



CMTupdate™

Fall 2015

We're Here To Help: The Hereditary Neuropathy Foundation's Healthcare Provider Directory

By Allison Moore, CEO and Founder of HNF

The Hereditary Neuropathy Foundation is thrilled to announce the launch of the first online health care provider directory that has ever been offered to this community to include comprehensive testing to certify health care professionals (HCPs).

HNF's Health Care Provider Directory enables patients to research and find the HCPs who address the unique needs and considerations of those living with Charcot-Marie-Tooth (CMT) and other inherited neuropathies (INs). Participating HCPs can utilize the directory to find the information and resources to better serve the CMT and IN community.

Why did we decide to launch this directory now?

We are at a critical point in our understanding of these rare diseases. While the collaboration among academia, government, and industry has made great strides in developing advanced diagnostics and treatments for CMT and INs, there are still no cures.

Without a cure, patients of inherited neuropathies require a multidisciplinary approach for managing symptoms and maintaining quality of life. A CMT patient's functionality, quality of life, and disease management depend on working with a team of HCPs, such as neurologists, physical therapists, pain specialists, orthotists, and other specialists.

Finding those HCPs has been especially challenging for the inherited neuropathy community. There hasn't been a reliable resource available to find local HCPs who are familiar with the complexities of treating the whole person with CMT or INs.

Until now.



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.

Inside This Issue

Featured Article	1
TRIAD	2-4
GRIN	5
Community	6-7
Team CMT	8-9
Events	10-11





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.

HNF's Health Care Provider Directory is that resource, facilitating and nurturing the crucial connection between patients and health care providers:

“Living with CMT can generate great stress for the individuals impacted, as well as their families—and that's on top of the disease's physical burdens. Patients want to live their lives as ‘normally’ as possible, yet their disease can isolate them because relatives, loved ones, and even their circle of caregivers are not familiar with the health care dynamics of managing CMT and INs on a daily basis and progressively over the years.”

~ Dr. Mark Gudesblatt, M.D., South Shore Neurological Associates, P.C.

We are excited to offer this robust online tool to serve people within the CMT and IN patient community. The directory will provide medical practitioners with information to accurately diagnose, offer, or refer treatments to improve quality of life and stay up-to-date on cutting edge treatments and clinical trials.

HNF's Health Care Provider Directory currently includes tools and links to help patients find additional information about the professionals listed in the directory, map their location, and print reports to share with their entire health care team.

We anticipate the directory to evolve over time into a powerful patient-centered care platform serving as a care portal for patients and HCPs.

HNF has partnered with the following to help build, grow, and promote the directory:

- American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM)
- Inspire Community
- National Organization for Rare Diseases (NORD)
- Neurology Reviews
- Professional Testing Corporation
- Rare Disease Report

Our ultimate goal is to make this directory the place where patients, loved ones, and HCPs unite to help all of those living with these rare, inherited neuropathies lead healthier and happier lives, and bring us closer to a cure.

The Directory is made possible thanks to grant support from [Pharnext](#).

HNF: Raising Charcot-Marie-Tooth Awareness At The Child Neurology Society Meeting (CNS)

By Courtney Hollett, Fundraising Coordinator - HNF

October 7-10, 2015:

Allison Moore, CEO of HNF, and Lori Sames, ED of Hannah's Hope Fund, helped raise awareness for Charcot-Marie-Tooth (CMT), Giant Axonal Neuropathy (GAN), and other forms of Inherited Neuropathies (INs) at this year's Child Neurology Society Meeting.

HNF presented the medical community with information on their HCP Educational Outreach Program. This program targets pediatric neurologists and their participation in a comprehensive health care team to support your family.

The network opportunities were endless, and HNF is pleased to report they vetted over 20 pediatric neurologists to join the HCP Directory.

Moore states:

“This is exciting as we continue to support research and make the clinician a high priority stakeholder in HNF's research program, Therapeutic Research In Accelerated Discovery (TRIAD).”





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.

Current Trends And Future Implications For Diagnosis And Management Of Charcot-Marie-Tooth

By: Courtney Hollett, Fundraising Coordinator - HNF

Original publication from NCBI PubMed found [HERE](#).

Current Charcot-Marie-Tooth (CMT) research is getting closer to developing the technology that can detect the entire spectrum of CMT mutations. Determining the genetic diagnosis of CMT is critical for accurate disease prognosis, effective genetic counseling, and developing targeted therapies. CMT has a high degree of genetic heterogeneity: a phenomenon in which a genetic disorder may be caused by any one of a multiple number of mutations.

Clinical features, inheritance pattern, gene mutation frequency, and electrodiagnostic features all help to create targeted testing strategies, but they fall short in sensitivity and efficiency.

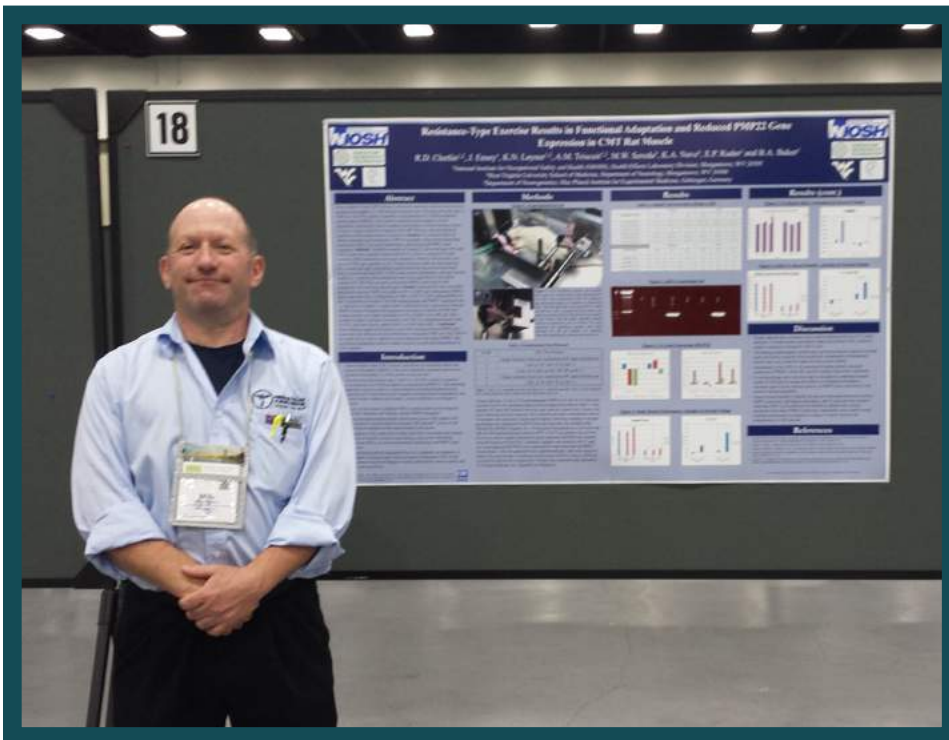
The researchers in this article state that next-generation sequencing (NGS), combined with multigene testing panels, is rapidly overtaking targeted testing strategies as first-line genetic testing. They predict that as

technology improves and costs come down, NGS and multigene testing will completely replace targeted testing.

While this type of testing is the future, its application is still in its infancy. Researchers warn that clinical understanding and awareness of CMT are still necessary to manage the shortcomings encountered with NGS.

Resistance Exercise Reduces PMP22 And Enhances Dynamic Muscle Adaptation In CMT Rats

By: Sean Ekins, CSO - HNF



At the recent American College of Sports Medicine annual meeting, Dr. Chetlin and Dr. Baker presented two posters that summarized their work with Dr. Sereda (Max Planck Institute of Experimental Medicine) that was funded by HNF. They used the CMT1A rat model to show that chronic resistance training type exercise over 4.5 weeks increased dynamic muscle quality and muscle performance, and reduced PMP22 gene expression. The 4.5 week training period for the animals is approximately equivalent to a 6-month training period in humans. These results suggest the need to translate the findings to human CMT patients, in order to determine if CMT-related quality of life and PMP22 expression may improve with a resistance training program. HNF is fully supportive of such future clinical studies.



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Target For Therapeutic Treatment For CMT2D Has Been Identified

By: Sean Ekins, CSO - HNF

CMT2D is caused by mutations in an enzyme called glycyI-transfer RNA (GlyRS). A recent study published in the journal [Nature](#) by Weiwei He and colleagues identified how these mutations lead the enzyme to bind to the neuropolin 1 (Nrp1) receptor.

The Nrp1 receptor is needed for motor neuron function. Failure occurs in a critical signaling pathway for the survival of motor neurons when the mutated GlyRS enzyme competes with the vascular endothelial growth factor (VEGF) and binds to Nrp1. Studies in mouse with VEGF were found to improve the motor function in the CMT2D mouse model. The study suggests that CMT2D could be treated

with VEGF to restore the VEGF-Nrp1 signaling pathway to normal.

In addition, this study indicates that other proteins with mutations could also cause similar, unwanted interactions with important signaling pathways, resulting in neurodegeneration.

Time will tell if this is verified, but in the meantime, a target for therapeutic treatment has been identified and will likely be addressed by future gene therapy.

Please make sure to join the HNF's clinical patient registry, [GRIN](#) to support therapy development for CMT 2D.



It starts in infancy

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

everything seems ok until her...

 <p>FEET START TO LOOK DIFFERENT</p>	<p>MUSCLES ARE WASTING</p>	<p>TOES START TO CURL</p>	<p>SHOES DON'T FIT AS WELL</p> 	<p>NEUROPATHIC PAIN</p>
<p>ABILITY TO HOLD, GRASP & TURN THINGS IS LOST</p> 	 <p>BALANCE BECOMES UNSTABLE</p>	<p>Even if she is lucky enough to get a <i>proper diagnosis</i> of this genetic disease, there are no real treatments & it is progressive. But HNF is on track to finding treatments and cures.</p>		



Clinical CMT Trials

Clinical trials play a central role in helping researchers test and develop effective treatments for CMT.

But the success of clinical trials often relies on how much is known about the patient prior to participating in the study. A complete patient profile gives investigators a snapshot of the “natural history” of CMT and the effects of the disease on the patient.

This is why the Hereditary Neuropathy Foundation (HNF) created the Global Registry for Inherited Neuropathies (GRIN). HNF is a strong advocate on the patient perspective of these rare, inherited diseases.

GRIN was established to fill the gap of patient-reported outcomes (PRO) measures, helping researchers and industry identify early symptoms of CMT and disease progression. Valid outcome measures for clinical trials can be challenging with many diseases, especially rare diseases like CMT. Establishing baseline patient data before the start of a trial helps researchers more effectively determine whether a particular treatment is working.

If you, friends, or family members are interested in participating in clinical trials that may lead to cures and treatments for hereditary neuropathies, please join our patient registry. Clinical trials for the most common form of CMT, CMT1A, are starting soon, and your participation is vital to its success and the success of future clinical trials. Register with [GRIN](#) today. Don't wait. Come join the movement of curing CMT!

Meet HNF's CMT Warrior 2015: Mariah Palombo

My daughter Mariah Palombo was diagnosed with Charcot-Marie-Tooth disease when she was just becoming a teenager. She was being bullied and made fun of in school because of the way she walked.

After seeing several doctors, a neurologist finally had an answer for us that was very hard to hear.

Following her CMT diagnosis, Mariah had two surgeries on her feet. She chose to drop out of her high school and be home schooled. She's had a lot of stumbles and falls on her way to get to class and sometimes her hands would lock up on her. But she keeps going.

Despite her pain and infections from her surgeries, Mariah graduated with a high school diploma. She is currently in her last year at Akron University striving for her degree as a biology major. She also works as a server in her grandparent's restaurant.

Mariah has saved money to travel the world while completing her education. She's been to Thailand to help with elephant rescue, to Africa backpacking, and to Costa Rica. She is currently dreaming up her next adventure. All at the age of twenty three!

Mariah's dream one day is to teach children all around the world. She doesn't want to be labeled as a disabled person, and she doesn't want CMT to define who she is.

She is truly amazing and I'm so proud of her. Mariah is a CMT Warrior!



Hot Topics In Our Inspire Community!

By Courtney Hollett, Fundraising Coordinator - HNF

The Charcot-Marie-Tooth (CMT) Inspire Community is an online forum connecting CMT patients, their families, friends, and caregivers, for support and inspiration. The Hereditary Neuropathy Foundation sponsors the community and is an Inspire Trusted Partner.

[Click here](#) to join discussions, find answers, or post questions!

1. Tendon Transfer

Post: Has anyone gone through the process of having the tendon transfer done to stop the foot drop? If so, how long have you had this and what were, if any, some of the “wish I knew that before getting it done” moments?

Reply: Yes, when I was 10 years old. My foot drop was severely pronounced, so once my feet stopped growing we went ahead. I am 32 now and that procedure has held up the best out of the many other ones I have had. My only regret is doing both at the same time instead of alternating. The total wheelchair dependence (and dependence on others) and inability to put weight on either foot for 6-7 weeks were really rough. Crutches are terribly difficult too, but it does afford a tiny bit more independence while you recover.

Reply: The tendon transfer can definitely help with foot drop, if you're a good candidate for it. I had my surgery on Monday and my doctor concluded that we should not do the tendon transfer because my tendon wasn't strong enough to make it worth it. He assessed that tendon strength was a “4”, and said that the tendon loses a point upon transferring, so it would be a “3”, and therefore not worth transferring to the top of the foot. He did straighten my toes and fuse the side-to-side joint below my ankle to make my foot less “floppy.”

[Click here](#) to see more replies about Tendon Transfer.

2. CMT & Stomach Issues

Post: Does anyone have severe stomach issues related to their CMT?

Reply: I do...and it drives me nuts. I have bloat issues, digestive issues, and very uncomfortable a lot of the time. HNF's Global Registry for Inherited Neuropathies has questions related to digestive issues. If indeed stomach issues are related to CMT, we want to document and address those concerns. Please join the patient registry at www.neuropathyreg.org and anyone else that feels their issues may be related to CMT. I have found that by eliminating my cafe lattes (no dairy) and eating a gluten free diet there is

some improvement. I have been tested twice for Celiac and now gluten sensitivity and I do not have a problem. So I'm not sure what the link is here. The cleaner my diet, the better my stomach feels. I drink lots of herbal teas, mostly Tevana, all day long. I now take supplements and have increased my fiber intake which also seems to help. I have had my stomach scoped and at the time there was no evidence of damage. It's been 5 years. I have read that the villi in the intestine can be compromised for those affected by neuromuscular diseases.

Thank you for sharing. It's important that we all connect to support each other and establish potential trends with symptoms associated with CMT.

Reply: I was in the ER a few weeks ago with bad lower abdominal and lower back pain. After being there for 5 hours and having numerous tests done, they could find “nothing wrong.” The doctor on call felt it was spasms brought on by CMT. I had never heard this before. Now I read this blog and maybe there is something to this.

[Click here](#) to see more replies about CMT and Stomach Issues.

Why I'm An Active CMT Patient Advocate

By: Joy Aldrich, Advocacy Director - HNF

I recently decided the best way to find a cure for CMT is to become an active patient advocate.

I attended the Global Genes RARE Patient Advocacy Summit this past September with over 500 other rare disease patient advocates. The two-day summit was packed with informative presentations, networking opportunities, and endless inspiration.

Topics at the summit included:

- Clinical Trial Training: When and How Patients Should Become Engaged with Industry
- The Importance of Sharing Genetic Data with Researchers Patient-Centered Outcomes Research

- 21st Century Cures - Community Call to Senators, Building Comprehensive Care Centers

- How You Can Bring Your Voice to the FDA Drug Approval Process.

As the summit came to an end, I felt more empowered than ever to make a difference for those living with CMT. I met so many patients simply trying to find a way to get an organization started, or create a clinical registry, or interest researchers in their disease.

I also walked away from the summit with a renewed sense of gratitude for the tireless work HNF has done to build a thriving patient community.

[Continue on page 11](#)

Tips For Living With Charcot-Marie-Tooth During The Holidays

By: Allison Moore, CEO - HNF

The holiday season is upon us!

The season brings family, friends, and community together to celebrate and share the many holiday traditions across cultures and religions. While the holidays should be a time of joy and celebration, it can also be a time of increased physical and emotional stress. Traveling, dietary challenges, family issues, and financial stress can make the season difficult for even the most holiday hearty among us.

Being mindful of managing these additional stresses during the holidays is especially important for those living with Charcot-Marie-Tooth (CMT). CMT patients face those holiday challenges with the additional daily stress of living with a progressive neuropathy.

With proper planning and preparation, CMT patients can give themselves the best opportunity to stay healthy and happy this holiday season. Here are a few helpful holiday tips.

Physical Activity & Exercise Tips:

If you are currently in an exercise program, don't stop! Keeping physical activity as a part of your daily routine will keep your mind and body strong. You may also want to consider introducing yoga as part of your exercise program. A consistent yoga practice can help reduce stress and bringing harmony and balance to the body, mind, and spirit. Something we all need during the holidays!

** Be sure to discuss physical activity with your healthcare provider to develop an exercise plan that meets your particular needs.

Diet Tips:

You can have your pumpkin pie and eat it too.

Staying on a consistent, healthy, balanced diet IS possible during the holiday season. The key to maintaining a healthy weight and enjoying yourself during the season is planning and preparation.

- Always have healthy snacks available to grab and go.
- Cook once, eat three times. Cook larger batches of food so you have at least 3 days of healthy meals ready to eat.
- Be mindful of caffeine, alcohol, and sugar intake.
- Eat before you head out to a party. "Saving" your calories for an event usually results in overeating.
- Stay hydrated. Hunger is often mistaken for thirst.
- Honor your food allergies/intolerances.

This can be challenging. However, more people are becoming aware of food allergies and intolerances. If you are comfortable, tell the host about your concerns and offer to bring

something. If a discussion isn't in the cards, be sure to eat something before you go.

- Relax! Anxiety about food often results in making poor choices.
- Remember the holidays aren't just about food. Make connecting with family and friends the top priority.

And if you are still struggling, you can try this helpful mantra: There will always be pie. The world is not going to run out of pie. You don't have to eat every last bite. There will always be pie!

Travel Tips:

If you are traveling this holiday, whether by car, train, or plane, set aside plenty of time to plan and prepare for your trip.

- Call ahead to make arrangements to accommodate any mobility issues.
- Mind your hand hygiene. Travel can increase your exposure to germs.
- If you are traveling by car, schedule in plenty of break times to get out and stretch.
- Bring along healthy snacks.
- If you are on prescription medications, make sure you have enough to cover the time you are away.

Emotional Health Tips:

The season can challenge the emotional well-being of even the happiest of holiday spirits. It's important to have access to support if you are feeling the holiday blues.

- Connect with other CMT patients on HNF's online [CMT Support Community](#).

[Continue on page 9](#)

One More Rep: Ed Moore is Working Out For Charcot-Marie-Tooth Awareness

By: Courtney Hollett, Fundraising Coordinator - HNF

We love to shine the spotlight on the brave and courageous CMT community members who inspire us and the world around them every single day.

Today, we recognize Ed Moore, a Team CMT leader who is committed to spreading awareness of CMT with a pretty creative and bold fundraising strategy.

Let's find out more about Ed and how he discovered HNF, what inspires him, his fundraising strategy, and what it was like to open for Cyndi Lauper.

HNF: How did you discover The Hereditary Neuropathy Foundation?

Ed: I was searching for more information on Charcot-Marie-Tooth disease after a friend told me she had it. I read about Bernadette Scarduzio's documentary online, so I ordered the DVD and viscerally experienced the cruelty and devastation of this disease. Bernadette's story really made me want to do something about it.

One of the extras on the DVD is an interview with Allison Moore, founder of HNF. She spoke about the HNF website, so I hopped online and explored it. It was there that I joined Team CMT, ordered the singlet, and created a fundraising page. I am committed to helping to find a cure.

HNF: Tell us a little bit about yourself...

Ed: Whoa, that's always a tough one!

Where to start... well, I'm currently a self-employed web designer and developer. I got into the field accidentally when I returned to school in 1997 to finish a Fine Arts degree. I took an HTML elective, got bit by the web bug, and that was that. I also got into IT, and have worn a System Administrator hat at a couple of companies.

And I've got a cat. Could I be any more nerdy?

But wait, there's more...

Before the whole computer thing I played keyboards in a few bands, and even got signed to CBS Records back in the late 80s and early 90s. The most memorable gig was opening for Cyndi Lauper. We spent the next day at the beach with her, Rick Derringer, and the rest of her band. She rode in the back of my pick-up truck with that crazy hair (it was all colors back then), and had a great time. She is one of the nicest and most talented people I've ever met. I still enjoy composing, arranging, and performing music in

my spare time.

HNF: Where do you live?

Ed: I live in the beautiful Harbor City of Melbourne, on the Space Coast of Florida. It's about 20 miles south of the Cape, and I love watching the big rockets go up. The rumble of those mighty engines as they light up the sky... it's a thrill each time.

I've loved rocket launches and space exploration since I was a kid. We would travel with the Boy Scouts to Patrick Air Force base to camp, and then we would watch the launches at Cape Kennedy.

HNF: What are your favorite hobbies?

Ed: Bicycling and running on alternate days, with Sundays off for bad behavior. I've got a 15-year-old Wal-Mart Huffy mountain bike – I think the thing cost \$89 bucks. I recently got involved with a biking group on our local meetup.org, and I really enjoy taking longer rides with them. For now I run on my own; none of my neighbors wants to get up at 5:30 to go for a morning jog.

HNF: How has Charcot-Marie-Tooth disease changed your life?

Ed: I met a wonderful person who has Charcot-Marie-Tooth disease, and it made me focus on giving back, and on returning the kindness that she showed me. I had several debilitating conditions before we met, and now they're gone, and I believe it was because of her.

My back was in bad shape. Like, 'move wrong and be in bed for three days' bad. I have two compressed discs (L4, L5), and could barely even walk a quarter mile, much less run. A few weeks after meeting her, my back was completely healed. I can run, lift, kick, jump... you name it.

I was hypothyroid and on Synthroid for years. Two months after we met I went in for my customary six months blood work to check TSH levels. The doc looked at the results, looked at me, and said, "I'm taking you off Synthroid; your thyroid's kicked in. I'll see you in a year."

I was depressed for a decade and a half. The depression is gone. I'm feeling things I haven't felt for a long time. I can laugh, and cry, and love, and it feels fantastic! My energy levels are through the roof and the world has colors again. Yes, this could all be coincidence. Yet aren't the odds of recovering from this assortment of physical and

psychological conditions simultaneously and in such a short time pretty astronomical? Truthfully, if it hadn't happened to me I wouldn't believe it either.

So I've found another purpose in life as a spiritual being on this planet: in the short time remaining for me to dance here I want to help find a cure for CMT, and to repay her for what she did for me.

Gratitude debt is the best kind of debt, don't you think? With help from HNF, I set up a [fundraising page](#).

And here's my offer:

For every dollar you donate, I will do a rep of the exercise of your choice, and put the whole set in a personalized video just for you on YouTube. I'm usually pretty shy, but I'm brazen and shameless for this cause. If you donate \$35 I'll do the work-out shirtless. For \$50 I'll exercise in skin-tight compression shorts. And if you kick in \$100 I'll work out in a Speedo and the FCC may shut me down!

C'mon folks, make me sweat!

HNF: What suggestions can you give others who know people with CMT?

Ed: It's tough to tell how hard Charcot-Marie-Tooth is on a person from the outside. Learn more about it, about its effects, symptoms, and progression. Be alert for signs of fatigue, cramps, and pain. Be mindful of muscle weakness and balance issues, and of the emotional swings that come from having a nervous system slowly going haywire. If you are close to anyone living with CMT, offer massages, and help with stretching and exercise. And most of all, keep the faith that a cure exists – it has just not yet been



discovered.

HNF: What's a favorite quote of that you think of often?

Ed: "Hold on tightly, let go lightly, and never cut what you can untie." It's a mash-up of two quotes, which I think can be attributed to Richard Carlson and Robert Frost.

Thank you so much for letting me ramble on, and for making it so sweet and simple to help.

And thank YOU Ed for being part of HNF's ever-growing community of CMT heroes! If you would like share your story on living with CMT, we'd love to hear from you!

Please contact us at info@hnf-cure.org.

Continued from page 7

- Establish a holiday support group in your community.
- Engage in activities for the mind, like classes, artwork, or community work.
- Reduce emotional stress by getting plenty of rest and practicing relaxation techniques.
- Stay physically active.

I hope these tips will help you enjoy and celebrate the holiday season in good health and spirits! Do you have

any helpful holiday tips you would like to share? We'd love to hear from you!

Share and connect with us on all of our social channels:

Facebook: <https://www.facebook.com/HereditaryNeuropathyFoundation/>
Youtube: <https://www.youtube.com/user/HNFoundation>
Twitter: [@CMTNeuropathy](https://twitter.com/CMTNeuropathy)
Instagram: [@hereditaryneuropathyfoundation](https://www.instagram.com/hereditaryneuropathyfoundation)
Pinterest: <https://www.pinterest.com/HNFCure/>
Vimeo: <https://vimeo.com/user29044114>

Poker Tournament

By Courtney Hollett, Fundraising Coordinator - HNF

The Scarduzio family and their friends came together in Pennsylvania on September 19, 2015 to honor an amazing husband, father, and friend...John Scarduzio.

John's daughter, Bernadette Scarduzio, organized and hosted the Charity Poker Tournament to benefit The Hereditary Neuropathy Foundation's TRIAD Program and to honor her late father. Bernadette is one in 2500 living with Charcot-Marie-Tooth. When her father, who also shared the disease, passed away, Bernadette resolved to raise herself from suffering in obscurity to become 'the face' of CMT.

The charity event was part of September's Charcot-Marie-Tooth Awareness Month. The poker tournament was such a great success and the Scarduzio family plans to turn it into an annual event every September.

HNF and the Scarduzio family would like to thank all who participated in the tournament. See you next year!

Holiday Shopping & Charcot-Marie-Tooth Research

By Courtney Hollett, Fundraising Coordinator - HNF

What if every purchase you make this holiday season could earn dollars for Charcot-Marie-Tooth research?

This holiday season, The Hereditary Neuropathy Foundation is participating in the Americana Manhasset Champions for Charity®.

From Thursday, December 3, through Sunday, December 6, over 70 participating Americana Manhasset and Wheatley Plaza stores will donate 25% of designated full-price, pre-tax purchases to the participating organization(s) of the customer's choice.

Purchases are not automatically eligible; you must register for a complimentary CHAMPION CARD, designate the Hereditary Neuropathy Foundation as your charity of choice, and present your CHAMPION CARD when making purchases during the event.

To register for your card, visit championsforcharity.org or call 800.818.6767.

****Not nearby? You can still participate by shopping via telephone and have your gifts mailed.****



CMT 6 Football Event

By Debi Houliares, Board Member - HNF

On October 23, 2015 the Victor New York Blue Devils Football boosters and coaching staff dedicated their first playoff game from their undefeated season to team manager Zach Houliares.

Zach has CMT6. In lieu of 50/50, Victor cheerleaders passed football helmets throughout the first half of the game raising \$777.07!

100% of all the proceeds collected went to HNF's Team Zach to fund research for CMT6!

Thank you to the Victor community for all your support!



#GivingTuesday: Giving Back This Holiday Season

By Courtney Hollett, Fundraising Coordinator - HNF

#GivingTuesday: Giving Back This Holiday Season

On Thanksgiving, we give thanks.
On Black Friday, we get deals.
On Cyber Monday, we get online.
And on #GivingTuesday, we give back.



Since its inaugural year in 2012, #GivingTuesday has become a movement about celebrating and supporting philanthropy during the holiday season. #GivingTuesday unites countries around the world by sharing our capacity to care for and empower one another.

#GivingTuesday harnesses the power of social media amplifying the small acts of kindness by organizations, families, and individuals.

The Hereditary Neuropathy Foundation is proud to continue our support of #GivingTuesday. Come join us on December 1st and participate in this globally recognized movement of giving and philanthropy.

You can help individuals living with CMT by donating to HNF's Therapeutic Research in Accelerated Discovery (TRIAD) program on our donation page [HERE](#).

It doesn't matter how much you give, or what you give.
Only that you give.

Be sure to share the hashtag #GivingTuesday with your friends and families on all your social media channels and help spread the message of sharing and caring this holiday season!

Upcoming Events – Save the Date

Champions for Charity

Thursday, December 3 - Sunday, December 6, 2015
Americana Manhasset
Manhasset, New York

H.E.L.P. Fund Brunch, Boutique & Card Party

Friday, January 29, 2016
Broken Sound Country Club
Boca Raton, Florida

Casino Night

Thursday April 21, 2016
Strathallan Rooftop Hotel
Rochester, New York

[Continued from page 7](#)

Our engaged patient community is an invaluable asset for HNF. Here's how CMT patients can do their part and get involved:

1. Complete your profile on [GRIN](#) (including uploading ALL test results).
2. Join and participate in our [HNF/Inspire](#) online discussion and support community.
3. Consider fundraising and/or making a [donation](#) to HNF to support research efforts.
4. Like the [HNF Facebook page](#) and [follow HNF on Twitter](#).
5. [Let us know](#) how we are doing and what you would like to do to help HNF.



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HereditaryNeuropathyFoundation

KIRSTEN E. GILLIBRAND
NEW YORK



UNITED STATES SENATOR

September 1, 2015

Dear Friends,

I am proud to recognize this month of September as Charcot-Marie-Tooth Awareness Month. Charcot-Marie-Tooth is a rare disease also known as CMT which affects 1 in 2500 patients in the United States. While there is no cure for CMT, progress is being made through the efforts of organizations like the Hereditary Neuropathy Foundation.

Over nearly fifteen years, the impact of the Hereditary Neuropathy Foundation has continued to grow. Through its partnerships with leading companies, advanced drugs are being developed to treat CMT. I am grateful for the community of support the Hereditary Neuropathy Foundation has established. By building a robust patient registry to support clinical trials for potential treatment, the Foundation has provided opportunities for many individuals to receive possibly life changing treatment.

The effects of Charcot-Marie-Tooth disease significantly impacts the lives of individuals and families of those affected. Greater awareness is needed to address this crisis and increase research and testing trials. It is clear that early and accurate diagnosis of CMT is critical to improving the quality of life for those with CMT. It is my hope that our collective advocacy and greater awareness will increase global awareness of this disease.

During Charcot-Marie-Tooth Awareness Month, I send my best wishes to all those affected.

Sincerely,

A handwritten signature in blue ink that reads "Kirsten Gillibrand".

Kirsten Gillibrand
United States Senator