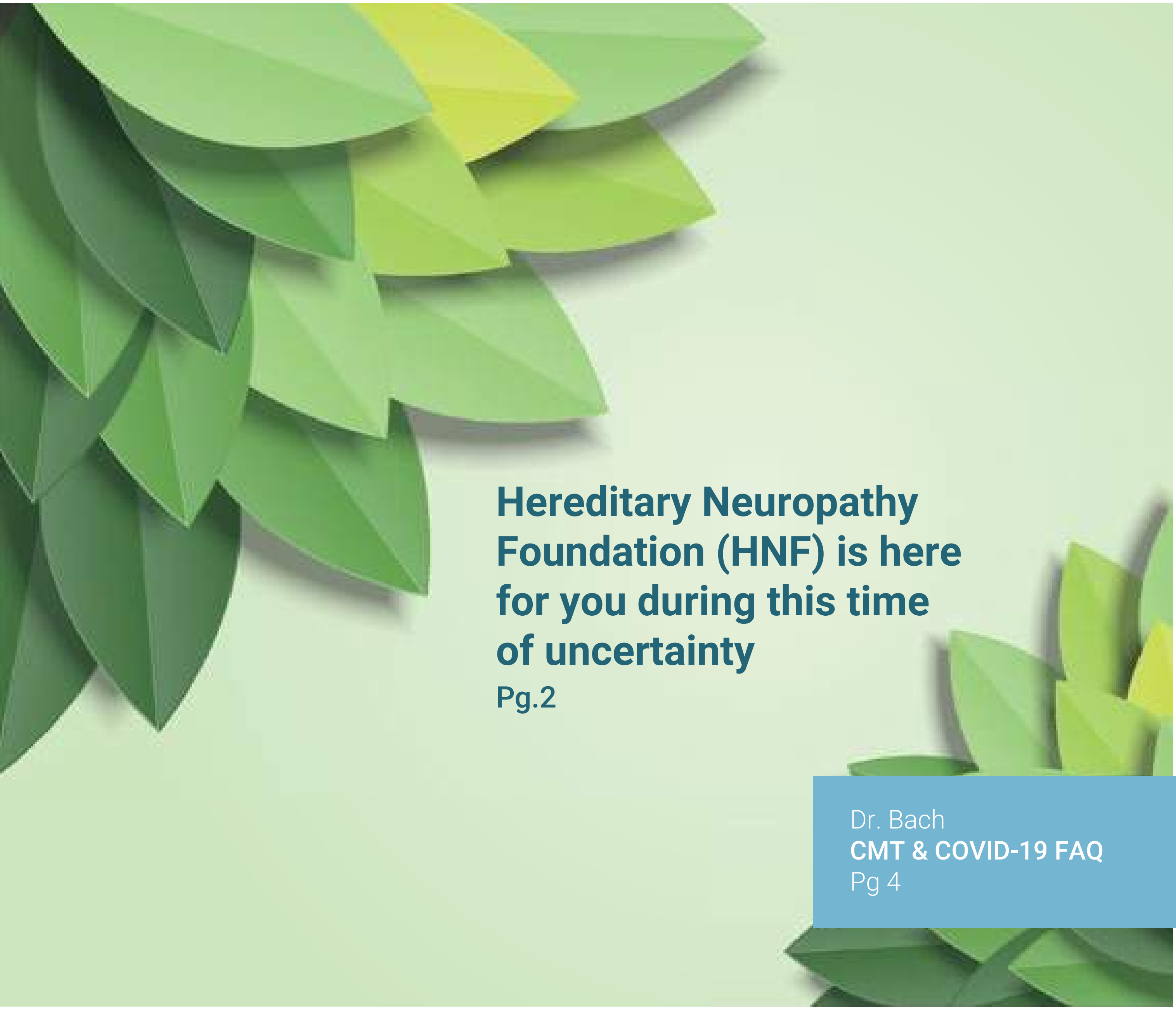
HEREDITARY
NEUROPATHY
FOUNDATION

SPRING 2020

cmtupdate



Hereditary Neuropathy Foundation (HNF) is here for you during this time of uncertainty

Pg.2

Dr. Bach

CMT & COVID-19 FAQ

Pg 4

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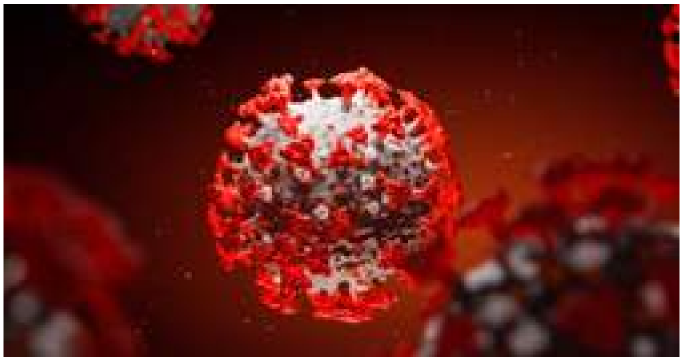
The Hereditary Neuropathy Foundation's mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related Inherited Neuropathies, support patients and families with critical information to improve quality of life, and fund research that will lead to treatments and cures.

www.hnf-cure.org

CMT UPDATE
SPRING 2020



YOUR SOURCE FOR CMT & COVID-19

CLICK HERE:
www.hnf-cure.org/covid19

Dear Friends:

I hope this message finds you and your family safe and healthy. As COVID-19 has spread across our blessed country with devastating effects, we, as a nation, are facing the greatest challenge of our lifetimes. With phrases like “shelter-in-place” and “social distancing” informing our new normal, Americans have rallied around family and community to do what we collectively have to do to stem the spread of this deadly virus. The outpouring of support for healthcare workers, first responders and those in need has been heartwarming even as we face some of the darkest times in memory.

As an organization, HNF has had to quickly adapt to the new realities of a COVID-19 world. All of our fundraising events have been postponed or cancelled all together. Medical conferences have been put on hold. Our newest and most exciting initiative Movement is Medicine™ Summit that was scheduled for November 13-14, 2020 has been postponed to November 5-6, 2021. While this has certainly been discouraging for us, the HNF team has risen to the occasion with informative and fun virtual events, new ways to fundraise, and video conferencing with our partners to keep our research initiatives moving forward. Where would we be without Zoom?!!

A few clear trends have emerged about the risks that COVID-19 holds for us. People with comorbidities like respiratory or heart conditions are experiencing higher mortality rates than those without those conditions. As CMT patients often have respiratory issues associated with their disease (see pg. 8-9 for some statistics), it is important that our patient community remain hypervigilant about hygiene, sheltering-in-place and social distancing!

Please remember that we are all in this together. The HNF team will continue to serve you virtually to the best of our abilities, until the day comes when we can once more see you in person.

All the best,

Allison T. Moore

Allison T. Moore, Founder/CEO, Hereditary Neuropathy Foundation

PS: HNF relies on the generosity of our community to help support our programs and research. With most of our fundraisers put on hold for the moment any donation is greatly appreciated. **CLICK HERE TO DONATE TODAY!**

HEREDITARY NEUROPATHY FOUNDATION (HNF) **IS HERE FOR YOU DURING THIS TIME OF UNCERTAINTY**

As you know, HNF is monitoring the COVID-19 situation as it continues. Along with other organizations worldwide, we have postponed all in person events through the end of July and will continue to assess future in-person events, as necessary.

The HNF team has been working tirelessly to produce content and programs to help the CMT Community during this time of uncertainty. As a patient advocacy group we thrive on providing you tools to help you navigate through life.

HNF Virtual Tools

Ask the Expert:

If you would like to ask a question, we invite you to do so by filling out the form below. We will be sending Dr. Thomas and Dr. Kafaie your questions and post their responses as they come in. Thanks in advance for your participation!

VISIT: www.hnf-cure.org/ask-the-expert

CMT-Connect Webinars:

This interactive series is designed to shed light on our community's most important topics. We seek out wellness experts, thoughtleaders, medical professionals, adaptive programs, emerging technologies, disability advocates, patients and so much more! Our educational and enriched online webinars, along with in-person workshops, are meant to support CMT patients, families, and caregivers.

VISIT: www.hnf-cure.org/cmt-connect

CMT Update:

Catch up on all of HNFs happenings, including the latest CMT research, in the quarterly *CMT Update*. HNF offers all content and newsletters, past and present, free to everyone on the HNF website.

VISIT: www.hnf-cure.org/newsletter-cmt-update

Covid-19:

Read the latest about COVID-19 with resources, a webinar on kid and family activities while you are passing the time in quarantine.

VISIT: www.hnf-cure.org/covid19

Global Registry for Inherited Neuropathies (GRIN):

HNF's patient registry collects vital data, allowing researchers to study why individuals experience different CMT symptoms and address what is most important to patients when thinking about drug development. Scientists can also learn how CMT mutations may lead to unique symptoms, which helps them develop treatments for all types of Inherited Neuropathies. By completing a profile, your de-identified information will be utilized to advance research and support clinical trial designs. Please participate in each survey to accelerate research. As a registrant, you will be informed when you may be eligible for clinical trials.

VISIT: www.hnf-cure.org/registry

Inspire Support Community:

The CMT Inspire Online Support Community connects patients, families, friends and caregivers for support and inspiration. HNF sponsors the community and is an Inspire Trusted Partner. We hope that you'll take the time to join the community and connect with others who share our concerns related to diagnosis, managing symptoms, and treatment options such as bracing, orthotics, and exercise. Most of all, you will find comfort that you're not alone.

It's easy to get started. After you create a personal profile, you can immediately start participating in discussions. Extensive privacy features allow members to control exactly how their personal information is shared with others.

VISIT: www.hnf-cure.org/online-support-community

Patient Care:

The HNF website offers a robust list of patient resources for those living with CMT. HNF takes a multi-modal approach, from bracing to surgery to physical therapy. HNF is committed to providing up to date patient care resources and information to help improve the lives of CMT patients.

VISIT: www.hnf-cure.org/patient-care

Podcasts:

Friends and CMT advocates Lainie Ishbia from Trend-Able.com and Estela Lugo from HNF are real, raw and perfectly imperfect in their informal discussions about the trials and tribulations of living with disabilities. Both women wear leg braces due to their CMT and are passionate about helping others feel confident in their own skin.

VISIT: www.hnf-cure.org/podcasts

Zooom-a-thons:

We need wellness and each other more than ever right now!
HNF is proud to invite you to a new worldwide event…CMT Zooom-a-thons! These free virtual events will be broadcast via Zoom with a different theme and rockstar ZJ (Zooom Jockey) each week! We'll workout, dance, cook, meditate, make art, laugh, show off our pets and most importantly, connect!

VISIT: www.hnf-cure.org/zooom-a-thon

As always, our dedication is to the CMT community. While we can't be together in person, we are continuously working to share ways for you to engage with each other virtually during this time.

If you don't already, follow us on Facebook, Instagram and Twitter for more updates, resources and stories from the community.

VISIT: www.hnf-cure.org/social-media-outlets

The HNF team is confident that progress in CMT research will continue and we are grateful to have you on our team.

CMT & COVID-19 FAQ WITH DR. BACH

Respiratory weakness is only recently being acknowledged as a symptom of CMT so there is still a lot that we as patients need to learn regarding standard of care so that we (and our loved ones) can be our best advocates. Having CMT doesn't necessarily put you in the "high risk" category for COVID-19, but if you have a weak diaphragm and reduced lung capacity please keep reading for answers to the most frequently asked questions.

On March 20, 2020, HNF teamed up with Dr. John Bach of Rutgers Medical School to answer some of our community's most vital questions regarding pulmonary health and the specific risks and precautions pertaining to COVID-19.

SHOULD I BE CONCERNED ABOUT THE EFFECTS OF COVID-19 DUE TO MY CMT/HNPP DIAGNOSIS?

If you have respiratory issues, yes, you may be considered "high risk" and you should take proper precautions such as isolation, frequent hand washing (for a min. 20 seconds), disinfecting surfaces, staying at least 6-9 feet away from anyone who may have been exposed to COVID-19. It can be spread by someone who is asymptomatic. The incubation period is from 2-14 days.

Studies show that the COVID-19 virus remains:

- In the air for up to 3 hours
- On cardboard for up to 24 hours
- On plastic and stainless steel for 2-3 days

WHAT ARE THE CLASSIC SYMPTOMS OF COVID-19?

- Fever (101°F)
- Muscle aches
- Shortness of breath
- Cough

WHAT ARE THE DANGERS OF COVID-19 FOR PEOPLE WITH NEUROMUSCULAR DISEASE?

The biggest danger is that if you are intubated, as you recover from the pneumonia the doctor will try to wean you from the ventilator. If the doctor feels it is not possible to extubate you quickly to CPAP or BiPAP (possibly with inadequate spans), it can be fatal. Let your family members know that they should NOT immediately accept a trach tube, but contact/use Dr. Bach's procedures for extubation for neuromuscular patients. (see webinar at about 57:00)
Webinar link: https://www.hnf-cure.org/covid19

IS IT POSSIBLE FOR PEOPLE WITH CMT TO HAVE DIAPHRAGM PROBLEMS WITHOUT KNOWING IT?

It may be possible, yes. Things that you can ask yourself to determine if you have a weak diaphragm include:

- Do you sleep mainly on your side because you can't breathe well when you're on your back (orthopnea)?
- Are you unable to take a deep breath and hold it for 20 seconds?
- Do you have fatigue, sleepiness during the day?
- Do you have morning headaches?

If you answered yes to these questions, you may consider visiting a pulmonologist (preferably one that understands neuromuscular disease – see Dr. Bach's list of centers)

Dr. Bach does not recommend a sleep study. Patients with a CMT diagnosis and limited lung capacity should be approved for a Respiratory Assist Device (RAD) by insurance – here is a link to the Medicare guidance on treating with RAD.

WHAT SHOULD I DO IF I'M SHORT OF BREATH AND PUT ON OXYGEN?

Dr. Bach suggests you let the HCP know that you have a neuromuscular disease that weakens your diaphragm and limits your ability to expel CO2, so they'll need to be prepared to intubate you if you stop breathing. "No O2 without ventilation" is the rule.

IS IT SAFE TO RETURN TO WORK NEXT WEEK?

Dr. Bach advocates isolation and social distancing for everyone at this time. The more quickly we stop the spread of COVID-19, the more quickly we can all go back to our normal lives.

WHAT EXERCISES CAN I DO TO INCREASE MY LUNG CAPACITY?
Lung volume recruitment exercises include breath stacking, and “frog breathing” or Glossopharyngeal Breathing. This will keep your lungs functioning at their best capacity.

CAN COVID-19 CAUSE FURTHER PROGRESSION OF CMT?
As with any virus, CMT patients often take longer to get over it completely and they often do experience progression of muscle weakness.

HOW DO I USE COUGHASSIST?
The CoughAssist settings are always the ones that give the highest flows. That is almost always 50 to 60 cm H2O in and out to full chest expansion then full chest retraction. It is not complicated! Do it manually to determine times if you want to use automatic, but manual is often better.

WHAT FOUR TOOLS DOES DR. BACH RECOMMEND ALL CLINICS WITH NEUROMUSCULAR PATIENTS HAVE?
1. Peak Flow Meter (like this) to measure cough strength
2. Oximeter (like this) to measure oxygen saturation in the blood
3. CO2 monitor (capnogram)
4. Spirometer (like this)

Dr. Bach’s instructions for use of Cough Assist with pneumothorax (collapsed lung) are at the 1:32 mark in the video.

Watch full webinar: www.hnf-cure.org/covid19

New Board Member Lisa McCarthy

Through their decades long friendship, Lisa was inspired by HNF's Founder/CEO Allison’s resilience and drive to help the CMT community live full lives and find a cure. After leading a Fast Forward session at the 2018 HNF Summit, Lisa felt compelled to get more involved.

Lisa spent 25 years at prominent media companies Univision, Viacom and CBS leading sales organizations responsible for billions in revenue. Recognized as a people-first leader and change agent with significant commercial impact, Lisa was named a “Woman to Watch” by Advertising Age and Crain’s New York “Business 40 Under 40.” As a senior executive and mother of three, Lisa experienced first hand the onslaught of today’s workplace: aggressive targets, back-to-back meetings, frequent travel, non-stop emails. The result? Short term thinking, being reactive and playing it safe. Feeling like a passenger instead of a driver. De-prioritizing personal commitments, thinking “this is what it takes to be successful”.”

Lisa knew it could be different. In 2010, she started designing workshops for her team to thrive professionally and personally amidst the demands of the modern workplace. The feedback across the business was so positive that in 2012 she took an exciting and uncomfortable leap. She partnered with her childhood best friend, Wendy Leshgold – an executive coach and former advertising executive – to launch a business focused on creating a new kind of workplace: one where professional and personal success go hand in hand. The program they developed gets people to challenge limiting beliefs, think big and be intentional in their work and life. Today, The Fast Forward Group partners with innovative companies of all sizes to provide training and coaching that drives growth and engagement. Clients include Facebook, Google, JP Morgan Chase, NBCU, Disney, Visa, Nike, Aon and YPO.

Lisa is an in-demand public speaker. Audiences say her Declare a Bold Vision and Choose a New Story sessions are provocative, life changing experiences. Known for her relatability, authenticity and candor – clients count on her to leave people inspired and in action. Lisa received her BA from Georgetown University. She lives an “overly fulfilled” life in Port Washington, NY with her husband and three children.

Novel findings of a new common type of CMT2 that might be the 1st step to a treatment: SORD gene deficiency, the most common autosomal-recessive type of CMT

Dr. Stephan Züchner and colleagues at the University of Miami (Drs. Andrea Cortese, Grace Zhai, Andriana Rebelo), along with the Inherited Neuropathies Consortium (INC) – a group of CMT academic experts led by Dr. Michael Shy at the University of Iowa – has discovered a new type of Charcot-Marie-Tooth (CMT): a mutation in the SORD gene that may may affect 60,000 patients worldwide and appears to be the most common autosomal-recessive form. HNF is a member of the INC and Dr. Zuchner is a collaborator with HNF's Therapeutic Research in Accelerated Discovery (TRIAD) Program.

Dr. Stephan Züchner

SORD, sorbitol dehydrogenase, is a protein coding gene. CMT patients affected with this mutation show elevated levels of sorbitol sugar in tissue and blood causing axonal peripheral motor neuropathy. Fortunately, there is a class of drugs called aldose reductase inhibitors that have been used to reduce sorbitol levels in diabetic neuropathy.

As shown in the scientific study, these drugs can normalize sorbitol levels in patient cells and prevented symptoms in a fruit fly model of the disease. The hope is that clinical trials can get underway relatively fast to bring this potential therapy, the first for CMT, to patients who carry the SORD mutation.

HNF is excited about this ground-breaking discovery and will continue to support Dr. Züchner's research in accelerating this potential treatment.

In addition to these findings, HNF works closely with Dr. Züchner and The Genesis Project – a large scale genomic data aggregation platform – to collect and curate the Global Registry for Inherited Neuropathies (GRIN) patients and families genomic data. HNF has added the SORD gene to its natural history studies and encourages all patients with SORD and other types of CMT, even if unknown, to join GRIN.

Good News for CMT1A Patients - PXT3003

ALLISON MOORE, FOUNDER/CEO, HNF

I'm excited by Pharnext's recent announcement that three major regulatory agencies in the United Kingdom, Europe and US have recognized PXT3003 as a lead drug candidate to treat CMT1A.

The United Kingdom has granted Pharnext a Promising Innovative Medicine (PIM) designation as an early indication that a medicinal product is a promising candidate for the Early Access to Medicines Scheme (EAMS) in the treatment, diagnosis or prevention of life-threatening or seriously debilitating conditions with unmet need.

Despite the climate of COVID-19, our industry partner, Pharnext SA, continues to plan for the additional pivotal Phase 3 PXT3003 trial for CMT1A in patients 16 years and older in the US and Europe.

> **"All existing data indicate that PXT3003 is a safe and well tolerated drug combination. We look forward to continuing our discussions with U.S. and European regulatory authorities to advance the clinical development of PXT3003 and initiate as quickly as possible an additional pivotal Phase 3 trial in the U.S. and Europe."**
>
> – **Daniel Cohen, M.D., Ph.D.,**
> Co-Founder and Chairman of the
> Scientific Advisory Board of Pharnext

You may be eligible to participate. By creating a profile in HNF's Global Registry in Inherited Neuropathies (GRIN), you may be considered as a potential candidate for the Phase 3 study.

JOIN GRIN TODAY!
www.hnf-cure.org/registry/

You can also help advance the knowledge of CMT and the impact on Quality of Life, by joining the CMT&Me App. The objective of the app is to better understand the impact of the disease on patients' daily lives: the burden of CMT, its natural history and treatment, and medical, social and pharmacoeconomic effects.

Read full press release from Pharnext
www.hnf-cure.org/research/pharnext-pim

Update: Movement is Medicine™ Summits 2020

Movement is Medicine™

New Dates

Movement is Medicine™ Summit Orlando

Orlando Summit Saturday, November 14, 2020. Stay tuned for registration details.

Movement is Medicine™ Summit Phoenix

Due to Covid-19 and the need for participants to travel, HNF has postponed the Movement is Medicine™ Summit to November 5-6, 2021.

Global Registry for Inherited Neuropathies (GRIN)
Respiratory Dysfunction Report

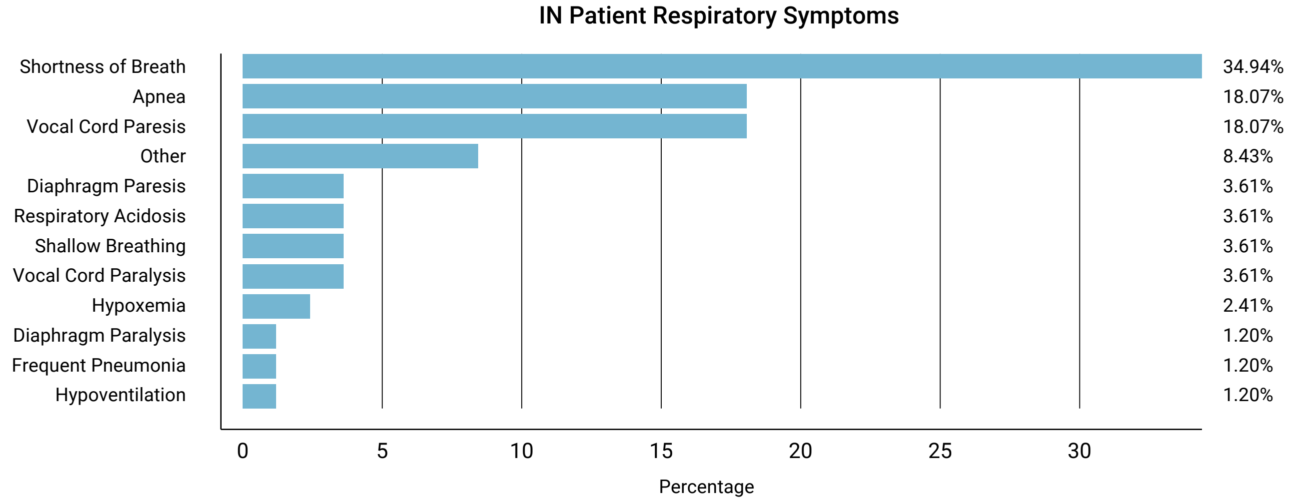
As we have learned more about the novel coronavirus Covid-19, it has become apparent that individuals with underlying respiratory weakness are at greater risk for a more severe case of the disease, if infected. It is for that reason that we share this GRIN Respiratory Report supporting our concerns and actions for Covid-19 and other respiratory viruses. If you have not already done so, please complete your GRIN profile and Respiratory Survey today. www.hnf-cure.org/registry

The Global Registry for Inherited Neuropathies (GRIN) is a proprietary, Institutional Review Board (IRB) approved patient registry which collects natural history data on patients affected by Charcot-Marie-Tooth (CMT) disease and other Inherited Neuropathies (IN). As of 04/14/20, GRIN has 2,541 patients in the registry.

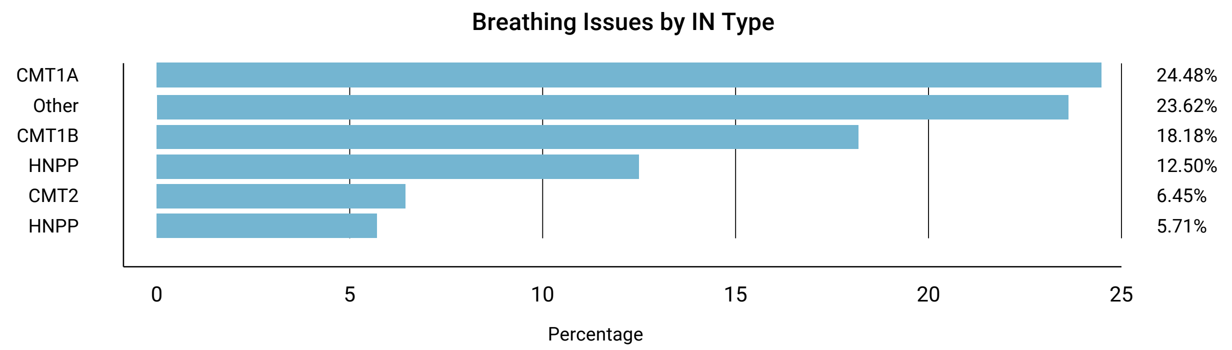
Respiratory impairment can often be a significant comorbidity for patients with IN. This report will examine correlations between this comorbidity and other patient attributes including demographics, genotype and phenotype.

Over 18% of GRIN participants cited respiratory impairment in association with their IN. Of this cohort, 35% reported using a breathing assist device at night. 12% of this population reported being on a ventilator, with 1.6% requiring a tracheotomy.

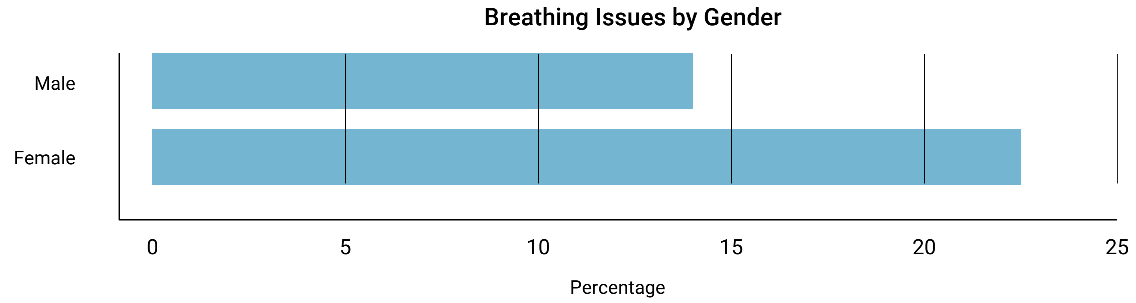
Patients reported a variety of symptoms associated with their respiratory impairment, with shortness of breath, apnea and vocal cord paresis being highly cited.



When examining patient respiratory issues by IN type, over 24% of CMT1A patients indicated some type of respiratory impairment. "Other" INs (rarer forms) had a comparable response, followed by CMT1B at 18%.



Female IN patients presented respiratory issues at a 60% higher rate than males.



The Institutional Review Board (IRB) is an administrative body established to protect the rights and welfare of human research subjects recruited to participate in research activities conducted under the auspices of the institution with which it is affiliated.

Have you downloaded the CMT&Me app?

Be part of the first groundbreaking research app for CMT! The CMT&Me app collects real-world data using 'bring your own device' (BYOD) technology – participants use their own smartphones to complete questionnaires or surveys at their convenience. The app immediately submits the information patients provide to a central database. A Scientific Advisory Board (SAB) oversees the CMT&Me study, and includes clinicians who care for CMT patients, Patient Advocacy Organization (PAO) representatives, and experts in patient-reported outcomes (PRO) and data management. Non-commercial researchers and PAOs can apply to the SAB for access to aggregated data via dashboards. Researchers can then use that data to better understand CMT and improve patient care. All patient data remains anonymous, and researchers who access the CMT&Me study database will not be able to identify patients.

Available now in Spanish!

Download available on Android or iOS device at the app store

Download today! https://www.hnf-cure.org/cmtme-study


MT Disease..
Google it!
938
937
939
VIP ENTRY


FIT State University
New York

Meet the **Reillys**

My name is Kerin Reilly. I have three people in my life that I love beyond measure. They are my three absolute favorite people and two of those people have CMT Disease. That means that 50% of my family is impacted by this terrible disease!

My husband Joe and my daughter Dakota live with and battle this disease every day while my son Patrick and I do everything we can to provide support. My husband's case is milder than our daughter's, which can occur in hereditary diseases, and because of this our focus has primarily been on Dakota.

After Dakota's diagnosis at age eleven, we began dedicating all of our altruistic efforts to finding treatment options, building awareness and fundraising. I joined the Board of Directors for HNF in June 2014, which opened up our world to possibilities, contacts, and the most amazing group of individuals I have ever met! This incredible connection to HNF has allowed me to provide my daughter with invaluable contacts, information and opportunities. Saying yes to the board seat six years ago remains one of the best decisions I have ever made.

Our family participated in the TD Bank Five Boro Bike Tour two years in a row to raise money and awareness and in November of 2018, I proudly crossed the finish line of the TCS New York City Marathon in my Team CMT shirt! These events are high energy and so much fun, but they are not easy and what gets us through is that we do it all for our beautiful, strong and courageous Dakota!

This year, my husband Joe and I have teamed up to run the TCS New York City Marathon together! It is the 50th Anniversary of the Marathon, which makes it even more special! Joe and I are training together and our early morning runs are getting easier and longer as we build our strength and endurance, all the while with our fantastic daughter in our thoughts.

Dakota cannot run so we run for her. I would switch places with her in a second if I could, but since I cannot, I will continue to do everything I can to help find a cure for CMT and stop this disease in its tracks.

They say that finding a cure is a marathon not a sprint – *well, we can do that....after all it's what we've been training for!*

Donate to Kerin and Joe Reilly

CLICK: https://bit.ly/3eirzzc

New Survey Findings Highlight **Gene Therapy Knowledge Gaps** Among HCPs

NORD and FMC Illustrate Need for Increased Education and Awareness to Overcome Potential Treatment Barriers

Parsippany, NJ – April 14, 2020 – With the availability of several promising gene therapies and more on the horizon, a recent survey published in Neurology Reviews' 6th annual *Rare Neurological Disease Special Report* indicates that many potential prescribers are unaware of the life-changing potential of gene therapy. The survey, a joint undertaking by the **National Organization for Rare Disorders (NORD®)** and **Frontline Medical Communications (FMC)**, was completed by a representative sample of health care providers across a variety of specialties and practice settings. Nearly two-thirds of respondents (63%) were unaware of FDA-approved gene therapy options, such as Kymriah™, Luxturna® and Zolgensma®, and although respondents reported treating an average of five patients with a rare genetic disorder, few recognized the range of potential benefits of gene therapy, how it is administered, long-term impacts, and mechanisms by which it works.

A notable finding is the limited comfort level expressed by respondents in their knowledge base and ability to discuss genetic concepts with patients. Just 24% rated themselves as comfortable or extremely comfortable explaining somatic vs. germline mutations, and responses also identified unfamiliarity with gene delivery and administration options. The survey underscored the need for provider education on topics related to gene therapy, which is currently being seen as a potentially curative treatment for some rare disorders.

Concern that gene therapy will be cost-prohibitive (69%) and/or that patient access will be limited due to lack of insurance coverage (67%) ranked highly as perceived barriers.

"It is vital to develop strategies to ensure consistent and viable reimbursement models and to create multi-faceted, accessible educational outreach programs for the medical community at large," said Katie Kowalski, Senior Program Manager of Educational Initiatives for NORD. "It is important for rare disease patients to be offered the opportunity to participate in clinical trials, and for clinicians to have accessible platforms to learn more about gene therapy so they can inform their patients about these treatment options."

Full survey findings are discussed in the article, Gene Therapy Survey Highlights: Knowledge Gaps and Educational Opportunities. Readers can also read more about barriers preventing health care providers from embracing gene therapy advances as therapeutic tools in the 6th edition of the *Rare Neurological Disease Special Report*.

To learn more about the rare disease initiatives through the Neurology Reviews and NORD partnership, contact Elizabeth Katz, Publisher of *Neurology Reviews*, at 973-224-7951 or ekatz@mdedge.com. Details and information on all FMC/MDedge digital brands, print publications, and custom programs are available at www.mdedge.com/neurology visit weekly for the latest innovative programs and multimedia initiatives.

NORD Launches Financial Assistance Program for Rare Disease Community Members Impacted by COVID-19

At this time of crisis and with the health, safety and well-being of patients and caregivers as its top priorities, the National Organization for Rare Disorders (NORD®) today launched its COVID-19 Critical Relief Program to provide much-needed assistance to members of the rare disease community affected by the COVID-19 pandemic. The program provides financial relief that may be utilized to support critical, non-medical needs.

> **"Providing financial assistance to help meet the unique needs of the rare disease community has been central to our mission for over 37 years.The NORD COVID-19 Critical Relief Program enables us to provide desperately needed support to rare disease community members whose lives have been directly impacted by the current pandemic."**
>
> **— Jill Pollander, RN, MSN**
> Director of Patient Services for NORD

Through the new program, NORD will provide financial assistance to eligible patients, covering up to $1,000 annually. It provides funds for essential expenses including, but not limited to, unexpected utility expenses; cellular or internet service; emergency repairs to car, home or major appliances; and rent or mortgage payment assistance. Interested rare disease patients and families can reach out to NORD to find out if they meet eligibility requirements.

For more information on the NORD COVID-19 Critical Relief Program and to apply, please contact NORD by telephone at 203.242.0497, via email at COVID19assistance@rarediseases.org, or visit rarediseases.org. To show your support, please consider making a donation to the program so that even more people can be helped. Finally, to stay informed, the NORD COVID-19 resource center presents information and links relevant to the rare disease community during this pandemic.

Art Auction for CMT
Bid to Win!

CMTresearch.givesmart.com

Auction ends June 12th at 5:00pm.

Painting By Mouth – Kaileen Selig

My name is Kaileen. I am 28 years old and I am a mouth painter living in Greater Vancouver, Canada. I am a Student Member of the Association of Mouth and Foot Painting Artists (MFPA). I have a very rare form of Charcot-Marie-Tooth - type 2D. For a detailed description, please use our good friend, Google. To sum it up in a few words, my muscles are very weak and progressively worsening.

I would say my love for art started at a young age. When I was 7 years-old, I was hospitalized for five weeks and I remember colouring a picture for the front of my medical binder and loving doing that. I took many art classes throughout highschool; it was always my favourite class. I did everything with my hands at that point, from sketching to pointillism. It was hard for me, took me more time than other students and made me tired, but I never considered stopping. Creating art allowed me to express myself in a way nothing else could.

Over the past 10 years I have lost many abilities, one of which is the use of my arms and hands for most things. Due to this, I had gone a long time without creating much art. In November 2017 that all changed.

My boyfriend casually mentioned to me that there is an association called the Mouth and Foot Painting Artists. This association consists of people who paint using their mouth or feet. For some reason that sparked something inside of me. I didn't have any painting background, but I decided to give painting with my mouth a try! I ordered cheap watercolour paint, paper, and paint brushes from Amazon and was ready to start. Except then I realized I didn't have a way to reach the paper... so I propped up a Lady Gaga book I had and used it as an easel. Then I was really ready to start!

Since then, I have been teaching myself how to paint with watercolour paint, acrylic paint and oh, an actual easel! But most importantly, I’ve learned how to paint using only my mouth.

Mouth painting is as simple as holding a paintbrush in my mouth and painting. However, there is a lot a mouth painter needs to consider when preparing for painting.

First, you don’t want to put just any type of pencil in your mouth to sketch your ideas. Why? Erasers. Have you ever

tasted an eraser? I highly recommend that you don't. Yes, there are pencils without erasers on the end, but with many pencils you can see the top of the lead at the end. Much like erasers, lead is not something you want to taste while sketching.

My solution is to wrap tape around the end of the pencils that I use. I also wrap tape around the end of my brushes to reduce the breakage of the paintbrush material from my teeth. But even then you have to be careful as you don't want to use a tape that will become soggy, or one with a super sticky adhesive that will get in your mouth. I've experienced this the hard way.

Other things I have to consider are the size and weight of the paintbrushes I use. I'm not going to get very far in a painting if my mouth is sore after a few brush strokes. I don't use any special brushes, I'm just strategic about the ones I use.

I also need to have my palette at a specific height so that I can reach it to mix colours and apply paint to my brush. I have two paintbrush stands that were made for me, which allow me to pick up and put down my brushes as needed. I also have a clipboard stand that allows me to reach a paper towel to clean my brushes.

My completion time really depends on the subject, size, and type of paint used. If I'm painting a smaller sized painting without a reference and using acrylic paint, I can finish the painting in about three or four hours. If I'm painting a detailed acrylic painting, I spend around a week or two working on it, a few hours each day. If I'm doing an oil painting, it takes much longer as the paint is slow drying. Oil paintings have taken me about a month sometimes, although most of that time is waiting for layers to dry.

I've noticed people are curious about what inspires me to paint. I have to admit, I don't have an exact answer for that. What I do know is that I want my art to evoke a feeling when someone sees it. I also want people to see how I taught myself to paint with my mouth and realize that losing an ability you once had doesn't mean you have to lose something you love.

Many of my paintings have a dark side to them, which was never the intention. I think that the difficulty of living with a progressive disability tends to express itself through my art. I am a positive person, but sometimes life is hard and can suck. But that's okay in my opinion.

I'm most active in sharing my work and behind the scenes of my mouth painting experience on Instagram @artbykaileen. My website artbykaileen.com has an online shop page where you can see what I have for sale. As I am a Student Member of the Association of Mouth and Foot Painting Artists, many of my paintings are sent to the association so I don't sell a lot on my site. You can also find me on Facebook and Twitter @artbykaileen.

I still have so much more to learn, but am a firm believer in the statement that we really never stop learning.

So that's my journey as a mouth painter! Sure I'm no pro; however, I can say with my whole heart that I love painting. My dream is for it to be my career and I will never stop working towards that goal.

To support CMT research I will be auctioning off a painting and all proceeds will go to HNF.

Art Auction for CMT, Bid to Win! CMTresearch.givesmart.com
Auction ends June 12th at 5:00pm.

Align with Happiness

How do we tap into our peace, joy and best selves during a pandemic? This question and many more regarding mental and emotional health have become a rising concern for all of us during this confusing time. **"Our community was already facing feelings of isolation, anxiety and grief long before this pandemic; now it just seems as if all of those emotions have been magnified by COVID-19" –** Estela Lugo, HNF Program Development Manager

The HNF team reached out to three thought leaders and Harvard scientists, Dr. Nivedita Jerath, Dr. Aarti Jerath and Dr. Tal Ben-Shahar to shed some light on this important topic with a new CMT-Connect webinar titled, "Align with Happiness" on April 3rd.

Dr. Nivedita Jerath, AdventHealth Neuromuscular Director and head of one of HNF's newest CMT Center of Excellence, opened the discussion with an introduction of her team's multidisciplinary approach to treating CMT patients at her brand new facility located in Winter Park, Florida. Dr. Jerath spoke on the disappointment many patients are currently coping with, including the postponement of our collaborative Movement Is Medicine Summit™, originally scheduled for March, 21.

Next, was Dr. Nivedita Jerath's twin sister, Dr. Aarti Jerath, a board certified psychiatrist treating adults and children at Miami Counseling Center. According to Dr. Nivedita, "There are similar ways to cope with a chronic illness and COVID-19." She then broke down several effective methods including mindfulness, gratitude, owning our own feelings and more.

To close out the discussion was founder of the Happiness Studies Academy, Dr. Tal Ben-Shahar. "Whenever we reject painful emotions, they intensify. Give yourself permission to be human." Dr. Tal shared many eye-opening and science-based examples on how we can all shift our perspective on chronic illness and the current COVID-19 crisis. It's easy to see why his course on positive psychology was deemed Harvard's most popular class to date!

For the full webinar, visit
https://www.hnf-cure.org/cmt-connect-webinars/

PAST WEBINARS

- Work From Home Job Training & Placement
- CMT & Telemedicine
- Align with Happiness
- CMT & Capture Proof
- CMT & Genetic Testing
- CMT & Covid-19
- Healing from the Inside Out
- CMT Resources with Inspire
- Dating & CMT
- How to Exercise in the Pool with Bernadette Scarduzio
- accessibleGO.com: A New Way to Travel with Disabilities
- Bemer Technology
- Panetta Physical Therapy
- CMT & Balance
- CMT & Your Nutrition
- CMT&Me App
- CMT & Finances
- Ability360 Sports & Fitness Center
- Active Hands
- Cannabis & CBD for CMT
- CMT & Canine Companions

VIEW PAST WEBINARS:
www.hnf-cure.org/cmt-connect-webinars

CAUTION

COVID-19 and hydroxychloroquine:

Is it in the family of fluoroquinolones, which are known to be neurotoxic and contraindicated for CMT patients?

Is this drug safe for CMT patients?

From Dr. Louis Weimer, MD, Columbia University, HNF Center of Excellence:

No, hydroxychloroquine is a separate class. It is better known as Plaquenil used for various rheumatological conditions. There is toxicity associated with the drug but very rarely muscle and less nerve involvement. Most people take it for years without issue. It is relatively benign. Retinal toxicity is the main concern but that is usually rare and less common than thought even a few years ago. The benefit against COVID19 is still preliminary. I don't think advising against usage if the benefit is promising is wise.

ASK THE EXPERT

Do you ever wish you could have direct access to a Neurologist for your CMT questions? Now you can! HNF is proud to present our new web page featuring real questions from CMT patients across many topics. Submit your questions directly from our site to Directors of the Hereditary Neuropathy Foundation Centers of Excellence at St. Louis University, St. Louis, MO, and at Hackensack University Medical Center, Hackensack, NJ, Dr. Florian Thomas and Dr. Jafar Kafaie today!

Q: What should I be getting myself checked for with a doctor?

As a child doctors would measure and document my strength and offer me options that could facilitate my life. Now that I'm not a child, I don't know what I should be doing or getting checked for in regards to CMT.

A: Dr. Florian Thomas: Regular evaluations by a neuromuscular physician and rehab therapists make sense to me, with the frequency being individualized. I have several suggestions:

- At any point in a person's life independent conditions can damage the same organ, e.g. nerves. I take care of several CMT patients who 10 years after their first visit developed diabetes, which further damaged their nerves. So that is an issue that your doctors need to check for periodically.
- As we get older more of us become B12 deficient. y. As patients with CMT get older they may need bone densitometry tests and, if abnormal, may need to be treated for bone loss.
- Patients may not need ankle braces when they are younger, but need them as they get older.
- Patients may have no problems with finger/hand function when they are younger, but may require adapted ("gloved") tools later, such as pens, kitchen utensils, tooth brushes, hair brushes, etc.
- Talking to a counselor is often helpful.Some patients worry about how CMT affects their lives in the personal, social, and professional world with issues such as: having children, performing at work, others thinking that the patient is drunk when the patient walks abnormally. They may also worry about their appearance when they have very skinny legs. Patients may be reluctant to use canes or ankle braces because they don't want to "look" or "feel" sick, but not doing so may increase their fall risk.

Have a question?
https://www.hnf-cure.org/ask-the-expert

Virtual Jobs & Training for the Disability Community

In recent days, the number of American workers currently seeking unemployment benefits has surged to unprecedented levels, bringing the total number of unemployment applications to nearly 26 million since the coronavirus pandemic shut down large sections of the U.S. economy.

In addition, a third of Americans who remain employed say their employer has cut jobs, reduced hours, or frozen hiring as a result of the coronavirus outbreak, marking an 18-percentage-point increase in companies implementing a hiring freeze since mid-March. And part-time workers are more likely than those employed full time to report these negative effects on their workplace.

COVID-19 could represent the ultimate test of resiliency for companies in every industry. As the pandemic brings many businesses to a halt, some temporarily and others likely permanently, companies who want to weather this storm must be nimble to sustain operations. Organizations large and small are focusing on transitioning employees to working remotely, thus enabling their workers to follow "safer at home" initiatives while continuing to support business. Those who can transition easily to working at home may unveil opportunities for businesses to move to a work-at-home model even after the current COVID-19 crisis ends.

Ed Loyd, Director of Public Relations at Fifth-Third Bank stated, "We have relocated our call center employees into five different physical locations in accordance with CDC guidelines. Other teams have departed to work remotely. We will continue to evaluate (our efforts) and are proactively making additional modifications to care for our employees who aren't able to work remotely due to the nature of their service to our customers." The same situation exists throughout the call center industry. Companies around the world that provide contact center services are sending literally hundreds of thousands of employees home to help prevent the rapid spread of COVID-19.

However, even before the pandemic struck, remote work was accelerating throughout the United States. According to the Federal Reserve, the number of remote workers has tripled over the past 15 years. Factors leading to a remote shift include the ascent and refinement of collaboration software, infrastructure to support remote work, the cost of living in high population areas, and most recently COVID-19.

Companies that have not embraced remote work in the past now find themselves transitioning to remote work nearly overnight and on an epic scale. What companies learn over the next few months will surely shape the future of work. In times like these, certain organizations and people who have needed skills are well-placed to come out of this challenge ahead of where they may have been otherwise. If anyone is an expert in adapting to challenging situations and finding creative ways to meet unplanned developments, it is individuals and organizations within the disability community. As such, NTI@ Home is here to help.

As an American with a disability, you may know you have the knowledge and skills you need to make a meaningful contribution to the workplace. But your disability can make it challenging to work or to find an employer willing to give you a job. Common daily tasks like commuting, working eight hours, and sitting or standing for long periods of time may present a challenge for you. If you need accommodations, you may be reluctant to share that information with potential employers in fear of not being chosen for a job. But there is an alternative work environment available to you--one in which you will be comfortable and know your needs can be met. It is your own home!

For the past 25 years, NTI@Home has provided free work-at-home job-services for individuals with disabilities from asthma to spinal cord injuries and Charcot-Marie-Tooth disease to cancer. NTI@Home is a non-profit disability organization that provides free training and help finding home-based customer service and IT help desk jobs across the nation. By partnering with companies who need call center agents and are willing to let them work at home and then training disabled Americans to do those jobs, NTI@Home has helped many individuals and families gain financial freedom and independence.

Funded by government agencies including the Social Security Administration and IRS, and by commercial employers such as John Hancock, Meier, IBM, Sykes, Amazon, and Bristol Myers, NTI@Home provides free training for and access to full and part-time customer service positions. As a result, NTI@Home has become the leader in helping disabled Americans find rewarding work they can do from home.

When an individual registers for NTI@Home, they are invited to an information session where the process is explained. If they are interested and want to continue, they then have the opportunity to brush up on skills needed for the jobs available including attending an online 3-day call center training workshop. Upon the successful completion of training, a recruiter works with the job seeker to find the role that is right for them from among the jobs that are currently available through NTI@Home's many employer-partners..

Diane who succeeded in the NTI@Home program stated, "I love my job with Meijer. It has been a long time since I could actually say, and mean, that. I truly look forward to "going" to work each day. I enjoy speaking with most of the customers and my support team is wonderful. Thank you for urging me to apply for this position."

In addition to helping Americans with disabilities, NTI@Home is now opening its free training and job services to family caregivers who need to stay home to care for a disabled family member. An estimated 43.5 million adults in the United States provide care to a person with a disability. Government programs exist that allow family members of veterans and people with disabilities to get paid for the care they provide, but sometimes those programs refuse to pay family members who happen to live with the person for whom they are caring. By allowing family caregivers the choice to work from home, NTI@Home is still supporting disabled Americans which is their mission as a nonprofit.

Employment not only provides income, access to health insurance, and other benefits, it is also beneficial to overall wellbeing. People who have left the workplace due to a disability, retirement, or life change often find themselves wanting to reenter the workforce at some point. They miss the opportunities work can provide to contribute to a greater cause, interact with coworkers, and meet and overcome new challenges and goals. If you are experiencing these feelings, you are not alone, and NTI@Home may be a good fit for you!

Starting on the road back to employment can be overwhelming, especially during these challenging times. You may not know where to find answers and support. NTI@Home has 25 years of experience helping people get back to work, and they are a great source of information. If you want to learn more about free training, job resources, and vocational rehabilitation services available to you, you can watch a free webinar where Michael Sanders of NTI@Home discusses the many options and support services available. NTI@Home has helped tens of thousands of disabled Americans overcome barriers and find successful employment.

TO LEARN MORE ABOUT THE PROGRAM, VISIT WWW.HNF-CURE.ORG/CMT-CONNECT-WEBINARS

Meet Aravindhan Veerapandiyan, MD

University of Arkansas for Medical Sciences/Arkansas Children's Hospital

ARAVINDHAN VEERAPANDIYAN, MD (DR. PANDA), CHILD NEUROLOGIST AND ASSISTANT PROFESSOR AT UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES/ARKANSAS CHILDREN'S HOSPITAL

Aravindhan Veerapandiyan, MD

Aravindhan Veerapandiyan, MD (Dr. Panda) is a Child Neurologist and Assistant Professor at University of Arkansas for Medical Sciences/Arkansas Children's Hospital with specialized interest and training in neuromuscular disorders in children. He is the Director of the Comprehensive Neuromuscular Program, Director of the PPMD Certified Duchenne Care Center, and Co-Director of the Muscular Dystrophy Association Care Center at Arkansas Children's Hospital. Dr. Veerapandiyan earned his medical degree from the K.A.P. Vishwanatham Government Medical College in India. He completed a residency in Child Neurology at Rutgers University – New Jersey Medical School in Newark, New Jersey and a fellowship in Neuromuscular Medicine at University of Rochester – Strong Memorial Hospital in Rochester, New York. He also has post-doctoral research experience in Child Neurology at Duke University Medical Center. Dr. Veerapandiyan has a passion for clinical research and education. He has published more than 30 peer-reviewed articles and has presented his work at national meetings. He is actively involved in clinical trials focusing on neuromuscular disorders in children.

Q: TELL US ABOUT YOURSELF?

Growing up as the eldest child in my family, I had the privilege of witnessing the challenges my father experienced as a family physician.

The satisfaction he received from treating and earning the trust of his patients, inspired me to pursue a career in medicine. I earned my medical degree from KAPV Government Medical College in India. My strong desire to improve and increase my knowledge, skills, and abilities, coupled with a desire to keep abreast of new advances in medicine compelled me to pursue a career in pediatric neurology.


Arkansas Children’s Hospital

I completed a residency in Child Neurology at Rutgers University – New Jersey Medical School. Investigating the complexity of underlying pathophysiology, thriving to diagnose patients with neuromuscular disorders as early as possible to help them live better and fuller lives, and providing lifelong comprehensive care, as well as my curiosity and interest towards genetics and genomics, made me develop a strong interest in neuromuscular medicine.

Q: WHY IS CMT YOUR PASSION?

Hereditary neuropathy, including CMT, is of major interest to me. Typically, this is considered as an adult disease. But this is a genetic condition that can be diagnosed early on if there is clinical suspicion and awareness. Many of these cases go undiagnosed until later in life. CMT is a condition that is commonly seen in neuromuscular clinics but there is nothing for me to offer to these children and families as treatment. It is critical that our neuromuscular community works towards the goal of finding treatment for this condition in this era of modern genetic and precision medicine.

Q: TELL US WHAT PATIENTS WILL EXPERIENCE WHEN THEY COME TO THE PEDIATRIC NEUROMUSCULAR PROGRAM AT ARKANSAS CHILDREN'S HOSPITAL?

Arkansas Children’s Hospital is the only children’s hospital in the state and it serves patients and families in Arkansas and beyond. Our comprehensive neuromuscular program includes experts from rehabilitation medicine, nursing, care coordination, pulmonology, cardiology, endocrinology, physical therapy, neuropsychology, gastroenterology, genetics, palliative care, nutrition therapy, social services, and orthopedics. We have a dedicated multidisciplinary “Neuropathy Clinic” for children with inherited and acquired neuropathies. The unique feature of our clinics is that patients and families see multiple specialty providers and undergo testing on the same day under one roof. Patients and families experience a standardized, transparent, and evidence-based care, which is critical to improve the quality of life of these patients.

Q: WHAT DO YOU LOVE MOST ABOUT YOUR PRACTICE?

I firmly believe that there is a genuine collaborative environment in our practice. Our goals revolve around helping the children and families with neuromuscular conditions lead a good quality of life.

Q: HOW CAN PATIENTS MAKE AN APPOINTMENT AT ARKANSAS CHILDREN'S HOSPITAL?

Please call 501-364-1850 to set up an appointment with me first. You also can reach out to me over email: aveerapandiyan@uams.edu

Arkansas Children's Hospital
1 Children's Way
Little Rock , AR 72202-3591
Primary Care Appointments:
(501) 213-1883
Specialty Care Appointments:
(501) 819-3520

COVID-19 & CMT

Telemedicine FAQs with Dr. Govindarajan, MU Health Care, Columbia, MO

Dr. Raghav Govindarajan

Q: WHAT IS TELEMEDICINE?

The practice of caring for patients remotely when the provider and patient are not physically present with each other. There are two methods of communication:

#1. Store & forward – A video or photo is captured and shared with the physician prior to the consultation

#2. Live – A live video or audio is used via a virtual such as Zoom Healthcare Plan or Telehealth.

Q: DOES THE DOCTOR NEED TO RESIDE IN YOUR STATE TO MAKE A TELEMEDICINE APPOINTMENT?

Yes, the doctor needs to be licensed in the same state the patient resides. However, some doctors are licensed in multiple states via Interstate Medical Licensure Compact, which was launched in 2017 by the Federation of State Medical Boards and offers a voluntary expedited pathway to licensure for physicians looking to practice in multiple states.

Q: DURING THIS TIME OF UNCERTAINTY WHY IS TELEMEDICINE MORE IMPORTANT NOW THAN EVER?

Telemedicine is a great option for CMT patients to limit exposure to COVID-19 and reduce the following:

- Difficulty and expenses of travel
- Reduced risk of injury and getting sick (COVID)
- Time gaps between exams

Q: DO I GET THE SAME LEVEL OF CARE?

Yes, patients get the same level of care with telemedicine. A doctor seeing the patients in their home environment gives him or her a sense of how that patient functions in their space in a day-to-day setting.

Q: DOES INSURANCE OR MEDICARE COVER TELEMEDICINE?

Yes. Most insurance companies (including medicare) cover telemedicine right now due to COVID-19.

Q: CAN I GET A PRESCRIPTION VIA TELEMEDICINE?

Yes, a doctor can write a script for medication, genetic testing, bracing, PT, etc.

Q: WHAT ARE THE BENEFITS AND/OR DISADVANTAGES OF TELEMEDICINE?

Benefits: Reduces outside risk or exposure to sickness and injury.
Disadvantages: The exam is limited and can not cover all areas or testing like an in-person exam.

Q: HOW WILL THE DOCTOR KNOW MY MEDICAL HISTORY?

It is requested by the doctor prior to your appointment.

Q: DO YOU OFFER REFERRAL RESOURCES TO OTHER TELEMEDICINE HCPS?

Yes, there are many different networks, specialists and providers available depending on your needs.

Watch Dr. G's full webinar, "CMT & Telemedicine"
www.hnf-cure.org/cmt-connect-webinars/

To schedule a visit with
Dr. Raghav Govindarajan
Phone: 573-882-1515
E-Mail:
govindarajanr@health.missouri.edu

Dear Kristin,

Throughout this ordeal, I have been stuck inside of my house for three weeks. I have noticed a huge increase in my CMT symptoms, my body feels weaker and my pain has increased. I also noticed I am much more anxious than usual. This pandemic and isolation is really taking a toll on my body and I am not sure how to deal with it.

From Kerry

Dear Kerry:

You are not alone unfortunately, this is a common problem among those who have chronic conditions. Living with chronic illness offers a unique set of challenges, we are considered an at risk group and social distancing is creating decreased contact with the outside world. This can bring up a mix of emotions from anxiety of wanting to keep ourselves and our family safe and fear what could happen if we do contract it. It's important to take care of your mental well-being during this time. Here are some tips on how to do that.

- **Make sure you have a doctor that you can contact.** Ask them if there are any extra special precautions you should be taking. Make sure you are as prepared as you can be. Is there any medication you need to stock up on or no longer take? This can help you feel a little more prepared and make sure you're both on the same page.
- **Accept your feelings.** There is no wrong way to go through this. This is new for all of us. If you feel scared that's ok. We are all scared at times. Understand that this fear and anxiety are feelings and they will pass. Try not to think too much into the future. That can make us feel even more overwhelmed and play out worse case scenarios. Understand this is just a way of our brains protecting us.
- **Try to connect with friends or a therapist.** One of the "good things" is that many therapists are doing tele-health, so if you have a difficult time getting around try to find one in your area to set up a tele-health session with you. If you have a close friend or family member, connect with them. Reach out and let them know how you're feeling. Ask them how they're feeling.
- **Keep moving!** You don't have to do much but sitting on the couch or in bed all day isn't healthy either! Check out YouTube or instagram. There are regimens out there that you can tailor to your set of needs. Even if it's just simple stretches. Make your goals attainable. Set aside five minutes a day to move around and slowly increase it.
- **Don't be afraid to unplug!** Shut off your devices and take a breath. Unfollow, unsubscribe, keep the news off for a day. It's ok. Our minds need a break.

We will get through this together. Whether you're feeling big emotions or little, it does take a toll on your body. This is a difficult time to navigate but we are in it together. Be kind to each other, be kind with yourself. Be supportive to those around you and know we will get through this.

Kristin Gelzinis LMSW
HNF Patient Advocate
info@hnf-cure.org

HNF's CMT Centers of Excellence

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

ARKANSAS

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Stanford Neuroscience Health Center Neuromuscular Clinic
Palo Alto, CA
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jnfisher@stanford.edu

CONNECTICUT

Hospital for Special Care
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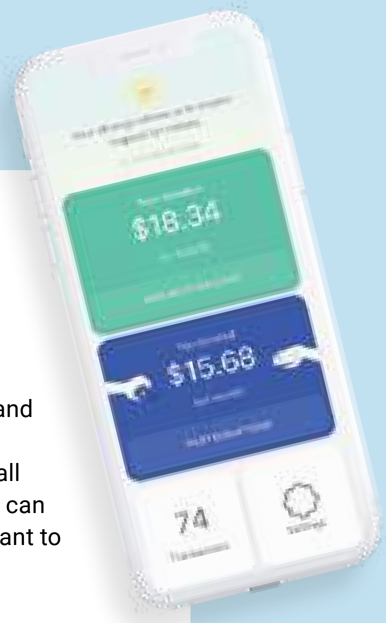
Spokane, WA
Contact: Ann Cooper
509-939-8079 coopera@st-lukes.org

* Pediatric Center of Excellence



Help Support HNF with the RoundUp app!

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

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

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

Thanks,
Courtney

**HEREDITARY
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Events

Get Involved and Join us at an Upcoming HNF Event

Movement is Medicine™ Summit Orlando

November 14, 2020

Join us for a day of CMT-friendly exercise classes, workshops, and one-on-one consultations. Lunch will be provided.

Registration opening soon: www.move4cmt.org

Euchre Tournament, Rochester, NY

**** POSTPONED ****

Join us for a fun afternoon of Euchre with cash prizes, refreshments & more! All to benefit CMT6.

Register today: www.curecmt.org

Jaxon's Crusaders Clay Shoot, Fort Worth, TX

June 20, 2020

All ages are welcome to attend this family-friendly event. We will have live music, face-painting, and plenty of kid-friendly activities. All proceeds benefit Leigh's syndrome gene therapy research for Jaxson Flynt.

Register today: JaxClayShoot.givesmart.com

Million Dollar Bike Ride, Philadelphia, PA

Update now virtual

June 13, 2020

Register to ride with Team CMT on June 13th. Riders can select a 13, 34 or 72 mile route and funds raised will be matched by the UPenn Medicine Orphan Disease Center (up to $30k)!

Register today: https://bit.ly/2W1LvAA

PA 4 CMT, Newtown Square, PA *

September 18, 2020

The evening will be filled with cocktails, food, music and amazing silent auction items. Take a chance on the 50/50 raffle!

Join us: PA4CMT.givesmart.com

Movement is Medicine™ Summit, Phoenix, AZ

November 5-6, 2021

Join our Summit waiting list for 2021 – space is limited! Sign up to receive notifications about this event.

Learn more: https://bit.ly/2TBFOaJ

TCS New York City Marathon

November 1, 2020

Please consider making a donation to our participants who are 0.5 % of the population that will conquer this amazing feat!

Donate here: www.hnf-cure.org/tcs-new-york-city-marathon-2

PHARNEXT

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