THE CMTA Report

JULY/AUGUST
2014

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ **www.cmtausa.org**

CMTA
Charcot-Marie-Tooth Association

OUR MISSION:

To support the development of new drugs to treat CMT, to improve the quality of life for people with CMT and, ultimately, to find a cure.

OUR VISION:

A world without CMT.

EMAIL CMTA AT:
info@cmtausa.org

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1.5 Million Reasons to Say Thank You!

We did it! Two families came to the CMTA earlier this year to offer a challenge to our community; they would each contribute $500,000 if the CMT community would raise $500,000. Their offer was the largest gift ever pledged, and it would become the largest matching challenge ever achieved in the 30-year history of the CMTA.

We took on the challenge, and you shared our excitement. Gifts, large and small began to pour in. Fundraisers were held across the country, from large formal parties to smaller, simpler asks of friends and family. Our community galvanized together to meet the challenge, and the challenge met its match!

Today we celebrate! Because of the generosity of thousands of people like you across the country, the CMTA met its fundraising goal. And, thanks to your support, the challenge raised a total of $503,000—all of which will be invested in scientific research on CMT, a disease that impacts an estimated 2.8 million people worldwide

That means that each contribution triples the impact by designating $1.5 million to the CMTA's Strategy to Accelerate Research (STAR), which is speeding the discovery of treatments for CMT.

So, thank you to everyone who supported the STAR-POWER Challenge. You've just made history!

Be sure to visit our website at www.cmtausa.org to learn more about STAR and how the CMTA supports the CMT community. ★

NCATS Director Headlines CMTA Fundraising Event

The CMTA hosted a fundraising event and cocktail reception on May 15th, just outside Washington, D.C. in Bethesda, MD, that featured the leading government official responsible for speeding the delivery of treatments for diseases including Charcot-Marie-Tooth.

The event, themed "Our Time Is Now," was headlined by Christopher P. Austin, MD, Director of the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health. NCATS partners with the CMTA to equip and staff a lab dedicated to conducting cutting-edge research on CMT.

Austin, a graduate of Princeton University and Harvard Medical School, told some 75 guests about the innovative work of NCATS, which assembles diverse teams with expertise in biology, informatics, biomarkers,

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INSIDE:

DC FUNDRAISER

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clinical trials, public health and other areas to address the bottlenecks that delay the delivery of diagnostic methods and treatments to patients with a wide range of diseases.

Chief Executive Officer Pat Livney spoke after Austin and described the close partnership between NCATS and the CMTA that is producing essential research helping to drive the CMTA's groundbreaking Strategy to Accelerate Research (STAR). During his talk, Livney surprised Austin by producing a table napkin from a dinner between them eight years earlier with the outline for the organizations' partnership scribbled on it.

Peter Warfield, the newest member of the CMTA Board of Directors, introduced Austin by first describing his CMT diagnosis, which led him to become a pediatrician. Also in attendance were Herb Beron, Board Chairman, and Board Members Gary Gasper and Steve O'Donnell.

Several members of the Support & Action Group for the Washington, DC metro area attended the event, all proceeds from which went to the STAR initiative and were twice matched by the anonymous families behind the CMTA's $500,000 fundraising challenge.

NCATS partners with the CMTA to equip and staff a lab dedicated to cutting-edge CMT research.

Prior to the event, a small group of CMTA supporters was treated to a tour of NCATS and the CMT lab there. The tour was led by Jim Inglese, PhD, who heads the Assay Development and Screening Technology Laboratory at NCATS and serves on the CMTA's Scientific Advisory Board.

The group also heard from Trish Dranchak, PhD, and Brittany Wright, PhD, research associates at NCATS whose funding comes in part from the CMTA. Dranchak and Wright serve on the CMTA's STAR Scientific Team.

That evening, at a dessert reception following the conclusion of the speaking program, Livney declared the day a success and announced to a small group of CMTA staff and volunteers that the event would definitely be held again next year. The group agreed that planning should begin immediately—but after a few days' rest! ★

THANK YOU TO OUR CORPORATE SPONSORS:

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GeneDx DNA DIAGNOSTIC EXPERTS

Patrick Livney, CMTA CEO, Patricia Dranchak, NCATS research associate, and Missy Warfield, CMTA Support and Action Group leader, visited the robotic lab during the Washington, DC, event.

CMTA Launches Strategic Partnership with GeneDx

GeneDx can now test for 22 genetic causes of CMT.

On June 1, 2014, GeneDx launched the Hereditary Neuropathy Panel, a genetic testing panel aimed specifically at testing for different types of CMT. The Hereditary Neuropathy Panel will test for 22 genetic causes of CMT. Because CMT1A comprises 70 percent of all CMT, GeneDx also offers a single gene test for PMP22, the most common genetic cause of CMT and HNPP (hereditary neuropathy with liability to pressure palsy). GeneDx delivers an exact genetic diagnosis for 50-70 percent of people with symptoms of CMT. The GeneDx panel includes 50 genes that are known to cause various types of peripheral neuropathy that often mimic CMT symptoms.

GeneDx brings many features to the genetic testing space: a patient-friendly billing policy, access to over 70 genetic counselors and geneticists, a 10-week response time for the Hereditary Neuropathy Panel and a 4-week response on the CMT1A/HNPP (PMP22 duplication/deletion) test.

Patient-Friendly Billing Policy:

- GeneDx accepts all commercial insurance
- Patients pay only the co-pay, co-insurance and unmet deductible. If the expected out-of-pocket cost for a patient is more than $100, a GeneDx representative will call the patient to discuss.
- Financial assistance is available for those who qualify.

The partnership between the CMTA and GeneDx will give the CMTA community access to genetic counselors working at GeneDx through the local Support and Action Groups.

GeneDx, with headquarters in Gaithersburg, MD, is a highly respected genetic testing company founded in the year 2000 by two scientists from the National Institutes of Health (NIH) to address the needs of patients and clinicians concerned with rare inherited disorders. GeneDx launched the Hereditary Neuropathy Panel June 1, 2014, aimed specifically at testing for different types of CMT. They also offer sequencing and deletion/duplication testing for inherited cardiac disorders, mitochondrial disorders, other neurological disorders, inherited cancer disorders, prenatal disorders and other rare genetic disorders. GeneDx also offers whole exome sequencing, next-generation and microarray-based testing. At GeneDx, the technical services are matched by their scientific expertise and customer support. Their growing staff includes more than 70 geneticists and genetic counselors who specialize in clinical genetics, molecular genetics, metabolic genetics and cytogenetics and who are just a phone call or email away. We invite you to visit the website www.genedx.com to learn more about them and the services they offer.

To request a genetic test to be performed by GeneDx, talk to your health care provider about ordering a neurology test requisition from GeneDx. ★

CMTA POSTS FUNDRAISING IDEAS FOR EVERYONE

Check out the *brand new* fundraising page on the CMTA Website!

You may have noticed the new bright orange button on the top of the home page of cmtausa.org that reads "TEAM STAR for CMT." If not, head on over and take a look!

Fundraising in the community is a huge part of the success of the STAR program. Without fundraising and community volunteers, the CMTA would not be able to do what we do. We have put together articles with tons of ideas and ways for you to get involved and help us toward our goal—treatments for CMT! We even have a list of Lazy Ways to fundraise! Better yet, some of these ideas involve donuts and puppies.

What is Team STAR, anyway? To find out, visit www.cmtausa.org/fundraising. Together, we can, and will, make a difference.

Paratriathlon Event Produces a Winner

BY DONNA DEWICK

On Saturday, June 28, Donna DeWick raced in the International Triathlon Union World Paratriathlon Event held in Chicago and placed third in her division. Donna, founder of the CMTA's CMTAthlete group, took up triathlon in 2007 as a way to manage her CMT.

I was diagnosed with CMT1A in 2004. I did a midnight breast cancer walk in May 2003 with my friends, and my left foot really hurt afterwards. I thought it was my shoes, so I went to my local running shop. But they wouldn't sell me shoes. Instead, they sent me to my doctor to get my feet checked out as they thought something funny was happening. One thing led to another, and I received my diagnosis of CMT.

By 2007, I couldn't ignore my diagnosis any more. Walking up stairs was becoming extremely difficult for me. I decided that if I wanted to stay mobile, then I needed to get strong and fit. I took up triathlon as a way to manage the way CMT impacts me. I thought it would be good total body fitness, with swimming, cycling and running. Of course, I hadn't run since I was about nine, but that didn't stop me from giving it a go!

In 2010, I heard about paratriathlon—a category of triathlon which levels the playing field and creates an inclusive environment for athletes no matter what their physical impairments. So, I set a personal goal for myself to participate in the US National Paratriathlon Championships.

I met the qualifying standard in 2011, so in 2012, I went to the US National Paratriathlon Championships in Austin, Texas. In parasport, you need to go through "classification," a process which validates that the athletes meet a minimum impairment standard for participation at an elite level, which is the way entry into the Paralympics is achieved. I fell "out of class" in Austin, no longer meeting the minimum impairment threshold.

I decided at the start of 2014 to participate in major US paratriathlon events in the Open Physically Challenged category. The USA rolled out a new category of paratriathlon this year to encourage grassroots participation. Triathlon has given so much to me—I am stronger and healthier than I have ever been because of the sport—so I set my goal to do a few major US races this year in support of USA Triathlon's initiative. I decided to go to Chicago to race.

The opportunity to race as an elite paratriathlete came up, and, although I was incredibly nervous, I raised my hand to participate. It's hard to consider myself an elite athlete when as a kid I was always the slowest in class, with an exemption from PE from the time I was 13! You can't imagine how thrilled I felt to be included as a part of Team USA, especially since I am managing some serious ongoing problems with my knees that have had me contemplating life without triathlon.

The experience was just phenomenal. The ITU uses blue carpet for its elite races—and it

Donna DeWick triumphantly crosses the finish line in third place at the paratriathlon in Chicago.

really was like a blue-carpet dream come true for me. An elite paratriathlon is an amazing event with accommodations to give the athletes every chance for their best possible race. For example, we each had our own chairs in transition, making it really comfortable to put on my ankle braces before the run leg. I felt spoiled!

To my surprise I placed third in my category PT4 (the least impaired category of athletes who race using standard bicycles). My dream came true.

To top off the day, I was able to celebrate my success with the CMTA. Pat Livney and Jeana Sweeney, as well as the Support and Action Groups of the Greater Chicago Area, held a fantastic mixer to mark the occasion of my race. I have to admit, everyone was so welcoming and so generous I found myself tearing up periodically throughout the night! A big thanks to Dale Lopez, Chicago Area CMT Support and Action Group Facilitator for organizing the venue and entertainment, and to Chuck Barrett, Chicagoland (North) Support and Action Group Facilitator, for the fantastic Chicago goodies that will help me to always remember my Chicago paratriathlon experiences and the generosity of the CMTA.

Thank you to everyone at the CMTA for supporting those of us with CMT and for helping us to have a community. Whether or not we are experienced athletes or just looking to get started with physical activity as a way to manage our CMT, the resources and community of the CMTA makes it all seem less terrifying. You are all truly a part of my family. ★

To learn more about Donna and her journey with CMT and triathlon, you can read her blog at www.beatinglimitations.com, like her Facebook page at www.facebook.com/beatinglimitations, or follow her on Twitter @donna_de.

To join the discussion about being active with CMT, check out the CMTA's CMTAthlete group on Facebook at www.facebook.com/groups/cmtathletes.

CMTA'S "WORDS WITH FRIENDS" TOURNAMENT HAS THREE WINNERS!

Christopher Gartland, Carol Andrews, and Lorraine Nacson claimed honors in the CMTA's latest "Words with Friends" tournament!

When Carol Andrews laid down all seven tiles in her opening move, Christopher Gartland knew that winning the championship of the CMTA BBB (Bigger, Better and with a Bonus) "Words with Friends" tournament was not going to be easy. Chris and Carol were among 32 CMTA supporters who took part in this spring's "Words with Friends" tournament, along with players from all over the country and even one participant from New Zealand.

This spring's tournament, the second held so far, included an array of prizes for first, second, and third place, including plaques, gift certificates, and recognition in the CMTA newsletter. After coming back mid-game with a seven-letter play of his own, Christopher went on to win the championship, with Carol Andrews placing second, and Lorraine Nacson claiming third. Congratulations to the winners and to everyone who played and generously gave their support to the CMTA! Because this spring's tournament took place while two matching pledges were in place, each player's $25 entrance fee/donation was tripled, resulting in a total of over $2,000 raised for the CMTA and the STAR initiative.

When not tearing up the Scrabble board, Christopher Gartland lives with Angela, his wife of 11 years, and their three children in Southampton, Pennsylvania. Angela has CMT1A. Christopher was one of the many players who do not have CMT, and we thank all of them for their generosity. Also, a special thanks to Iris Anderson and Denise Snow for bringing so many of their friends into the tournament.

We've already begun a new tournament for this summer—the "Words With Friends" World Cup Championship—which features a "World Cup" style first round and guarantees each player at least three games—no more eliminations after one game.

Stretching and CMT Health

BY KATY EICHINGER, PT, DPT, NCS, CMTA ADVISORY BOARD

The calf stretch helps improve or maintain flexibility and range of motion for CMT patients.

Stretching is an important component of exercise in individuals with Charcot-Marie-Tooth (CMT) disease. Stretching improves or maintains flexibility and range of motion (ROM) of joints affected by muscle imbalances. Muscle imbalances occur when there are uneven opposing tensions around a joint. In CMT, disease-related weakness often results in muscles on one side of a joint being weaker than the muscles on the opposing side. For example, at the ankle joint, the muscles in the front of the lower leg, the ankle dorsiflexors, are often weaker than the opposing calf muscles, the plantar flexors. Over time, muscle imbalances can result in decreased range of motion of the ankle joint and can impact functional activities such as walking and going up and down stairs.

In individuals with CMT, muscle imbalances also contribute to deformities in the feet and hands. In addition to the ankle, hands and feet, muscle imbalances and subsequent loss of range of motion are also commonly seen in the knee, hip, and wrist in individuals with CMT (Carter et al., 1995). Therefore, it is important to minimize muscle imbalances through a regular stretching program.

> A regular stretching program can help minimize muscle imbalances.

Stretching of the calf (ankle plantarflexor muscles) is recommended for most individuals with CMT at the time of diagnosis. A yearly evaluation by a physical therapist can help identify other joints that lack full range of motion.

There is a lack of research regarding the optimal frequency and duration of stretches performed by an individual with CMT. However, for healthy individuals, the American College of Sports Medicine recommends that static stretches, stretches that occur when the muscle is at its maximum length while maintaining proper joint alignment, be held for 10-30 seconds at a time, with 2-4 repetitions per stretch in order to attain 60 seconds of stretching per muscle group (Garber et al., 2011). Additionally, it is important that stretching occurs when the muscle is warmed, either with light physical activity or a hot bath. For most individuals, a stretching program can be performed 2-3 times per week; however, it has been noted that greater joint range of motion can result from daily stretching. Therefore, for individuals with CMT who are more prone to range of motion limitations, daily stretching is recommended.

Participating in a yoga program may also be a way of improving flexibility and joint range of motion (as well as strength and balance). While there is no published literature regarding the use of yoga in individuals in CMT, its benefits have been well documented in other populations. Consulting with your health care providers and a yoga instructor is ideal for safe and effective participation. ★

Applying for Disability Insurance: *My Experiences*

BY MICHAEL NEEDLEMAN, ESQ., CMTA ADVISORY BOARD

IMPORTANT DISCLAIMER: I will share my experience here, but not the companies involved because this is not intended to either promote or decry any particular insurer. I will voluntarily offer personal details; please don't hold any undesirable physical traits against me.

THE OVERVIEW

As many of you know, disability insurance is intended to provide a benefit for any period of time when an injury or illness prevents a policyholder from working. Many of you, I am sure, have a short term disability policy through your employer. These normally provide some benefit (usually 60 percent or so of your weekly income) after some qualifying period (usually 7-14 days). Some employers also provide long term disability insurance, which provides some amount of income (again, usually 60 percent) after 180 days, and which usually expires after a policyholder has been injured/ill for two years. Almost all employer-sponsored disability plans rely on Social Security benefits to come into play after two years.

The goal

As many of you know, the possibility of one of us sustaining an injury that prevents us from working for a significant period of time is quite real. In January 2012, while playing outside with my young children, I slipped on an icy sidewalk and left the hospital four hours later with a concussion and a broken nose. I was ordered out of work for three days.

Short term disability

Short term disability is usually defined (again specific insurance policies may have different definitions) as a period of time between 7 and 180 days in which an injury or an illness prevents a policyholder from working. The injury or illness need *not* have occurred at work. That is a workers compensation issue, which is a whole different kettle of fish. Most short term disability policies expire after 180 days.

Long term disability

Long term disability provides a benefit even if the injury/illness did not arise out of work. Long term disability benefits come into play after short term disability benefits have expired. While almost all employer-sponsored plans expire after two years, a private long term disability plan is intended to provide income continuation benefits long after that expiration date. The benefit a long term disability policy provides is to make up your monthly income (i.e., the 40 percent not paid by an employer-sponsored plan, or 100 percent if no plan is available through work). It is important to note, though, that, unlike a life insurance policy, income continuation benefits stop once the policyholder either recovers and is able to work, or dies.

I was due to change my life insurance plans anyway, so I asked about disability insurance. Except for the diagnosis of CMT when I was 22, I am and have been pretty healthy. I am 5'11" and I weigh about 150 pounds. I have had my share of broken bones, of course. I share this embarrassing information for no other purpose than to show I had a reasonable expectation that disability insurance would be a relatively easy process. I have never had a problem getting life insurance.

THE APPLICATION PROCESS

The company through which I applied for disability insurance has a reputation for being thorough during the application process but fair during the claims process. The application process is simply the steps required by an insurance company to complete an application for insurance. Though the number and extent of the steps involved varies, an applicant must be completely truthful at every step. The claims process, however, is when the insured (formerly the applicant, now approved) needs the benefit of the policy. It is shocking how untruthful and evasive insurance companies can be at this stage.

The records

First, I was instructed to fill out a three or four page disability application. (Of course, the very

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DISABILITY INSURANCE

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same information was sought—and provided—in the life insurance application.) After completing the application, most of which had to do with medical history, I was then asked for the name and address of every physician, specialist, chiropractor, podiatrist, school nurse and witch doctor I had ever been treated by in the last 10 years. For each provider, I was then required to sign a release so that the company could obtain my records from each provider. Those records, once obtained, were sent to a nurse employed by the company to review. (If you will forgive me a point of personal privilege here: I was absolutely shocked by the speed with which these providers replied with records. As a lawyer, I have subpoenas sent all the time to doctors' offices. I consider it a victory if I get a response within three months and do not have to file a motion to compel the records.) I was told by the nurse assigned to this application she had loads of paper to go through, but much of that had nothing to do with my records; she had to research and review articles on CMT, as she never heard of the condition before.

The interview

Following the completion of the application, I was called three different times by claims representatives from the insurance company. I was asked the same thing each time (though in slightly different ways). I assume this exercise was to ferret out fraud, but it also did not escape my notice that each of the representatives had difficulty pronouncing Charcot-Marie-Tooth.

The tests

Following what I imagine was a thorough review of my medical history, the nurse assigned to the application called to schedule an appointment at our house. She had a number of tests to run. In addition to the blood test required for the life insurance application, she did a complete physical examination. This included reflex testing; another blood test (yes); a balancing test (honestly—I had to try to stand on one leg while the nurse timed me); and an EKG. (My wife, on the other hand, who does not

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THE CMTA PROUDLY PRESENTS THE

4TH ANNUAL "I'M A STAR!"/"I'M A SHOOTING STAR!" CONTESTS

All CMT patients are special individuals. They face the challenges of everyday life those without CMT can't begin to imagine. Do you know an extraordinary person living with CMT? Please share that person's story with us and he or she may be selected as the recipient of the Fourth Annual **"I'M A STAR!"** Award (ages 18 and up) or the **"I'M A SHOOTING STAR!"** Award (ages 10–17).

In 500 words or less, please tell us about your extraordinary individual. How old was that person when he or she was first diagnosed? What type of CMT does the person have? How does living with CMT affect his or her ability to have a full and rewarding life? Or does it? What does that person do to rise above disability and prove his or her abilities on a daily basis? What does that person excel in?

Any additional information you can provide about the person such as family life, community involvement, mentoring, sports, hobbies, and interests will all be considered in the selection of our winners.

You can submit your entry by emailing your submission to: info@cmtausa.org or by mailing your entry to: CMT Extraordinary Person, c/o CMTA, Po Box 105, Glenolden, PA 19036.

All entries must be submitted or postmarked by midnight, August 23, 2014.
Winners will be announced during Charcot-Marie-Tooth Awareness Month, September 2014.

This contest is sponsored by the CMTA.

Regrettably, please note that employees of the CMTA, Support and Action Group Facilitators, or their immediate family members, are not eligible for participation in this contest.

have CMT, but who applied for life insurance and disability insurance, had only a blood test.) About the only pleasure this whole experience produced was watching my 7-year-old pick up the ticker tape from the EKG reading and pretend he could read it like a cardiologist.

The results

Not surprisingly, my test results revealed I have CMT. They also revealed I am a healthy 36-year-old male who could stand to exercise a bit more and eat brownies a bit less but who otherwise was in good shape. My cholesterol levels were quite good; my blood sugar was in line; and, except for my 14-year-old diagnosis of CMT, I was pretty healthy. All of which makes the final determination regarding my insurance coverage so infuriating.

THE DECISION

After having undergone the application process and the testing process, two more weeks would pass before a decision was rendered. (As with every insurance company, the process of reviewing the application and coming to a decision whether to underwrite the policy takes much longer than it should. And, as often as not, the final decision bears fairly little resemblance to the facts contained in the application.) I cannot pretend to know what exactly happens over those two weeks, but my guess is there is a lot of sitting around and blindfolded dart-throwing; whichever three policies this dart lands closest to will be underwritten, while the others will be denied.

I am happy to report I was approved and issued a disability policy, along with my life insurance policy. However, I am most unhappy to report there is a significant exclusion in my disability policy. Any period of disability caused, in part or in whole, by my CMT means I am not entitled to benefits under the policy. This sounds simple enough and fair enough. If I can't work due solely to CMT, I can accept that. I intend the disability policy, however, to cover those situations in which I am injured and cannot work for some period. I know my family won't starve (though they might wish they would if they have to put up with me around the house for more than a week).

> I was approved and issued a disability policy, along with my life insurance policy.

However, consider that CMT is a progressive disease, and that with all progressive diseases, it plays a larger and larger role in our lives as we age. Two years ago, during a snowfall I took our kids sledding. On their way down the hill, one of the kids bumped into me, and since my legs are weak, I hit the asphalt face first. A broken nose and a concussion later, I was restricted from driving for one week and could not return to work for three days. (I just worked at home remotely.) Was that injury just one of those things that happens, or was it the CMT (or did my kids do it on purpose)? I will never know, to be sure. If in the future, however, something more serious happens, I have no confidence I will be covered for disability. Playing devil's advocate, I can envision the insurance company taking the position that CMT is always, at least to some extent, a cause of the disability. The irony here is that as I get older and need the disability insurance more, the more likely it is that CMT will have caused the disability.

Any disability decision can be challenged, of course. However, that is almost always a long and painful process, and more often than not, ends with the same result. To pursue a challenge/appeal, one needs medical records and usually some form of evidence (testimony or an affidavit or something along those lines) of an expert who can offer an opinion that CMT did not in any way cause the disability. This, of course, must be done while trying to recover.

In the end, I cannot say having the disability policy is worth the premium. However, I look at it like chicken soup: I don't think it's worth much, but it can't hurt!

An interesting note: In most states, insurance companies do not have any obligation to disclose to you if you were turned down for, say, life insurance, because of a condition found or diagnosed during the insurance company-administered test. Most state insurance regulations require companies to provide you with a copy of the blood test results, but not their underwriting decision. Thus, if you are turned down for life insurance because of a blood test, you may want to see a doctor. ★

Parenting with Pleasure: Connecting Heart to Heart

BY ELIZABETH, K. MISENER, PHD, LMSW, CMTA ADVISORY BOARD

As I was preparing to write this article I was reflecting on the past year and thinking about what I could focus on. Dave (my husband of 21 years with CMT 1B) had foot surgery due to his CMT last June, and I met amazing parents and children at the family conference in Orlando with the CMTA in November. They inspired and guided me regarding my 9-year-old son's bilateral foot surgery in December, due to his CMT.

However, it was the reflection my son made a month ago about this past year that stood out to me the most. He said to me, "Mom, one of my best memories this past year was when I had my surgery and was in my wheelchair for two months because I have so many special memories of our time together as a family." Wow! This kind of comment after six months of his life being turned upside down made my heart skip a beat.

I am a social worker by training, and my area of expertise is depression and anxiety. I have spent many years building my skills in teaching people how to shift their thoughts to shift their feelings, and I know it works. This was how I started preparing, many months ahead of time, for the surgery that Ethan was having. We could see that we could not avoid the surgery any longer. He was complaining of pain as he walked and was walking on the outside of his feet. We finally made a choice about where to have the surgery. We chose a Shriner's Hospital for two reasons: the surgeon had done many such surgeries on children with CMT, and we could talk with the surgeon. He treated all of us like humans and would ask Ethan if he had any questions. What we did not realize was the hospital had two Child Life Specialists. Their role was to support Ethan when he was in the hospital, and they did an amazing job.

Once we had picked the setting, I had to do my job of

RESOURCES AT THE CMTA FOR PARENTS

- The medication list (www.cmtausa.org/medicationlist). I always had a copy for all appointments and talked about it with every person before each surgery.
- The CMTA has articles for parents and a *Teaching Kids about CMT* video at www.cmtausa.org/parentarticles.
- The *My Child Has CMT* guide (www.cmtausa.org/images/docs/mychildhascmt.pdf).
- "Stepping it up for CMT"—This school program was so helpful educating the school so they understood why he was having surgery. (Contact jeana@cmtausa.org for information.)
- The CMTA has a parent page on Facebook (www.cmtausa.org/fbparentsgroup) that is a great place to find support from other parents.
- CMT Support and Action Groups (www.cmtausa.org/supportgroup).

BOOK SUGGESTIONS FOR PARENTS

1. *Trauma Through a Child's Eyes: Awakening the Ordinary Miracle of Healing; Infancy Through Adolescence* by Peter Levine and Maggie Kline
2. *The Whole-Brain Child: 12 Revolutionary Strategies to Nurture Your Child's Developing Mind, Survive Everyday Parenting Struggles, and Help Your Family Thrive* by Daniel J. Siegel, MD, and Tina Payne Bryson, PhD
3. *The Four Agreements* by Don Miguel Ruiz
4. *Feeling Good: The New Mood Therapy* by Dr. David Burns, MD
5. *Being Happy: You Don't Have to Be Perfect to Lead a Richer, Happier Life* by Tal Ben-Shahar

laying the foundation for the surgery and figuring out how to support him from a mental health perspective. I started reading books, looking at research, and listening to other people's stories to find out what factors helped promote a positive experience for surgery. Our intention as parents was for Ethan to "be okay" after his surgery, since it might just be the beginning of other surgeries.

The two books that guided me the most were *Trauma Through a Child's Eyes: Awakening the Ordinary Miracle of Healing; Infancy Through Adolescence* by Peter Levine and Maggie Kline and *The Four Agreements* by Don Miguel Ruiz. Both helped me focus on what was important as we moved toward the surgery. The trauma book gave advice based on research for positive mental health outcomes about how to approach the surgery, such as the parents being with the child until he "fell asleep" for the surgery in the surgery room and being in the post-op when he woke up.

The Four Agreements reminded me what was important during a very stressful time in our lives when it can be easy to get overwhelmed and be too scared to move forward. The first is "Be impeccable with your words." This helped us really think about how to explain the surgery to our son and what words to use so he was not too scared. The next one was "Don't take anything personally," which helped guide us during his recovery when he would get upset or angry or frustrated at

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BIATHLON RAISES $100,000 FOR CMT RESEARCH


Steve O'Donnell added biking to his usual swim to help fund CMT research.

The first Annual CMTA Oxford Biathlon took place on May 30, 2014, under a beautiful blue sky and almost perfect weather conditions. Gathering at the Oxford Yacht Club, biathlon participants enjoyed a leisurely morning of chit-chat and event preparation before taking the ferry across the river to the tiny town of Bellevue and the start of the swim. At 9:30 AM the whistle blew and the swimmers hit the water. Too early in the year for sea nettles, and with the tide out, the Tred Avon was in perfect condition for the mile-long swim. The first swimmers emerged from the water a mere 20 minutes later.

After a brief award ceremony and a complimentary breakfast, about a dozen riders mounted their bicycles and headed out on a 21-mile tour of Maryland's beautiful Eastern Shore. Led by Team Captain Steve (tough as nails) O'Donnell, riders included Jaime (just as tough and twice as cute) O'Donnell, Sue (can we at least break a sweat) Baile, Chris (I can do anything Sue can do) Glotzbach, Mark (the professor) Scheideler, Stuart (I train with Steve) Gray, and Clark (dear God just let me finish) Semmes. Support van driver Bridget (the goddess) O'Toole endeared herself to everyone with cold Gatorade as the ride concluded with another ferry ride back to Oxford.

At the after-event celebration at the Masthead restaurant and bar, more CMTA supporters joined the party and discussed plans for next year's swim and ride. We are proud to announce that the event raised over $100,000 for the CMTA and CMT research, mostly thanks to Steve O'Donnell and everyone who contributed to his efforts. Next year we hope to triple the size of the event, raise even more money, plan a route on even-less-trafficked roads, and bring more cold drinks in the support van. If you would like to take part in the Second Annual Oxford CMTA Biathlon, please contact Steve O'Donnell (steve@stevenfodonnellinc.com) or Clark Semmes (tcsemmes@comcast.net). Participants are free to take part in both the swim and ride, just the swim, or just the ride.

Safety on Stairs to Avoid Falls and Fractures

BY HELEN LANN, WASHINGTON, DC CMT SUPPORT AND ACTION GROUP MEMBER

It should have been common sense, yet nobody ever mentioned that one of the most common causes of fractures from falls in the home is people walking down the stairs in socks. I knew that falls most commonly occur in the bathroom, so as my CMT progressively impaired my balance and I developed more lower-extremity weakness, I did have grab bars installed in the shower and bought a new, higher toilet. But, except for acknowledging that I was having more difficulty going up them and that it was harder to go up and down while wearing my braces, I didn't think about the stairs.

On February 20th, I made four big mistakes for anyone with CMT, and, consequently, I fell down my stairs, broke my right leg and tore a tendon in my right shoulder. Because my balance is so bad and due to my upper-extremity weakness from the CMT, I could not use crutches or a walker while the doctor ordered "no weight bearing on the cast." And so, for someone who is generally active and quite mobile, being confined to a wheelchair for almost three months has been a real challenge, one which I hope to avoid facing ever again by following the four rules below. My already weakened leg muscles are now quite atrophied; the recovery period after a fracture is much more difficult for those with CMT.

Here's what I learned and wish I had focused on prior to the fall:

1 Don't carry things while on the stairs. As my neurologist says, "Your brain doesn't know where your feet are" due to the neuropathy of the nerves which normally transmit the position sense of your limbs. If you are carrying things, you can't see your feet. I was carrying my gym bag, and my right foot hit the step just a few inches too far forward.

2 Don't wear socks on stairs. Whether you have hard wood or carpeting on your stairs, socks are slippery and increase the risk of falling. Go barefoot or wear shoes or slippers which have a good grip on the soles.

3 Always hold on to a railing. Even if you can see your feet, CMT impairs your balance and you are at a greater risk of falling during the moment when you are standing on one foot while lifting the other to the next step. This "never stand on only one foot" rule for me also applies to getting dressed. Two years ago, I fractured my foot while I was putting on a pair of pants. Standing only on my left leg when I went to lift my right leg into the pants, I fell and caught my foot in the waistband. Always sit down when putting on shoes, socks and pants.

4 Keep your brain focused on where your body is. On the morning when I fell down the stairs, I was thinking about everything I needed to do at work that day. By being present in the moment, focusing on where your body parts are and what you need to do to move them, many falls can be avoided. When thinking about other things and making sudden turns to answer the phone, getting up quickly from a chair or bed or just walking and forgetting to lift your feet, falls will be more likely to occur. It is hard to be mindful of your movements all the time; I've found that practicing some mindful meditation daily helps me stay more focused when I need to be.

Fractures for those of us with balance and mobility issues can lead to a lot of secondary complications. Avoid fractures and be safe on stairs. Fall prevention needs to be a priority for all of us with CMT. ★

"SLIME-ING IT UP" FOR CMT

Talk about taking one for the CMTA! The winner of the "Stepping it Up" for CMT school program at Richland Elementary in Johnstown, PA, got to slime the principal! Thanks, Tom Smith and everyone at Richland Elementary, for your continued support! The school raised over $7,000 for the CMTA STAR Program!

If you want more information on how to bring "Stepping it Up" to your child's school, contact Jeana Sweeney at jeana@cmtausa.org.

GIFTS WERE MADE TO THE CMTA

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CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank-you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, P.O. Box 105, Glenolden, PA 19036.

Honorary Gift:
In honor of (person you wish to honor)
____

Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____

Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding
☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)
____

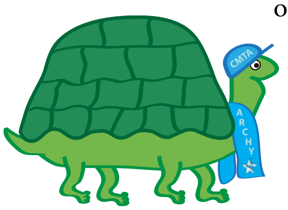
Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____

Amount Enclosed: ____________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card # ______________________________
Exp. Date ______________________________
Signature ______________________________

Gift Given By:
Name: ______________________________
Address: ______________________________
____

Ah, Summer. Bah, More Rain

This has been the year of precipitation. I suppose that some would regard that as a good thing, but as a kid who likes to play outside and swim during the summer months, this endless rain is getting a little annoying.



Our mascot "Archy" writes about his experiences as a turtle with CMT.

On the bright side, our garden is doing really well, although we have had to add new soil to avoid the plants being waterlogged. One of the problems that we are blaming on the weather is the arrival of small armies of rodents who are relentlessly eating our vegetation. We've never had this problem before, but now, as soon as my Dad plants new seedlings, the (fill in the appropriate descriptive adjective) mice and rats eat them right down to the roots. It's a contest that we are not winning. Fortunately, some of our plants were already big enough when the rodents attacked that they left them alone, and we've already eaten peppers, some tiny tomatoes and one (the only one that survived) snap pea.

Summer is also my usual time for heading off to camp, and this summer was no exception. I think I'm getting too old for camp, but my mother insists that it gives me new experiences and lets me meet more new friends than staying home would. She's right, of course, but what she doesn't realize (and doesn't really want to know) is that every year I go through the somewhat painful issue of answering everyone's questions about my braces and my incredibly slow movements. There are always a few friends back from previous years who know the story and usually try to help me dodge the really embarrassing questions and deflect the kidding and criticism of my lack of coordination.

Being small is already an issue I have to deal with, but CMT just makes everything worse. I'm pretty accepting of what I can and can't do, and when I'm home I feel safe and protected by my family and friends. At camp, I feel vulnerable because all the campers are "feeling their oats," as my mother would say. That seems like a horsey analogy if you ask me, but they all want to feel like they are the smartest and most athletic campers during their week. Picking on the weakest kid is the way some of them achieve their "power." We do hear lectures (lessons) from the camp counselors about being good examples of thoughtful and kind behavior, but the ones who need the lessons the most seem to be the ones who hear the least.

I'm beginning to see my own analogy here. I'm like the newly planted pea plant and I'm attacked by the (fill in the blank) rats. Well, there's a lesson to be learned. Shore up your defenses before the storm and the rats can attack, and you will be the snap pea that makes it through the summer. ★

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START YOUR OWN CMTA CIRCLE OF FRIENDS TODAY!

SAG FACILITATORS SPOTLIGHT:

Lynne Krupa, Southern Connecticut

Lynne Krupa was motivated to become a SAG leader when her son was diagnosed with CMT.

Lynne grew up with a mild form of CMT, but she knew that she walked differently, was never going to master the balance beam, and that wearing high heels was definitely out of the question. She didn't give much thought to a condition with which she, alone, in her family had been diagnosed. Things changed nearly six years ago when her son was 12, and he started to exhibit some difficulty walking. Lynne didn't consider the possibility that he might have CMT because she was unaware that it was hereditary. "It wasn't until his pediatrician asked Tyler to stand on his tiptoes and he couldn't that I suspected he might have CMT," she said. Testing confirmed that her son did have CMT and, unfortunately, it is more advanced than his mother's.

"I realized how little I knew about CMT and I wanted to learn as much as I could about how to help my son," she said. "I became a member of the CMTA and the information they provided was a tremendous resource after Tyler's diagnosis."

A few years went by and when Lynne received an email from the CMTA looking for new facilitators, she felt it was something she needed and wanted to do, even though it was definitely outside of her comfort zone. "I was nervous before our first meeting, but everyone there was so great. I think we were all so happy to meet others with CMT and to have the opportunity to share our stories, that my nervousness quickly subsided," said Lynne. This was Connecticut's first SAG and there is now a second group in the Hartford, CT, area, facilitated by Roy Behlke.

"We have a wonderful group of people who are determined to create a greater awareness of CMT in Connecticut as well as raise research funds," she said. "We were proud to have our group member, Michele Kekac, named last year's CMTA "STAR" and are grateful for the very successful fundraiser she and her husband, John, organized. Some of our other members have obtained the Governor's CMT Awareness Month proclamation, elicited donations while sharing personal stories with a Rotary Club, and shared Reiki talents with the group," Lynne explained.

The Southern Connecticut SAG meets five to six times a year and has hosted speakers on a variety of topics. "We're planning a fundraiser for September 26th at the New Haven Country Club, and since it'll be held in a different town this year, we'll be creating awareness in a new area of the state with the hope of generating more funding for the CMTA's STAR program," said Lynne.

"I'm grateful for the people I've met and the knowledge I've gained as a facilitator and this experience has strengthened my belief that we will make the CMTA's vision of 'A world without CMT' a reality." ★

CMT AWARENESS MONTH, SEPTEMBER 2014, IS RIGHT AROUND THE CORNER:
www.cmtausa.org/aware

September is CMT Awareness Month

Charcot-Marie-Tooth or CMT is a neuromuscular disorder affecting over 2.6 million people worldwide.

CMTA
Charcot-Marie-Tooth Association

SUPPORT AND ACTION GROUP NEWS

- **AZ – Phoenix Area**

At the May 17th meeting CMTA updates were discussed, including The Patient & Family Conference at Stanford, the *CMT Survivor's Guide*, webinars on the CMTA website, the Words with Friends challenge, and CMTA Awareness Month.

- **CA – San Diego**

The group welcomed Mary and Chris to their first meeting. Topics discussed included: Type 1 vs. Type 2 CMT, doctors who specialize in CMT research and treatment at Cedars Sinai Hospital, drug therapy, gene therapy, cell therapy and gait analysis.

- **CA – South Bay Area**

Thanks to the 45 members that attended the June 7th meeting. Mitch Warner, CPO, served as guest speaker. Mitch invented the Helios orthosis in 1997 and currently specializes in leg bracing for CMT. We thank Mitch for the interactive presentation and the time he took with all members before, during and after the meeting. Thanks also to Ryan Whitman for making this meeting happen!

- **CT – North Haven**

There were 15 members at the April 29th meeting. They discussed the unprecedented Strategy to Accelerate Research (STAR) fundraising opportunities. They talked about an idea for an upcoming BBQ and Beer tasting fundraiser. Two group members shared their experience of attending the CMTA's patient and family conference in Los Angeles in February. Their guest speaker was a group member who is a Reiki master and teacher with her own studio. She spoke about how Reiki has made a positive difference in her life and how it has helped her deal with her CMT.

- **FL – Tampa Bay Area**

Twenty-four people attended the meeting. A newly diagnosed person joined the group, which always makes them happy because they are expanding their local CMT community. Thanks to Tom, who helped with the set-up and even brought snacks for the group. They talked about "Shark-O-Marie-Tooth" t-shirts, the "Easy Thousand" fundraisers, CMTA webinars, the *CMT Survivor's Guide*, confidentiality issues, Patrick Major's story, and the upcoming adaptive yoga seminar.

- **MD – Easton**

There were eight new faces at the June CMT gathering! They came from all over the Eastern Shore of Maryland and came because they had read about the meetings in the newspapers. By sending concise, factual publicity via email to many of the area dailies and weeklies, we have been able to reach many people in our area who have CMT or are members of a family where CMT exists. The interaction among the attendees is so valuable for each of us to share what we do daily to make the most of our CMT lives and to realize that we are not alone.

- **NJ – Central New Jersey**

David Tannebaum, psychotherapist, served as guest speaker for the May 3rd meeting. Nineteen members were in attendance. David spoke about the emotional side of having CMT. He said that depression and anxiety affect the physical aspect of CMT and that talking about what is upsetting us and the difficulty of dealing with this disease is a huge step in the right direction. He noted that we should ask ourselves what is important in our lives and reminded us to focus on that, and not our CMT. He discussed healthy independence

(continued on page 19)

TURN SHOELACES INTO FUNDS AND AWARENESS

Amp up those shoes of yours with these funky and fresh laces! Yes, that's right—we want you to sport these shoelaces all during September and after! Share these laces with your friends and family. It's just another fun way to create awareness!

The blue laces are 54 inches long and are printed with the text "Charcot-Marie-Tooth Association" and the CMTA logo. You can purchase the laces at www.cmtausa.org/url/bluelaces.

CMT Support and Action Groups in Your Community

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Northern Ontario CMT Action and Support Group
Brenda Spencer
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Southern Ontario CMT Action and Support Group
Kelly Hall
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Mexico
(This group will be in Spanish.) México CMTA Grupo de Apoyo y Acción
Gina Salazar
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hotmail.com

Most Support and Action Groups can be accessed at www.cmtausa.org. They can be found in the CMTA Online Community under Support and Action Groups.

WHAT'S ON YOUR MIND? ASK DAVID.

David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life," says David. Write to David at info@cmtausa.org.

Dear David,

I always find it awkward when friends or even strangers will suggest some new treatment or therapy they heard about that they are certain will be helpful for my CMT. It can be really irritating, especially if I am not enthusiastic in my response, and I sense that they feel I am ungrateful. How do I handle this?

David Tannenbaum answers:

That's a good question since I am sure we have all experienced this same situation. I try to take the high road and thank them for their concern and assume that they are coming from good intentions. Then I might say something like "I will check with my doctor." However some "well-meaning" people can be really aggressive with their "suggestions."

In those situations, I will still manage to say thanks and then change the subject. Often with some of these suggestions to try the latest "vitamin xyz" or "sure-fire cure," I experience their desire to help as a bit controlling, and my instinct is, at this point, to generally try to be polite. Inwardly, it leaves me feeling a little depressed because there is no one who would like a cure for this condition more than I would. I have been discouraged so often with things that I think will work only to be let down. Sometimes I feel guilty and a little shameful and anxious in thinking I am not doing enough, but I remind myself that if something new comes out we will hear about it through the CMTA and that simply keeping as healthy as we can by the basic rules of good health of good nutrition and moderate exercise is doing a lot.

Having a neurologist who knows about CMT is the best thing we can do for ourselves along with joining a support group or social media site. I have always been a big proponent of alternative healing methods, but keep in mind that what works for you might not work for everyone. Most of all, keep your stress level down and try to value the good people and things in your life. ★

PARENTING

(continued from page 11)

the whole situation. The third one, "Don't make assumptions," guided us with the medical field. We asked so many questions—anything we did not know, we asked someone until we got an answer. We always checked the medication list the CMTA had with the medications everyone was giving him. The last one, "Always do your best," gave us space to breath when we were scared or exhausted from the surgery. We would refocus on the opportunities we had to all just sit and watch a movie together or to lie in bed and read a book.

It was the small things that we all enjoyed that helped focus us during the recovery. So, when our son made that comment it made me cry because the one fear I had had—that he would hate us for making him have surgery—did not come true.

We chose a Shriner's Hospital because they had done many surgeries on children with CMT.

In the fall I will be facilitating a one-hour-per-week complimentary virtual applied learning experience, face-to-face via your computers, for 10 mothers of children with CMT, ages birth to 12, applying the concepts I wrote about above. The series will last five weeks.

If you are interested, please email me directly at emisener@gmail.com or visit my website at http://elizabeth-misener.com to find out more information. ★

The CMTA Report is published by the Charcot-Marie-Tooth Association, a registered non-profit 501(C)(3) health organization.

SUPPORT GROUP NEWS

(continued from page 16)

and accepting help. He described how, if we let people help us, those people feel good helping. The group discussed how anger is just the tip of iceberg and that beneath anger is fear, hurt, sadness, or pain.

- **SD – Hartford Area**

One member showed up, with one new member also coming, to the April 26th meeting. They discussed STAR, a 5K, and doctors in the area they could see.

- **TX – El Paso**

Three people were in attendance at the May 3rd meeting. The meeting was used as a time to get reacquainted and go over STAR updates, the "Easy Thousand" fundraiser, and spreading CMT awareness through the media.

- **WI – Milwaukee Area**

Chicago orthotist Sean McKale, an expert who really knows a lot about CMT, presented a program about braces, orthotics, etc. There were lots of questions, lots of sharing, and lots of laughter. The group welcomed several new members.

- **WV – Vienna Area**

The group had eight people in attendance at their May meeting. They watched part of Patrick Major's video, discussed STAR research, and possibly advertising through the media. Thanks so much to Jerry and Debbie Beardmore for donating $265 in change for our "Change for Change" jar. This amount was applied to the 2-for-1 STAR challenge. Heartfelt tears were shed by the group while discussing children with CMT and the role they have as parents in dealing with the emotional and physical sides of CMT. ★

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THE CMTA Report

The Charcot-Marie-Tooth Association
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1-800-606-CMTA (2682)   FAX (610) 499-9267
www.cmtausa.org

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):
Vinca alkaloids (Vincristine)

Moderate to significant risk:
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Eribulin (Halaven)
Gold salts
Ixabepilone (Ixempra)
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:
5-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Fluoroquinolones (Cipro)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in US)
a-Interferon

Negligible or doubtful risk:
Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

WHAT IS CMT?

- CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- CMT may become worse if certain neurotoxic drugs are taken.
- CMT can vary greatly in severity, even within the same family.
- CMT can, in rare instances, cause severe disability.
- CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- CMT does not affect life expectancy.
- CMT is sometimes surgically treated.
- CMT causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- CMT has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- CMT is usually inherited in an autosomal dominant pattern, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- CMT Types that can now be diagnosed by a blood test include 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN.
- CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.