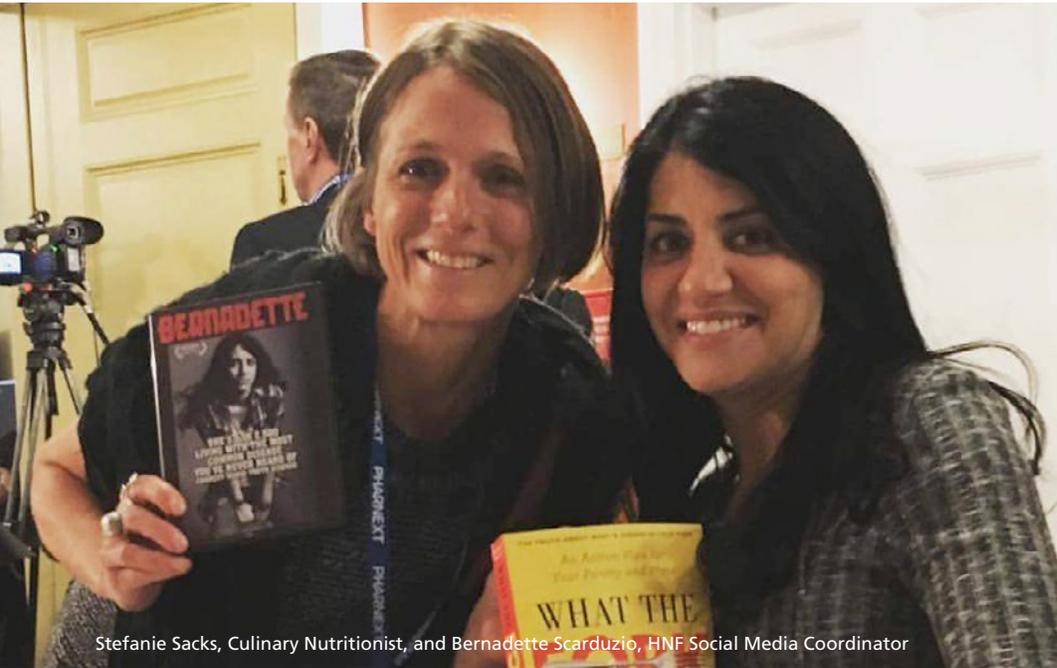




cmtupdate



Stefanie Sacks, Culinary Nutritionist, and Bernadette Scarduzio, HNF Social Media Coordinator

Inaugural Patient-Centered CMT Summit Successfully Breaks New Ground

BY ALLISON MOORE, CEO/FOUNDER, HNF

On October 6, 2016, HNF presented the first-ever Patient-Centered Charcot-Marie-Tooth Summit at the 3 West Club in New York City.

The Summit hosted over 160 attendees, including CMT patients, caregivers, and top leaders in industry, research, and treatments. This landmark event focused on the CMT patient, providing a unique opportunity for patients to voice their needs and concerns, learn about the latest in research and clinical trials, and connect with others having CMT in their families.

The day began with opening remarks by HNF's CEO and Founder Allison Moore and HNF's Chief Science Officer Sean Ekins. We then had the honor of having Stefanie Sacks, culinary nutritionist, MS, CNS, CDN and author of *"What the Fork Are You Eating?"*, deliver an inspiring keynote, giving us an action plan for smarter nutrition as part of the patient prescription for healing and using food as medicine.

The rest of the morning was jam-packed with presentations discussing becoming a patient of the future, the state of gene therapy, public policy, and the latest research on translational drug discovery and clinical trials.

Gary Barg, CMT patient and caregiver advocate, led a panel and audience discussion during the lunch, taking questions from patients and caregivers about how to reduce caregiver stress, communicate effectively with health care providers, and the caregiver's role in clinical trials.

The afternoon featured a panel on nutrition and exercise and hearing from CMT patients about how they manage their symptoms. Speakers and patients also addressed gaps in patient-reported outcomes, barriers to therapy development, and knowledge gaps among health care professionals. We learned how to identify

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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.

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SUMMIT WRAP-UP

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providers well-versed in CMT, what patients should expect from their providers, and how they can advocate for themselves or their loved ones.

CMT patients also got the opportunity to hear first-hand about the latest developments in clinical trials and what they need to know before participating in a clinical trial.

The Summit ended with a surprise guest speaker: Mr. Charcot-Marie-Tooth himself!

Mr. Tooth was actually Robert Moore, husband to Allison Moore. Dressed up in a tooth costume to discuss a “man on the street interview” video about CMT, Mr. Tooth wryly pointed out to the audience that most people interviewed in the video thought that CMT was a dental disease. Robert made his point clear to the audience — we have a disease-name awareness problem. Saddled with a long and confusing name, awareness continues to be an uphill battle for the entire CMT community.

However, it’s a battle we are prepared to take on, and the success of this Summit is proof that we are moving forward with confidence. On-going initiatives like CMT-Connect, local fundraising events, and sharing on social media are pushing our community further into the spotlight, giving CMT patients the attention, treatments, and unique care they deserve.

After the closing remarks, attendees had a chance to get together for an evening reception, where everyone acknowledged the amazing turn-out and celebrated the success of the Summit.

Here’s what some of our attendees had to say about the Summit:

“For the past ten years I have basically been ‘going at it alone’ with regard to this health challenge, and I have to say that it was wonderfully reassuring to suddenly have so much support!”

— Katharine Le Mee

“It’s not very often you meet a room full of people from all over the world and immediately feel like part of the family, and that’s exactly how the conference felt. Although this terrible disease has brought us all together, together we are stronger!”

— Greg, Carlee and Jakeb Lutz

“I can’t thank HNF enough for allowing us this opportunity. Not only did we learn, we also met a lot of great people AND we got to tour NYC for the first time in our lives. My son benefitted so much from this event. He cried when he had to leave the conference because he felt so much at home with everyone there. I cried for him because I wish he could be around more people like you all who understand. It truly was a priceless experience for us and for him to know he is NOT ALONE!”

— Summit Attendee

All of us at HNF want to express our thanks to the CMT community, our sponsors, and speakers for making this first Patient-Centered Charcot-Marie-Tooth Summit such an outstanding success!

Top left: Courtney Hollett (HNF Fundraising Coordinator), Kristin Gelzinis (CMT Patient) Debi Houliares (HNF Board Member). Top right: Allison Moore (CEO/Founder HNF), and Dr. Mark Gudesblatt (South Shore Neurologic Associates, P.C.). Bottom left: Bernadette Scarduzio (HNF Social Media Coordinator), and Estela Lugo (HNF’s Creative Director). Bottom center: Robert ‘Mr. Tooth’ Moore (Allison Moore’s husband). Bottom right: Panel discussion on the “Art of Being a Successful Patient.”



Dear HNF Community Member,

Holiday greetings to you and your family at this most wonderful time of the year. At HNF, all of us want to express our immense gratitude to you for being a part of this ground-breaking year for the entire CMT community!

As I continue to fight for CMT awareness, advocate for patient-centered research, and support everyone impacted by CMT, I could not direct HNF's efforts and movement towards a cure without generous support from all of our collaborators, sponsors, volunteers, and donors. I feel pride that we are leading the fight in translating and supporting therapies to treat—and ultimately cure—CMT.

2016 has been such a momentous year for HNF and the CMT community. Just look at what we've accomplished together!

Therapeutic Research In Accelerated Discovery (TRIAD):

HNF has been actively partnering with industry to help facilitate clinical trials with focus groups, expert meetings, and clinical sites selection. In addition, we have been actively translating HNF's drug and gene therapy assets to treat various forms of CMT. HNF continues to collaborate with Pharnext on the phase 3 clinical trial for CMT1A. This is an exciting time for our community. Stay-tuned as we will be announcing shortly new clinical trials for various forms of CMT.

Inaugural Patient-Centered Charcot-Marie-Tooth Summit:

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

CMT/IN Natural History Study:

Over the Summer, the National Organization For Rare Diseases (NORD) announced that twenty rare disease patient groups were selected to partner with NORD to develop natural history studies, supported in part by a cooperative agreement with the U.S. Food and Drug Administration (FDA). The Hereditary Neuropathy Foundation (HNF) was proud to be included among the leading rare disease groups chosen for this major project. The effort will fill the research gaps currently challenging our understanding of how our disease progresses over time.

HNF-Designated CMT Centers of Excellence Network:

In the Spring, we announced our new national network designating medical Centers of Excellence (COE) for the CMT patient community. Our initial 10 centers have now been increased to

12 with the addition of Hackensack University Medical Center in Hackensack, NJ and the University of Michigan in Ann Arbor, Michigan. The designated COEs demonstrate expertise in providing excellence in CMT clinical care and research, and serve as a collaborative network to partner with HNF to continuously improve clinical care, encourage community engagement, run clinical trials, pursue research opportunities, and provide training/education.

CMT-Connect

HNF is proud of its newest program, CMT-Connect, an holistic educational workshop in New York. These workshops offer a safe environment to talk about the emotional dynamics of dealing with a chronic illness while encouraging and empowering participants to be proactive advocates for their own care, quality of life, and wellness needs. These innovative patient-centered workshops will be launching soon in other states.

Inspire Community Growth:

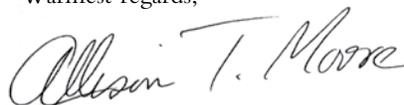
Since its inception in 2010, Inspire's on-line Charcot-Marie-Tooth (CMT) support group and discussion community has grown to over 3,500 members, connecting patients, families, friends, and caregivers with one another for support and inspiration. The Inspire community continues to host impactful discussions on CMT diagnosis, managing symptoms, and treatment options such as bracing, orthotics, and exercise.

While the year was filled with ground-breaking accomplishments, our work is not done: until we find a cure and every CMT patient has access to—and can afford—the health care they and their families deserve, the fight continues!

As a non-profit organization, we depend on your donations to support our programs and create new initiatives to advance and accelerate CMT awareness and research. Especially this giving season and throughout the New Year, we would be grateful for your generous support as we continue to work for you and your family. To make a donation today [CLICK HERE](#)

Thank you, and wishing you and your loved ones a healthy and happy New Year!

Warmest regards,



Allison T. Moore
CEO/Founder HNF



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.

Thank You to Everyone Involved with PLEO-CMT Trial!

CMT1A is the most common type of CMT, affecting approximately 2.8 million people across the globe. For those diagnosed with CMT1A, managing their disease is limited to orthotics, leg braces, physical, and occupational therapy or surgery because currently there is no cure or drugs approved for use.

The good news for our community is that, for the first time, a drug candidate has reached Phase 3 clinical trial, the critical last phase before potential FDA market approval. This pivotal Phase 3 clinical trial is testing Pharnext's lead investigational PLEODRUG[®], PXT3003 for the potential treatment of Charcot-Marie-Tooth Disease Type 1A (CMT1A).

Clinical trials are a vital part of the scientific research process and essential for developing therapies to prevent, treat, reverse and cure CMT. Clinical trials are staged as phase 1, phase 2 and phase 3 for testing before a therapy reaches its final review by the FDA for approval to be marketed.

It takes real teamwork to make a clinical trial successful! From the researchers and developers at Pharnext, the clinicians in the field and our designated Centers of Excellence, to the patients who have already participated — all contribute to this effort and play a vital and crucial role in moving a therapy forward.

HNF wants to say THANK YOU to all who are currently involved with the Phase 3 PLEO-CMT study, as well as those who participated in the earlier Phase 2 trials as well. Our community would not find itself at the cusp of having a potential therapy without everyone's efforts, especially the patients who have participated so far to get us here.

PLEO-CMT is an international pivotal Phase 3 study that was initiated in December 2015 and is planned to enroll 300 patients with mild to moderate CMT1A from Europe, U.S., and Canada by the end of December 2016. Patients are randomized in three arms — placebo and two PXT3003 doses — and will receive study treatment over 15 months. PXT3003, developed using Pharnext's R&D platform PLEOTHERAPY[®], is a novel oral fixed-low dose combination of (RS)-baclofen, naltrexone hydrochloride and D-sorbitol.

We are also pleased to hear that the independent Data Safety Monitoring Board (DSMB) has just completed its first pre-specified safety evaluation of PXT3003 in the on-going PLEO-CMT Phase 3 clinical trial. Based on a review of safety data from 100 patients who completed at least three months of study treatment, the DSMB recommended continuing the PLEO-CMT study as planned. The DSMB is an independent body of experts drawn from the fields of clinical medicine, biostatistics and study methodology, chartered to provide recommendations to Pharnext upon regular pre-specified review of the accumulated data during the conduct of the clinical trial.

“We believe this clinical trial has the potential to be a crucial turning point in the effort to finally provide an efficacious treatment for patients suffering from CMT1A,” said Daniel Cohen, M.D., Ph.D., co-founder and CEO of Pharnext. *“Today's therapeutic options are very limited and mostly palliative in nature. Our PLEODRUG[®] PXT3003 has already demonstrated safety, tolerability and improvements in CMT1A patient disability in a Phase 2 trial. Given this positive safety assessment by the DSMB, we are hopeful to bring this much needed potential therapy to patients suffering from this debilitating condition upon completion of this Phase 3 trial.”*

TO LEARN ABOUT MORE ABOUT INCLUSION AND EXCLUSION CRITERIA AND TO SEE A COMPLETE LIST OF LOCAL TRIAL SITES VISIT: WWW.CLINICALTRIALS.GOV AND ENTER PROTOCOL # NCT02579759.



HNF Supports Patient-Focused Drug Development (PFDD)

HNF firmly believes the patient's voice must be represented throughout the research and development cycle if we are to hope for future therapies and cures that meet our needs. If researchers have a better understanding of what patients' experiences are and what is important to them in their daily life, they will then have a more informed approach to how they develop new treatments. By ensuring the patient's perspective is built into the process already during the early stages of research, we can then play a major part—and be a strong partner—in the translational phase (moving from lab to clinic) to improve the outcomes of clinical trials.

As we move into 2017, HNF will continue its work to represent our whole disease population by growing our existing patient-reported data networks and implementing new ones that can be shared with those researchers, clinicians, industry partners, and governmental agencies that care about rare diseases. HNF is your voice about what symptoms and functions matter most to you and the families with CMT: we need to hear about it from you!

As we find ourselves with the first potential treatment

for CMT on the horizon—and others coming soon into the pipeline—HNF has the sophistication and the infrastructure to empower you as patients and caregivers to provide information that can be harnessed by others. With your input, we can continue to grow our robust data-sets of patient perspectives regarding living with CMT, which can, in turn, inform and improve drug and gene therapy development, regulatory reviews of trials, and standards of patient care.

We'll be taking this message on the road when we kick off 2017 by joining other groups for Rare Disease Day on February 28th in Washington, DC. HNF is planning to host a CMT-Connect Workshop to observe the day, and we will also be joining the EveryLife Foundation on Capitol Hill for Rare Disease Week to highlight the challenges facing those with rare diseases.

Be sure to share your voice because your voice counts—and HNF is fighting to make sure your voice is heard. There is much ahead to be hopeful about...and, with your help, we want to ensure that this hopeful future brings you what you need to improve your life with CMT!

HNPP Study Available for HNF Members

Ayse Deniz Elmali, MD is a neurologist and a researcher. Her never-ending intellectual curiosity has led her first to Istanbul University, Cerrahpasa Medical Faculty and then to residency at the same university. Being in love with the complexity of the human nervous system, she decided to specialize in neurology. As Hippocrates wrote "Wherever the art of Medicine is loved, there is also a love of Humanity." Acknowledging her patients as her loved ones based on that quote, she decided to devote herself to trying to improve their lives. Since CMT and related inherited neuropathies cause a huge impact in patients' daily lives, she developed a passion to understand these diseases further in order to find better ways to cope with them.

This study, which aims to uncover the rather unrecognized symptoms of Hereditary Neuropathy with Liability to Pressure Palsy (HNPP), was born from that passion: in order to get a clearer picture of HNPP, understand the patients better and find ways to help them more efficiently. A form of peripheral neuropathy, for those with HNPP even a short period of pressure can result in tingling, numbness, weakness, pain, or even paralysis of the affected area. Symptoms and their duration are variable, with palsies lasting from minutes to days, weeks, or even months.

HNF's members are invited to take part in a special online scientific study that hopes to uncover the unrecognized symptoms of HNPP. This scientific study, approved by the committee of the Istanbul University, Cerrahpasa Medical Faculty, is being conducted by Dr. Elmaliat Istanbul University, Cerrahpasa Medical Faculty, Neurology Department.

HNF members are being asked to participate as the control group. CMT1A and HNPP patients, as well as healthy individuals, will be asked to complete a survey, which will take 30-40 minutes

to complete, and will include demographic questions and five questionnaires to collect symptom information, including:

- Checklist for individual strength, fatigue.
- Epworth sleepiness scale, addressing daytime sleepiness.
- ID-Pain, addressing pain.
- Beck depression inventory, monitoring depressive symptoms.
- SF-36, measuring quality of life.

If at any point you feel uncomfortable with a question, you can skip that question or withdraw from the study altogether. If you decide to quit at any time before you have finished the questionnaire, your answers will NOT be recorded. Your participation remains completely confidential: your answers will only be used for scientific purposes and will remain anonymous.

The study outcomes will be presented in educational settings and at professional conferences, and the results may be published in a professional journal in the field of neurology. Sharing the results with other professionals promotes an enhanced understanding of what those with HNPP are experiencing and how best to treat them.

If you have CMT1A, HNPP, or are not affected by CMT1A or HNPP, please consider contributing to this special study so we all have better information that can be used to improve care and treatments! You can sign up for the study here:

THE LINK FOR BOTH CMT1A AND HNPP PATIENTS: [CLICK HERE](#)

THE LINK FOR THE HEALTHY CONTROLS: [CLICK HERE](#)





Natural History Study to Support CMT Research

BY JESSICA ROBERTS, WRITER, HNF

The Natural Organization for Rare Diseases (NORD)—an independent charity that built its natural history study platform for rare diseases and is supported by a cooperative agreement by the the U.S. Food and Drug Administration (FDA)—has awarded Hereditary Neuropathy Foundation (HNF) funding to build a robust natural history study to support the second most common type of Charcot-Marie Tooth (CMT) called hereditary neuropathy pressure palsies (HNPP), as well as the rarer types where there are major gaps of information, including CMT2A with visual impairment/optic atrophy, CMT2C, LMNA mediated AD-CMT2, CMT4 (4A, 4B1, 2 & 3, 4C, 4D, 4E, 4F, 4G, 4H and 4J), CMT6, Autosomal Dominant Optic Atrophy (ADOA) and Giant Axonal Neuropathy (GAN), which often has unique and severe symptoms that may be fatal.

HNF is proud to be one of twenty leading rare disease groups selected for this NORD initiative. HNF sees great opportunity in partnering with NORD to fill the research gaps that can lead to a better understanding of how these rare diseases progress over time.

Natural history studies are imperative in our understanding of rare diseases like CMT. Identifying the more unique symptoms among CMT patients—such as optic atrophy (including vision impairment and blindness), hand tremors, vocal cord paresis, hearing loss, and cognitive deficits—can produce the vital information needed for clinical trial design.

“To date, there is no cure for CMT/IN; however, there are clinical trials underway for the most common type, CMT1A,” shares Allison Moore, HNF founder and CEO, who herself has CMT1A, as do several members of her family. “But for the rarer forms, which often have very severe symptoms, there is less hope for treatments and cures. I am passionate about ensuring that all types of CMT/IN have pipeline drugs and gene therapies to support the patient community. Collecting patient-reported information will be invaluable and will be made available to any researcher or drug or gene therapy developer interested in creating therapies for CMT.”

“The new Natural History Study is part of HNF’s Charcot-Marie-Tooth Research Network (CMTRN) and enables us to provide a complete picture of each patient’s experience with CMT/IN,” adds Moore. “We are launching this initiative to help identify patients with HNPP and the more rare forms of CMT/IN. In order to improve patient care and advance therapy development, it is critical that we collect pertinent data to help our stakeholder community.”

To date there is very little data on the rare forms of CMT/IN, and finding patients all over the world is critical in therapy development. If you are a patient or a family member (or know

someone with CMT/IN), please join this critical study.

To help drive awareness and study participation, HNF will push outreach through all of its community programs, including Inspire On-Line CMT Patient Community, CMT-Connect Workshops, Health Care Provider On-line Directory, Patient-Centered CMT workshops, and HNF’s strong social media network.

“Our goal is to enroll as many patients, as possible,” explains Joy Aldrich, HNF advocacy director and moderator for HNF’s Inspire On-Line Support Group. “The success of this natural history study is dependent upon community participation: we need all CMT/IN patients to participate.”

“As the mother of a son with CMT6, it is so exciting to see our community having access to a study that not only includes the rarer forms of CMT, but enables us to track these diseases over time to identify and validate the daily physical and quality of life challenges we know we are struggling with—but have yet to have had a way to document and quantify these challenges in any sort of productive, scientific way for future research,” says Debi Houliares, community advocate and HNF board member.

The CMTRN supports natural history studies via electronic surveys that collect patient experience and disease progression information. Patients (or their caregivers or guardians) can enter information from anywhere in the world. 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. This format is approved by the study’s governing board, which includes scientists, healthcare providers and patient advocates.

NORD president and CEO Peter L. Saltonstall says, “NORD’s natural history studies platform empowers patients and families to drive research and eliminate some of the unknowns that still exist in rare diseases. We are glad to be working with the Hereditary Neuropathy Foundation, one of our member organizations, on this project, and we thank the FDA for its support and on-going commitment to help people with rare diseases.”

HNF is excited to be a part of NORD’s Natural History Studies Project. Stay tuned on our HNF Facebook Page or sign up for our CMT Update newsletter to stay current on the latest developments of this historical initiative! And if this study applies to you, once the study opens, be sure to sign up so we can make this study as effective as possible! And help us alert others to participate as well!

HNF'S CMT CENTERS OF EXCELLENCE NETWORK IS GROWING!

HNF is pleased to announce that Hackensack University Medical Center in Hackensack, NJ and the University of Michigan in Ann Arbor, MI have been added to our growing national network of medical Centers of Excellence for treating CMT.

"HNF's primary goal for our national HNF Centers of Excellence (COE) program and designation process is to ensure that care access and processes result in positive outcomes for each individual patient's clinical experience," shares Allison Moore, HNF founder and CEO. "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

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MICHIGAN

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Q&A on Essential Oils with Sarah Miller



Essential oils are naturally occurring, volatile aromatic compounds found in the seeds, bark, stems, roots, flowers, and other parts of plants. These oils can be used for food preparation, beauty treatment, and various emotional and physical wellness applications.

We wanted to learn more about essential oils and how they can be used to help manage the symptoms of the CMT patient, so we reached out to Sarah Miller, a Wellness Advocate with doTERRA essential oils.

Let's hear more from Sarah...

Q: Tell us about yourself...

A: I hail from Upstate New York, home of the best apple cider donuts, record-breaking cold winters, and the breathtakingly beautiful Adirondack Mountains. I ventured to NYC to pursue my acting career, which, oddly enough, is how I was introduced to doTERRA's amazing essential oils.

I am a proud Wellness Advocate with doTERRA, and I take great pride in being part of their company's mission. I have been sharing and educating people on essential oils and other wellness products for over a year and a half, and have been using them myself for even longer. It has been my pleasure to empower others on taking control of their physical, mental and emotional health by using Mother Nature's natural solutions.

Q: How did you get involved with essential oils?

A: I was introduced to essential oils through an acting class. I have found that as you reach a certain caliber of acting, you are surrounded by talent that is extremely in tune with the health and well-being of their bodies. I took a workshop on how essential oils could add value to my experience as an

actor was completely blown away.

I was taught what essential oils were exactly, how to use them safely and effectively. Whether it was teaching me how to service the cells in my body for increased energy, or helping me stay present and grounded when nerves arise, or keeping my immune system strong to stay healthy on set, as well as in everyday life, there seemed to be an oil for everything. And, like many actors here in NYC, I didn't have health insurance at the time—so learning how to take care of my own health and well-being naturally was truly empowering.

Q: How can essential oils help individuals within the CMT community?

A: Essential Oils will be able to offer a wide variety of support both, physically and emotionally, within the CMT community. For example, a major contributing factor to neuropathy includes inflammation of the nerves. Eucalyptus, helichrysum and frankincense essential oils are just 3 of MANY that have anti-inflammatory properties that would offer support for those who suffer from CMT.

Essential oils are also a great tool used in aromatherapy, providing amazing emotional support. Diffusing essential oils helps create a calming and serene environment that can lift your mood and help reduce stress, depression and anxiety. And believe it or not, all of this is just the tip of the iceberg in how essential oils can add value to your community.

Q: What are your favorite oils and why?

A: Truth be told, I have a lot of favorite oils and they change on a daily basis. One of my absolute favorites would have to be a blend called On-Guard that is a great immune booster. Plus,

it smells like Christmas! It is made up of clove, orange, cinnamon, eucalyptus and rosemary oils.

I also love peppermint oil, which I use for lots of things including releasing tension in my body and helping me focus. It also provides great respiratory support. Clary Sage is another essential oil staple found in my arsenal. I apply this to the top of my spine morning and night for hormonal support. I make sure to have at least 2 bottles at all times!

Q: What makes doTERRA oils stand out among other oils?

A: doTERRA is partnered with renowned botanists, chemists and scientists to research and test our oils and products. They even partake in 3rd-party testing to ensure purity. This not only legitimizes our oils, but it sets a higher standard for the industry as a whole.

All of doTERRA's oils are Certified Pure Therapeutic Grade (CPTG). Their company mission and ability to give back is equally impressive showing tremendous integrity. They have used their non-profit charity "The Healing Hands" to practice co-impact sourcing, which honors sustainable agricultural traditions with farmers around the world.

Just like HNF, the foundation strives to help people live free of disease and empower them with the tools needed to improve quality of life through both physical and emotional support.

UPCOMING WEBINAR!

Be sure to join us on January 12th at 7pm for the patient-centered CMT-Connect Workshop on essential oils. This session will be unique as we will be offering a webinar for those that are out-of-town to join in.

[REGISTER HERE](#)

COMING SOON!

HNF Takes CMT-Connect On-Line!

HNF is excited to announce our first CMT-Connect Workshop webinar on January 12, 2017 from 7:00-9:00pm.

We will be bringing the world of essential oils into your homes for an in-depth look at how these pure extracts can significantly improve daily life and overall health.

Sarah Miller, wellness advocate and essential oils enthusiast, will host a live workshop for patients with CMT-specific symptoms such as fatigue, digestive problems, numbness/tingling, respiratory issues, pain, migraines, circulation, skin irritation and depression.

She'll be sharing doTERRA testimonials, suggestions, and the medicinal science behind these natural oils. See page 8 to learn more about essential oils and Sarah's work.

Join us for a fun and interactive evening while empowering yourself towards better health in 2017!

REGISTER TODAY! [HERE](#)

COMMUNITY

RICK'S RV ROAD TRIP TO SPREAD AWARENESS FOR CHARCOT-MARIE-TOOTH

BY COURTNEY HOLLETT, FUNDRAISING COORDINATOR, HNF

On December 1, 2016, Richard Cole (Rick) began his journey on the road in an RV — and his road-trip will help spread awareness for Charcot-Marie-Tooth (CMT). His solo travels around North America will present new challenges to those he already faces every day while living with CMT.

Rick was diagnosed with CMT Type 2 in 1997. Both of his sisters are completely “disabled” by CMT, and his nephew and two cousins also have the disease.

Rick decided to take this journey to do some advocacy work for CMT'ers, and also to help others with disabilities live the RV lifestyle. Rick will be documenting his travels on his website, and he plans to shoot some video segments along the way so he can share all of his successes with us via his weekly blog.

Rick has not committed to any specific destinations on his journey—instead, he has decided to let the new people he meets along the way guide his travels.

HNF is excited that Rick will be documenting this amazing journey and sharing his experiences weekly with the CMT community. Be sure to visit CMTRVer.org to learn more about Rick's story.

And please check back to his website regularly to follow Rick on this amazing adventure! Visit CMTRVer.org!



September

= CMT Awareness Month!

This year's observation of CMT Awareness Month was filled with new initiatives and exciting events, providing the CMT community with tools, resources, and support to meet the challenges of living with this rare disease. Each year, your participation in CMT Awareness Month supports HNF's mission to increase awareness, raise research funds, and find a cure for CMT!

Our 2016 outreach community efforts included:

NEUROTOXIN WALLET CARDS

Thank you to the 254 individuals who donated to receive our Neurotoxin Wallet Cards! Tiny—but mighty—this card keeps you prepared with critical information to discuss with your health care providers. Don't have your card yet? You can still order a card today at: [CLICK HERE](#)

CMT MOON RUN

Thank you to everyone who donated and shared our Moon Run video on social media: [LOOK HERE](#). We're so excited to be teaming up with AlterG to promote this groundbreaking weightlessness rehabilitation therapy technology to CMT patients. We love hearing new running stories each week from our community, and we are dedicated to helping patients find a machine in their local area: [CLICK HERE](#)

CMT-CONNECT

Thank you to all of our "CMT-Connectors" for participating in our monthly local workshops as we continue to build out this new initiative. We love watching friendships grow as we step outside our comfort zones and take on new and empowering activities towards better health and living. Recent events have featured yoga, horseback riding, and wall climbing — and we have more great things planned ahead! Register for our January event [HERE](#)

2016 PATIENT-CENTERED CHARCOT-MARIE-TOOTH SUMMIT

The immense success of HNF's first Patient-Centered Charcot-Marie-Tooth Summit in New York City would not have been possible without your generous support. This ground-breaking event brought together patients, caregivers, HCPs, researchers, and industry in a comprehensive discussion that addressed what it means to live with CMT—and focused on what our community needs today to improve the care currently delivered while we aggressively work towards tomorrow's cures. We are forever grateful to all of our corporate partners and sponsors.



TOP 10

Ways to Spread CMT Awareness

BY COURTNEY HOLLETT, FUNDRAISING COORDINATOR, HNF

“You have what?”

This is a common response when you tell someone you have Charcot-Marie-Tooth disease.

We don't just have CMT: we have a disease name awareness problem!

How can we, together as a community of patients, caregivers, and health care professionals, work to solve this problem?

HNF HAS COME UP WITH TEN WAYS YOU CAN DO YOUR PART AND HELP ALL OF US SPREAD CHARCOT-MARIE-TOOTH AWARENESS:

1. Purchase a bumper sticker to display on your car [CLICK HERE](#)
2. “Share” posts created by HNF on social media outlets ([FACEBOOK](#), [TWITTER](#)) — and change your profile picture every now and then to show an infographic about CMT.
3. Educate friends, family and teachers by using the “Arlene on the Scene” books (for elementary school age) [AVAILABLE](#) through HNF or showing them the Bernadette Scarduzio video, also [AVAILABLE](#) from HNF.
4. [JOIN](#) “Team CMT” and wear your shirt around town, at the gym or at events you attend.
5. Reach out to local government officials and health care providers to educate them about CMT and give them the [ESSENTIAL GUIDE](#) from HNF.
6. Host an event or [START](#) a fundraising-letter writing campaign.
7. [JOIN](#) the online Inspire Community: if you already are a member, suggest to your CMT friends and family that they join as well.
8. [JOIN](#) HNF’s Global Registry for Inherited Neuropathy to improve future research efforts — and encourage others to do the same!
9. Work on your “elevator speech” — a quick, 10-15 second explanation of CMT and how it affects you.
10. Show your AFOs loud and proud!

UPCOMING 2017 EVENTS

Save the date!

1/12/17

CMT-Connect
Workshop Webinar
7:00pm

2/28/17

Rare Disease Day
Washington, DC

5/7/17

TD Five Boro
Bike Tour
New York City



BIKE NEW YORK

May 7, 2017

TEAM CMT

For the eighth year in a row, HNF will be participating as a Charity Partner in the 2017 TD Bank Five Boro Bike Tour! We are thrilled to again be a part of this extraordinary event where participants bike through all five New York boroughs to help increase awareness and raise dollars to fund Charcot-Marie-Tooth (CMT) research.

Scheduled for May 7, 2017 (always the first Sunday in May), the TD Five Boro Bike Tour is America's largest cycling event. The event provides riders the unique and fun experience of biking along a 40 mile, traffic-free route accompanied by 32,000 other cyclists.

The ride begins just north of Battery Park, runs up Manhattan, through Central Park, around a brief loop in the Bronx, and down to the Queensboro Bridge, passing countless New York City icons along the way. After a ride over the Pulaski bridge passing through Brooklyn, riders enjoy an incredible view from the lower deck of the Verrazano Bridge.

Bike New York brings in critical research funds to support finding a cure for CMT. Over the years, monies raised from Bike New York has made a significant impact on HNF's mission—we are excited and honored to take part in this event as we continue our quest to find better treatments and cures for CMT and inherited neuropathies.

HNF board member Matt Downing sums up his experience with Bike New York this way:

“2017 will be my tenth Five Boro Bike Tour, and my sixth riding in support of the Hereditary Neuropathy Foundation. Riding in the Tour for a charity partner like HNF is a fantastic experience. You get to ride through the city on traffic-free streets, while raising money for a great cause. You even get a preferred starting position, which comes in handy when you're squeezing through the narrow streets of New York with 30,000 other riders. I can't wait!”

Please join HNF and ride with us on May 7, 2017! All HNF riders get VIP treatment at the event:

Enjoy complimentary breakfast and lunch, priority start times, special bike parking at the start, and Team CMT swag. Registration is now open. You can sign up [HERE](#).



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Hereditary Neuropathy Foundation



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