center
2205 Commonwealth Blvd.
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MINNESOTA

University of Minnesota Health
Neurology Clinic
14500 99th Avenue N
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E-Mail: CNRU@umn.edu
For Clinic Appointments:
Phone: 763-898-1080

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Email: ellersc@slu.edu

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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

Events

6/2/18

7/21/18

9/28-29

11/4/18

UPCOMING 2018 EVENTS

Save the date!

An Evening for
Charity
New York City

Grace's Courage
Crusade's Summer
Celebration
Charlestown
Rathskeller Tavern

"Voice of the
Patient" Patient
Weekend
Washington, D.C.

TCS New York City
Marathon
New York City

TCS New York Marathon Update

On Sunday, April 15, 2018 HNF's Allison Moore and Joy Kaye participated in the SHAPE Women's Half-Marathon on a chilly spring day with more than 6,000 runners. In a show of support, Lorrie Burger, a long-time high school friend, joined the duo.

Allison and Joy used this half-marathon as a stepping stone to train for the big day, the New York Marathon, on November 4, 2018.

"Despite the cold temperature and blustering wind, it was great to be out with such a great group of strong women"

– Joy Kaye

Visit HNF's TCS New York Marathon page to learn more about all the runners:
<https://bit.ly/2K5gjHj>



An Evening for Charity

June 2, 2018 in New York City

HNF is excited to host this event at BH Kitchen & Bar — a newly renovated NYC restaurant — located in the heart of midtown.

The evening will be filled with dinner, drinks, and music!

You can also try your luck at the poker tables, or take a chance at the Blackjack or roulette table to win great prizes! There will also be an array of silent auction items to bid on through the evening.

All proceeds will go towards the Therapeutic Research in Accelerated Discovery (TRIAD) program, a collaborative effort with academia, government and industry, to develop treatments for Charcot-Marie-Tooth (CMT).

Purchase your tickets here:
<https://www.hnf-cure.org/an-evening-for-charity/>

Sign-up for September Awareness Month (Team S.A.M.)

HNF wants you to help spread the word about Charcot-Marie-Tooth (CMT) this September. Sign-up to be on Team S.A.M. and learn more about happenings and help make CMT the biggest disease everyone has heard of!

SIGN UP HERE:

<https://bit.ly/2lwhmmD>

Fundraiser for CMT2 in Rhode Island

Join Us For Grace's Courage Crusade's 10th annual fundraiser for CMT2. The summer celebration hosted by the Caldarone/Sidoti Family will take place Saturday, July 21, 2018 from 4:00pm - 8:00pm at the Charlestown Rathskeller Tavern. Enjoy games, tournaments, raffles, great food, karaoke, and relax by the fire pit!

All proceeds will go to the Hereditary Neuropathy Foundation to fund research for CMT2.

Register today: GCCcure.org



**HEREDITARY
NEUROPATHY
FOUNDATION**

hnf-cure.org

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New York, NY 10016

Hereditary Neuropathy Foundation

@CMTNeuropathy



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