HEREDITARY NEUROPATHY FOUNDATION

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CMTupdate™

Summer 2014

The Un-selfie Campaign
pg. 2

September is CMT Awareness Month

Get involved and be a part of finding a cure!

CMT awareness month is an entire month dedicated to building awareness, raising funds and finding a cure. The Hereditary Neuropathy Foundation (HNF) has committed to spend 30 days in September hosting local and national events, launching fundraisers, and spreading the word about the effects of Charcot-Marie-Tooth disease (CMT), all in an effort to help those living with this disease.

CMT has been referred to as "the biggest disease you've never heard of." HNF wants to change that, and with your help we believe that we can. Approximately one in every 2,500 people (2.6 million worldwide) live with CMT. CMT is a progressive disorder that causes the nerve cells leading to the body's extremities to slowly degenerate, resulting in the loss of normal use of the hands, arms, legs and feet. CMT does not discriminate - this disease strikes people of all ages, genders, races and ethnicities. Alarmingly, symptoms are often not diagnosed properly and unfortunately are routinely overlooked by doctors and medical professionals.

This is the time to get the word out about CMT and to increase the understanding of its impact on the lives of those living with the disease. Our goal this September is to expand our community in sharing our passion for people to understand the seriousness of CMT.

So don't wait, get involved today!

- Text2give Un-selfie4CMT campaign
- California Pizza Kitchen Fundraiser
- Dick Sharpe Memorial Golf Event
- NYC Spin-For-A-Cure

More is planned, so follow us on Twitter (@CMT Neuropathy), Facebook (HereditaryNeuropathyFoundation), and register with us to hear more about our CMT awareness programs.

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

Get Involved

The Un-selfies4CMT Campaign!

HNF introduces our latest initiative to reach millions of people worldwide and raise money for CMT research using Text2give.

The Un-selfies4CMT campaign is not about disability. It is about celebrating and sharing our passions for the activities we are blessed enough to enjoy. We want to encourage others to take a moment of reflection and gratitude for the activities their bodies allow them to do, whether it is playing with their young children, preparing a delicious meal, painting, swimming, running, gardening, dancing, weightlifting. These activities are gifts and should be recognized as so.

Charcot-Marie-Tooth (CMT) is only one of the many diseases that threaten and effect the passions we sometimes take for granted, and it is a disease that has been in the shadows for far too long. Even though the 2.6 million people suffering with CMT exceeds the 2.3 million people affected with Multiple Sclerosis (MS), there is much less awareness about our disease, and substantially less funding for research towards treatments and a cure.

We have the power to change this...let's put social media to work and celebrate our individual passions with action.

Its quite simple:

1. Download and print the unselfie flyer at www.hnf-cure.org/unselfies4cmt-campaign/

2. Fill in what you are passionate about, take your unselfie

3. Upload your unselfie at http://us2e.com/hnf/

Please don't wait, download your photo today at http://us2e.com/hnf/ as HNF prepares for the launch of Un-selfies4CMT campaign on September 1st.

Text CMT to 501501 to donate $10 and then share your un-selfie on social media! #UnSelfies4CMT

The Hereditary Neuropathy Foundation thanks Estela Lugo, the brains behind the Un-selfies4CMT Campaign. Estela was first introduced to HNF in 2009 when her physical trainer showed her a copy of a recent HNF Newsletter. Estela's trainer was also the trainer for Allison Moore, the Founder and CEO of HNF, who shares with Estela the common struggle of living with CMT. Estela has been actively spreading awareness via social media, fundraising, and participating in local events.
Let's all be CHAMPIONS, so we can be WINNERS this September!

Get Involved

Spread Awareness - Visit California Pizza Kitchen During September: CMT Awareness Month

Want to help fund research and spread awareness? Well here is your chance and mingle with friends and family while you dine! We have planned CPK FUNdraisers in states around the country for you to help with research for CMT. Visit one of these locations on the designated day and present the flyer to your server and 20% of your bill will be donated to CMT Research. Want to be the host at your local California Pizza Kitchen? Contact Courtney@hnf-cure.org for more details.

September 15th
11800 West Broad St. #1104
Richmond, Virginia 23233

September 15th - 17th
Park Avenue South
440 Park Avenue South
New York, NY 10016

September 15th - 18th
Northgate Mall
401 NE Northgate Way, #944
Seattle, WA 98125

September 16th - 17th
City Line
4040 City Avenue
Philadelphia, PA 19131

September 29th
Bayshore Town Center
5665 North Centerpark Way,
Unit N-141
Glendale, WI 53209

Visit www.hnf-cure.org/california-pizza-kitchen-campaign/ to print out the HNF flyer before you visit your local California Pizza Kitchen!

Get Involved

2nd Annual Dick Sharpe Memorial Golf Event

On Monday, September 22, 2014, HNF will host the 2nd Annual HNF Dick Sharpe Memorial Golf Event at the prestigious North Hempstead Country Club in Port Washington, New York. Dick was well known during his days in the radio industry, his numerous rounds on the golf course, and his never ending commitment to his friends and family. But we at HNF will always remember him as a strong mentor, charismatic leader, and most of all, our loyal friend.

Dick suffered from CMT1A as does his daughter and HNF founder, Allison Moore, along with many other family members.

Allison recalls a memorable evening out on the town with her Dad, and reminisces about their conversation: “Who would have thought that when we started HNF that we would have an impact on so many lives that are affected by CMT? Hopefully our legacy will live on...” That special moment was over 10 years ago, and she never thought she would lose her dad so soon. “I miss our daily phone calls, summer dinners and most of all someone that was always there to help us further our mission in raising funds to cure CMT.”

Allison and the board of directors have started a fund honoring Dick Sharpe that will live on. The proceeds of this fund will go to support CMT Research through the Therapeutic Research In Accelerated Discovery (TRIAD) program.

To register visit: http://weblink.donorperfect.com/2014GOLF

Grab Your Shoes and Spin CRANK Style NYC!

Dust off those spin shoes and come out to CRANK NYC (Upper East Side – 1658 Third Avenue) Saturday, September 27, 2014 from 1pm to 3pm and Spin-For-A- Cure! Join us as we have fun filled hours of energetic music and fun all for a great cause! All proceeds go to research for Charcot-Marie-Tooth. Make sure you check out the raffles for a chance to win some great items. Immediately following we will mingle for food and drinks at Parlor Steakhouse just two short blocks away from CRANK. Don’t live in the New York area? Host a spin in your community to spread awareness for CMT. We will give you all the tools you need. Contact Courtney@hnf-cure.org for details!
Visit http://hnf.donorpages.com/SpinNYC/ to register!

TRIAD
THERAPEUTIC RESEARCH IN ACCELERATED DISCOVERY

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.

Building Awareness on CMT and Supporting the Patient Community - HNF Announces Support from Pharnext

HNF recently entered into a partnership with the French biopharmaceutical company, Pharnext, to help raise awareness of Charcot-Marie-Tooth (CMT) disease and support the CMT patient community through several initiatives. Building awareness is key! Pharnext's support will assist HNF in distributing HNF's CMT Update quarterly newsletter, enhancing the Global Registry for Inherited Neuropathies (GRIN), setting up activities for CMT September Awareness Month in the US and strengthening the CMT Inspire Community.

Pharnext is an advanced clinical stage biopharmaceutical company discovering and developing new therapeutics that target multiple key disease pathways for orphan and common neurological diseases including Charcot-Marie-Tooth disease. The company's lead program PXT-3003 for the treatment of CMT 1A has completed Phase 2 clinical trials and pending discussions with the appropriate regulatory agencies will undergo Phase 3 clinical trials. PXT-3003 was recently granted Orphan Drug designation from the European Medicines Agency and the U.S. Food and Drug Administration. Learn more at www.pharnext.com or www.hnf-cure.org.

PHARNEXT

RESEARCH PROGRESS - THERAPEUTIC RESEARCH IN ACCELERATED DISCOVERY

DRUG DISCOVERY

Discovery Biology

- CMT 1A assay development
- CMT1A/1E high content screens
- CMT 2A mouse model
- CMT 2A assay development
- CMT2A low content screens in zebra fish

Translational Medicine

- "Proof of Concept" studies on an in vivo mouse model with CMT 2A
- Transgenic CMT 1A rats for testing various therapeutics
- Partnering with pharma/biotech (in process)
- "Proof of Concept" for RNA and CMT1A

DRUG DEVELOPMENT

Clinical Trials

- Partnering with pharma/biotech (in process)
- New outcome measure/biomarker for CMT1A/CMT2A (grant submitted)
- Alternate outcome measures for CMT (grant submitted)

Patient Outcomes

- Global Registry for Inherited Neuropathies
- Diagnosis Patient education (Quest/ Athena Diagnostics)
- Quality of Life study (grant submitted)

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Targeting PMP22 in CMT1A Patients with Gene Duplication

DR. LUCIA NOTTERPEK, HNF Grant Recipient

Progress in understanding the genetic causes of Charcot-Marie-Tooth (CMT) disease type 1A (CMT1A) is important for advancing the development of treatments for CMT patients. In the majority of CMT1A patients duplication of the peripheral myelin protein 22 (PMP22) gene results in overproduction of the PMP22 RNA and protein in myelin forming Schwann cells. The mechanism by which increased amounts of PMP22 impair the ability of Schwann cells to maintain healthy myelin is still under investigation, but decreasing PMP22 expression could correct the disease phenotype.

With recent advances in molecular biology it is now possible to turn off undesired gene products within cells and test for functional improvement. Our studies have identified specific regions in the PMP22 gene that are targets for regulation by small RNA molecules, called microRNAs (MiRNAs). These are non-coding regulatory RNA molecules that bind to precise regions of target mRNAs and prevent their conversion into protein. Therefore, miRNAs have the ability to correct undesired gene expression in a highly specific manner.

In previous collaborative work with a group of investigators including Dr Rolf Renne from the University of Florida, Dr. Alex Murashov from East Carolina University and Dr. Lynn Hudson from the NIH-NINDS, we validated a microRNA known as miR29a as a reagent that corrected the expression level of PMP22 in rodent Schwann cells. Our research suggests that miR29a may be able to work in mice, rats and possibly humans, prompting us to expand our work. In a pilot study supported by HNF we seek to demonstrate that PMP22 levels can be reduced by miR29a in cells from CMT1A patients. We will subsequently test if miR29a improves the phenotypes of these cells in culture. If successful, we will next determine if this approach also corrects the myelination impairment of Schwann cells with PMP22 overproduction. Completion of these pilot studies will demonstrate if miR29a is useful for therapy development.

Due to the sophisticated nature of the peripheral nervous system we need to use specific delivery reagents, known as liposomes or nanoparticles to target the cells in humans. Therefore the miRNA approach may provide an opportunity to explore novel treatment strategies for CMT1A neuropathies. Donate to CMT research at www.hnf-cure.org.

Introducing A New Scientific Advisory Board Member

Nadia Litterman, PhD is Collaborations Director at Collaborative Drug Discovery (CDD), where she aims to identify and develop collaborations for drug discovery using CDD's innovative informatics technologies.

She has a long-standing interest in finding therapeutics for neuronal disorders and rare diseases, with more than 10 years of broad research experience in the areas of chemistry, cell biology, and neuroscience.

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During postdoctoral research in the laboratory of Dr. Lee Rubin at Harvard University, she utilized stem cell models of the rare, genetic, early onset motor neuron disorder Spinal Muscular Atrophy (SMA) to search for novel therapeutic strategies. She identified an opportunity for drug repurposing of an anti-cancer compound for SMA and found that this approach may be broadened for a second disease of motor neurons, Amyotrophic Lateral Sclerosis (ALS).

As a National Science Foundation graduate fellow in the Pathology Department at Harvard Medical School, she led an investigation to explore biochemical processes that control protein trafficking in neurons.

Her undergraduate research in the Chemistry department at Princeton University focused on free radical toxicity as it relates to protein misfolding and neurodegeneration.

GLOSSARY

Schwann cells: There are two types, myelinating (cells wrap around axons of motor and sensory.

Myelin: is a material that forms the myelin sheath around the axon of a neuron. It is comparable to the insulation around an electrical cable and serves the same function, increasing the speed at which electrical impulses propagate along the myelinated nerve fiber.

microRNAs (MiRNAs): are a small non-coding RNA molecule found in plants, animals, and some viruses, which function to regulate of gene expression by binding to precise regions of target mRNAs and prevent their conversion into

Liposomes: a spherical vesicle made of a lipid bilayer that can be used as a means of encapsulating molecules to aid in administration of drugs.

Nanoparticles: are between 1 and 100 nanometers in size, an example of a nanoparticle of semi-solid nature is the liposome.

GLOBAL REGISTRY FOR INHERITED NEUROPATHIES

Support Hereditary Neuropathy Research by joining the Global Registry for Inherited Neuropathies (GRIN)

Help us answer questions that your doctors and the CMT Research Community aren't too sure about.

ALLISON MOORE, CEO of HNF

Dr. Sean Ekins is Principal Investigator of GRIN, which is now in its second year. Dr. Ekins is a clinical pharmacologist by training with over 18 years of experience in pre-clinical drug development, toxicity and computational drug discovery research in large Pharma (Lilly, Pfizer), biotech, informatics software companies (GeneGo, Collaborative Drug Discovery, Inc.) and start up drug companies (Phoenix Nest).

As Chief Science Officer of HNF, it is his responsibility to oversee the success of our TRIAD research program in which we fund translational research (pre-clinical and clinical) projects. HNF's goal is to expedite the research process from bench to bedside. While there has been a considerable amount of research on CMT there is urgency to provide the thousands of patients progressing rapidly, with a therapeutic that offers a benefit to them.

As we continue to translate our research and partner with various academics, industry leaders, government and not-for-profit stakeholders that are aligned with HNF's mission, your participation is an intricate and an important part of the process. Please Join us and contribute to GRIN, our patient registry, which will help us in our quest to cure CMT. www.neuropathyreg.org.

In Memoriam

The HNF family has lost two great people this summer: Franklin G. Downing Sr. (father of board member Matthew Downing) and George G. Gatta (father of board member Kathleen Zappola). We would like to honor these two individuals as they have provided us with great leaders in our board members. It is always hard to say goodbye to loved ones but we know they are with us daily as we continue our quest to cure Charcot-Marie-Tooth. HNF thanks all those that donated in memory to support the TRIAD Research Program.

Team CMT

Meet Elizabeth Stenz, Team CMT Member

Elizabeth lives on the east side of Milwaukee, Wisconsin, and is currently working at a non-profit organization. She enjoys exploring Milwaukee, running by the lakefront, and spending time outside.

Her sister was diagnosed with CMT when she was14, and since then her and many family members have become very familiar with the disease and have worked to raise awareness. She found out about Team CMT through her sister. What drew her to Team CMT was the fact that a team could be created along with a fundraising page, a great way to unite the family. “I decided this would be an incredible opportunity and would really motivate me to commit to running a half marathon.” Elizabeth accomplished that feat on June 14th at the Rock n’ Sole Marathon in Milwaukee.

CMT has made her realize how a physical disability can affect so many people, not just the person with the disability. It has also showed her it cannot strip anyone of motivation, optimism, and positivity. Elizabeth is in awe of her sister and her can-do attitude despite the struggles that CMT brings to her daily life, and this motivates her participation with Team CMT.

One of Elizabeth’s favorite quotes is “Be who you are and say what you feel, because those who mind don’t matter, and those who matter don’t mind.” - Bernard Baruch.

Join Team CMT - Be a part of finding a cure!

Team CMT is a grassroots community fundraising program founded by Chris Wodke, a CMT athlete that partnered with the Hereditary Neuropathy Foundation (HNF) to raise awareness for Charcot-Marie-Tooth disease. Building awareness helps us to create a better understanding of the challenges faced by those living with CMT and assists us in increasing support, research, and the likelihood of finding a cure.

You can join us, and truly make a difference. Register to be a Team CMT member and you’ll be part of an international effort to change the future for those living with CMT.

By joining the team and making a minimum donation of $25, we will send you a Team CMT shirt that you can wear to help build awareness. You can wear your Team CMT shirt to the gym, physical therapy, or to an athletic event. If you want you can fundraise too, and have a dedicated fundraising page to track your efforts: http://www.hnf-cure.org/team-cmt/

Team CMT is not just for adults. Check out our Team CMT Kids page to learn how to support children living with CMT by registering your school or team: http://hnf.donorpages.com/TeamCMTKIDS/

Thank you for your support…we could not do what we do without you!

COMMUNITY

WEDDING FOR A CAUSE!

A couple unselfishly decides to accept donations in lieu of gifts.

On a beautiful May day in St. Monica Parish, Whitefish Bay, Robert and Cheryl Kearney exchanged wedding vows surrounded by friends and family. They celebrated on board the Harbor Lady in Milwaukee.

After a champagne toast, guests cruised on Lake Michigan and were treated to views of the Milwaukee skyline, the Hoan Bridge, and the famous Calatrava at the Art Museum while indulging in a top notch buffet and dancing the day away.

Cheryl and Robert made the altruistic decision to ask their wedding guests to make a donation to HNF in lieu of traditional gifts. They are longtime friends of Chris Wodke, founder of Team CMT, and were the first two members to join Team CMT. Cheryl, Robert and Chris participated together in the first Team CMT running event and proudly wore the Team CMT singlet.

The couple decided to designate their donation interests to HNF after witnessing the tremendous efforts of their friend, Chris, who works tirelessly daily to raise awareness for CMT. They are both thankful to be healthy and want to give back to help those living with CMT.

Cheryl and Robert are honored to support HNF and help to raise awareness for CMT. They regularly participate in charity runs, marathons and triathlons, and always wear their CMT singlets.

HNF is extremely grateful for their kindness and dedication to HNF and Team CMT: To date Cheryl and Robert have raised over $3650 for research!

Check Out the Newly Designed HNF Website

The HNF team continuingly works to offer our community the best possible display of new information and research findings to help spread awareness and further our efforts towards finding a cure for CMT. A large part of our communication efforts involves updating our website.

We are thrilled to announce our new website design. The new HNF website provides a user friendly, easily navigational website with the most up to date information on research, treatment, alerts, fund raising efforts and more!

Please take a moment to check out the new HNF website to see how you can connect with our online community, sign up to receive email updates, join Team CMT, participate in upcoming CMT Awareness month events, donate to research efforts, and so much more! www.hnf-cure.org

Lyme Disease and Charcot-Marie-tooth: What You Need to Know

In August 2013, the Centers for Disease Control (CDC) changed its annual estimate for new Lyme disease cases. Previously, it was thought that 30,000 new cases of Lyme disease were contracted yearly. However, the revised estimate increased 10 fold to 300,000 new cases per year. This statistic has made Lyme Disease a genuine epidemic that should now be viewed as a public health crisis.

Sufferers of Lyme Disease and Charcot-Marie-Tooth often share many commonalities about their disease: both diseases can go undiagnosed or misdiagnosed for years, the medical community is uninformed about these diseases, and there is a lack of viable treatments for those with the most chronic conditions. In addition, Lyme disease sufferer's can have severe neurological symptoms including peripheral neuropathy. Chronic Lyme disease is one of the most controversial conditions today. Many medical experts believe that a 28-day regimen of antibiotics will cure the Lyme, but when patients still feel extreme weakness and fatigue, joint swelling, balance issues, memory loss and anxiety after the dose is complete, it becomes obvious to Lyme-literate doctors that Lyme is in fact a serious disease. What's important to note is that the long-term symptoms of Lyme actually mimic the symptoms of CMT!

Because of this, patients or anyone with a family history should be particularly aware of the increased health risks Lyme Disease or other tick-borne illnesses pose for CMT patients, especially if you live in high risk states in the northeast and spend a lot of time outdoors.

Lyme Disease often presents a multitude of symptoms that mimic other illnesses, which is one of the reasons a proper diagnosis can be so hard to obtain. Lyme and other Tick Borne Disease's (TBD) are transferred via the bite from an infected tick. Contrary to the popular misconception, a red bull's-eye rash does not have to be present for a person to have Lyme. Less than 50% of infected Lyme sufferers noted the presence of a rash when diagnosed. The bacteria or spirochete is called B. burgdorferi, and when it disperses through the blood stream its corkscrew shape burrows into human tissue, infecting joints, the nervous system tissues, and even the heart and brain. Because this bacterium doesn't follow a familiar pattern, immune cells have no way to identify the invaders. Expert researchers at the CDC have some preliminary evidence that the bacteria can continue on, dead or alive, in human even after a 28-day antibiotic regimen.

Some of the first Lyme symptoms may include a flu-like condition, with fever, chills, headache, stiff neck, achiness, and fatigue. Other symptoms can include pain in various joints and muscles, neurological

problems, heart involvement, problems with vision or hearing, migraines, low-grade fever or other symptoms. Lyme disease is often mistaken for other illnesses since the symptoms often mirror other medical problems, such as multiple sclerosis, arthritis, chronic fatigue syndrome, lupus or Alzheimer's disease. In some cases, Lyme disease patients can become paralyzed and/or comatose. Lyme and other tick-borne disease symptoms may come and go and be replaced by new symptoms. Symptoms may be subtle or pronounced.

It is critical that CMT patients are hyper vigilant when outdoors in high-risk areas. You should wear tick-repellent clothing, especially clothing treated with permethrin, an insecticide that repels and kills ticks. You may spray your own clothing with permethrin (good for six washings), or purchase pre-treated clothing (good for 70 washings) from a number of well-known clothing companies. EPA-approved insect repellent can also be applied to exposed skin for added protection. Light-colored clothing makes it easier to spot ticks. Wearing long pants, long-sleeved shirts, and a hat are helpful. Walk in the center of woodland trails, and by all means avoid walking along deer paths.

After any time spent outdoors, check for ticks while you are out and as soon as you get back. Showering is also helpful in removing unattached ticks from your body. Remember that some ticks are extremely small and some almost impossible to see. Putting your clothing in clothes dryer at high heat will kill ticks in about 30 minutes.

The neurological side effects of Lyme disease for anyone with CMT could be devastating, even lethal. If you think a tick has bitten you, go see your doctor immediately. The best hope of beating the diseases is a rapid diagnosis and prompt treatment. Remember, the medical community is as similarly uninformed about Lyme disease as they are about CMT; this means you need to make sure that you advocate for yourself when seeking diagnosis and treatment.

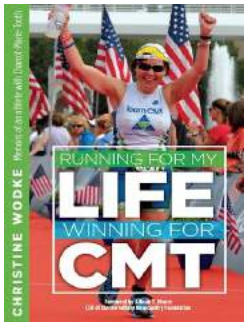
For discussions or to share your Tick bite or Lyme experience, visit Inspire CMT Community.

*Source: TBDAlliance.org, CDC and, Prevention.com

Support HNF

Running For My Life: Book is $16.95, $6 of each purchase will go to CMT Research. Be sure to use the coupon code at check out: **CU-RECMT**

tinyurl.com/CURECMT



Bernadette

Purchase a copy of this film to support HNF and CMT research at hnf-cure.org

bit.ly/1rQdjA6

Beware of Neurotoxins

The neurotoxins listed on the next page are medications that might worsen symptoms of Charcot-Marie-Tooth disease. Of the thousands of recognized medications, only a small number are known to damage nerves or cause neuropathy.

Most of these drugs fall into two broad categories: chemotherapies or antibiotics, but numerous other treatments are also known to cause nerve injury. You should always discuss potential risk of drugs with your physician.

continued on the next page ▸

Toxic Neuropathy for the CMT Patient

Generic Name (Common brand name/s)

Definite High Risk (including asymptomatic CMT)	**Moderate to Significant Risk**	**Uncertain or Minor Risk**	**Negligible or Doubtful Risk**
Vinca alkaloids (Vincristine)	Amiodarone (Cordarone)	5-Fluoracil (Adrucil)	Allopurinol (Zyloprim, Aloprim)
	Auranofin (Ridaura)	Adriamycin	Amitriptyline (Elavil)
	Aurothioglucose (Solganal)	Almitrine (not in U.S.)	Chloramphenicol
	Bortezomib (Velcade)	Atorvastatin (Lipitor)	Chlorprothixene (Taractan)
	Cisplatin & Oxaliplatin	Chloroquine	Cimetidine (Tagamet)
	Colchicine (extended use)	Ciprofloxacin (Cipro)	Clioquinil
	Dapsone	Cytarabine (high dose)	Clofibrate (Atromid)
	Didanosine (ddI, Videx)	Ethambutol	Cyclosporin A (Sandimmune, Neoral)
	Dichloroacetate	Etoposide (VP-16)	Enalapril (Vasotec)
	Disulfiram (Antabuse)	Fluoroquinolones	Gluthethimide
	Docetaxel (Taxotere)	Fluvastatin (Lescol)	Lithium (Lithobid, Eskalith)
	Eribulin Mesylate (Halaven)	Gemcitabine (Gemzar)	Phenelzine (Nardil)
	Gold salts	Griseofulvin (Grifulvin, Fulvicin)	Propafenone (Rythmol)
	Ixabepilone (Ixempra)	Hexamethylmelamine (Hexalen)	Sulfonamides
	Leflunomide (Arava)	Hydralazine (Apresoline, Apresazide, Marpres)	Sulphasalzine (Azulfidine)
	Metronidazole/Misonidazole (extended use) (Flagyl)	Ifosphamide (Ifex)	Sulfathiazole
	Nitrofurantoin (Macrodantin, Furadantin, Macrobid)	Infliximab (Remicade)	Sulphamethoxazole
	Nitrous oxide (inhalation abuse or Vitamin B12 deficiency)	Isoniazid (INH)	Sulfisoxazole
	Perhexiline (not used in U.S.)	Lansoprazole (Prevacid)	
	Pyridoxine (mega dose of Vitamin B6) (see NIH Fact Sheet)	Levofloxacin (Levaquin)	
	Stavudine (d4T, Zerit)	Lomefloxacin (Maxaquin)	
	Suramin	Lovastatin (Mevacor, Altocor)	
	Taxols (paclitaxel, docetaxel)	Mefloquine (Avelox)	
	Thalidomide	Norfloxacin (Noroxin)	
	Zalcitabine (ddC, Hivid)	Omeprazole (Prilosec)	
		Penicillamine (Cuprimine, Depen)	
		Phenytoin (Dilantin)	
		Podophyllin resin	
		Sertraline (Zoloft)	
		Sparfloxacin (Zagam)	
		Statins	
		Tacrolimus (FK506, ProGraf)	
		Trovafloxacin (Trovan)	
		Zimeldine (not in U.S.)	
		α-Interferon	

HEREDITARY NEUROPATHY FOUNDATION
hnf-cure.org
432 Park Avenue South, 4th Fl.
New York, NY 10016

@CMTNeuropathy
HereditaryNeuropathyFoundation

Ever feel like you want to get involved but don't have the time? Get started this September to support CMT Awareness month!

Contact Courtney@hnf-cure.org for details.

1. Launch an online fundraising page

2. Launch a letter writing campaign or email to friends to fund research for your type of CMT

3. Join the Global Registry for Inherited Neuropathies (GRIN) www.neuropathyreg.org

4. Join Team CMT: http://www.hnf-cure.org/team-cmt/

5. Participate in the Un-Selfies4CMT campaign. www.hnf-cure.org/unselfies4cmt-campaign/

6. Join the Inspire CMT Community: http://www.inspire.com/groups/charcot-marie-tooth-cmt/

Upcoming Events - Save the Date

Grace's Courage Crusade Brunch
Sunday, November 2, 2014
Newport, Rhode Island

Jillian's Cure Fundraiser
Saturday, November 8, 2014
Columbia, South Carolina

Zach's Team Fundraiser Havana Nights
Saturday, November 15, 2014
Fort Lauderdale, Florida

Champions for Charity
Thursday, Friday, & Saturday,
December 4, 5, & 6, 2014
Manhasset, New York

H.E.L.P. Fund Brunch, Boutique & Card Party
Friday, January 23, 2015
Boca Raton, Florida