THE CMTA Report

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

JULY/AUGUST
2011

CMTA
Charcot-Marie-Tooth Association

OUR MISSION:
To generate the resources to find a cure, to create awareness, and to improve the quality of life for those affected by Charcot-Marie-Tooth.

OUR VISION:
A world without CMT.

EMAIL CMTA AT:
info@cmtausa.org

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Maryland's Patient & Family Conference Attracts International Audience

BY ELIZABETH OUELLETTE

At the Bolger Center in Potomac, Maryland, on July 2, 2011, the Charcot-Marie-Tooth Association hosted an overwhelmingly successful Patient & Family Conference, attracting approximately 200 patients, clinicians, and researchers from around the globe. The speakers and attendees, who traveled from Japan, the UK, Spain, France, Belgium, Malaysia, and Australia, gave this conference an international flavor, boosting worldwide collaboration and partnership between the CMTA and international patient advocacy groups.

DC Support and Action Group facilitators Steve Weiss and Kimberly Hughes were the driving force behind this unique conference, which followed the CMT International Consortium. Steve, Kim, and their families organized and structured all aspects of this event, making it a memorable occasion for all.

President and Chairman of the CMTA's Board of Directors, Patrick Livney, kicked the conference off by welcoming all the attendees and presenters. He emphasized the CMTA's commitment and dedication to finding treatments for CMT under the banner of the STAR (Strategy to Accelerate Research) initiative. Livney admitted that uncovering the right drug to treat and/or cure CMT may be a challenging process, in which missteps are to be expected. But, much like Pat Livney's golf game, where even the most precise drive may end up hooking or slicing, missing the initial target, it may take several tries before we hole the ball. Whatever it takes, the CMTA is entirely devoted to "making par" and "in short order, finding treatments for CMT."

The 4th International CMT Consortium and the CMT Patient/Family Conference both took place at the Bolger Center in Maryland.

Dr. Steven Scherer, member of the CMTA's Medical Advisory Board from the University of Pennsylvania, spoke about, "Understanding the Different Types of CMT." Dr. Scherer explained that CMT is a hereditary disease of the peripheral nerves, causing dysfunction in the sensory and/or motor nerves. In CMT, either the axons or the myelin of these nerves is progressively compromised, slowing down the signals and causing muscle

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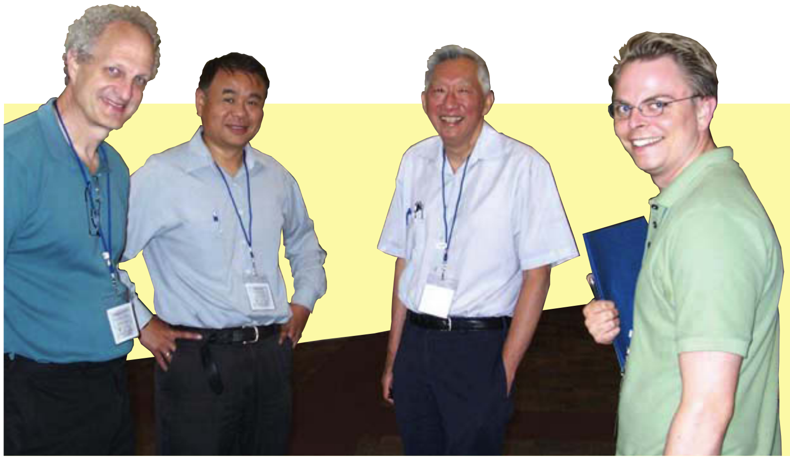

4th International CMT Consortium Recap

Four attendees of the Consortium continued the "talk" about CMT and drug therapies during the afternoon coffee break.

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4th International CMT Consortium Held

BY PAT DREIBELBIS

The Fourth International CMT Consortium was held at the Bolger Center in Potomac, Maryland, from June 29 to July 1, 2011. This year about 178 researchers and clinicians attended the three-day event. These consortiums meet every two years, alternating between the US and Europe. The meetings are designed to bring researchers together to learn from one another and to share potentially helpful work with animal models and cell lines, among other topics.

One of the most anticipated presentations was the report on the high-dose ascorbic acid treatment of CMT1A. Although this report was only preliminary, Dr. Richard Lewis did say that the results were not positive enough to lead him to believe that there would be future studies on this same high dosage (4 grams/day). They were pleased, though, with the compliance of the participants and with the standards of the scoring. This bodes well for future clinical trials.

It was exciting to hear Dr. Stephan Zuchner announce that there are now 50 identified genes which cause CMT, but it was a comment brought into focus by Dr. Steven Scherer who said that the fact that there are 50 identified causes simply means that there are probably another 50 to find.

As the science has improved dramatically since the consortium in Snowbird, Utah, so has the difficulty in understanding what these brilliant researchers report in their presentations. A colleague of mine noted something that I have long believed, that it's the questions after the presentations that help the non-scientists in the audience understand the purpose and results of the research.

We learned more about the use of zebrafish and fruit flies as models for testing or analyzing forms of CMT. The zebrafish are particularly useful because they are small, rapidly growing vertebrae. Added to the use of mice and rats, these animals will increase the work that can be done in watching for increasing loss of function in various forms of CMT as well as giving the researchers testing platforms that are more available than rodents.

Jess Morrow, London, England, reported on the use of magnetic resonance imagining (MRI) of muscle in CMT1A and shocked many in the audience with pictures of healthy muscle and muscle that has atrophied because of CMT1A. The CMT muscle wasn't composed of muscle. The muscle had been replaced almost entirely with fat. This demonstrates why it is impossible to rebuild muscles that are completely atrophied. Muscle fiber has turned to fat. The slides were startling, but very clear in their message.

There were presentations on gait analysis which showed that gait analysis can be an excellent preface to having AFOs made.

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Most of the Consortium attendees posed Friday afternoon for the traditional group photo.

PATIENT & FAMILY CONFERENCE

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Door prize winners: Robert Huang, Trina Kromere, and Linda Lawrence.

weakness and sensory loss. Dr Scherer's lifetime work lies not only in studying all aspects of the disorder, but also in training future generations of neurologists and researchers in the field of CMT to ensure a better future for CMT patients and their families.

Professor of clinical neurology, Dr. Mary Reilly, from the UK began her presentation, "Diagnosing and Evaluating Patients with CMT" with a quote from Charles Dickens, *"It was the best of times. It was the worst of times"* to illustrate where the current state of CMT research lies. We have moved forward in understanding what genes cause CMT and why, but we have not yet come up with treatments. Nevertheless, diagnosis is an important part of understanding this hereditary neuropathy, for researchers and for patients. Statistically, of the people diagnosed with CMT in the clinics, 92% have one of the following four genes: *PMP22, MPZ, GJB1,* and *MFN2.*

Next, Chairman of the CMTA's Medical Advisory Board, Dr. Michael Shy explained that since its inception, the CMTA's STAR initiative has been designed to turn scientific discoveries into treatments. With the input of the CMTA's STAR researcher, Dr. John Svaren of Wisconsin, the CMTA currently has identified three promising compounds thought to reduce PMP22 levels, which are about to be tested in laboratory models, with the hopes of launching human clinical trials in the near future. The CMTA plans to work on CMT Type 2 and CMT Type 1X over the next several months.

Following Dr. Shy, the CMTA's CEO David Hall spoke about the success of the CMTA's STAR initiative. Of the approximately 7000 rare diseases in the USA, of which CMT is one, only 200 have treatments, and none have a cure. From the CMTA's perspective, the system is broken, and from this broken system, STAR was born. STAR is a strategic research program structured to maximize breakthroughs in genetics and dramatically speed up the pace of CMT research. The STAR program has been funded solely by the CMTA. The CMTA has partnered with the NIH and various pharmaceutical companies like GlaxoSmithKline, Pfizer, and Sangamo to bring patients a treatment for CMT in the very near future.

Right before lunch, Jeana Sweeney, the CMTA's Director of Community Services, spoke about ways of getting involved with the CMTA and its quest to spread awareness and raise research dollars. After handing out a few door prizes, she reminded the audience to join the CMT community through the CMTA's new website: www.cmtausa.org and to get involved in CMT September Awareness Month activities.

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NEW GIVING OPTION PROVIDED

In an effort to make gift giving even simpler, when you choose to make a credit card donation on line, you can now choose to have the gift be recurring. If you log in to the CMT home page, you will see "Donate" on the top right side. Click on that and you can first choose whether your gift is to General Fund or STAR research. After you have filled in the gift amount, you will see an option to make it a one-time gift or a recurring one. If you choose recurring, then you can choose monthly, quarterly, semi-annually, or annually. Using this new feature will allow you to know that your gift to the CMTA will be made even if you are away from home or lose the campaign letter.

Should you wish to stop the recurring gift, just call Kim at 1-800-606-2682 or email her at kim@cmtausa.org and she will remove the recurring gift from your profile.

PATIENT & FAMILY CONFERENCE

(continued from page 3)

One of the highlights of this Patient & Family Conference was a segment called “Lunch with the Experts” in which participants had the opportunity to dine with well-known and knowledgeable CMT researchers and clinicians, and also CMTA staff and volunteers. This event facilitated conversation and communication with esteemed CMT experts from around the world, making for a true collaboration between CMT patients and physicians.

After lunch, Carly Siskind and Shawna Feely, genetic counselors from the CMT Clinic at Wayne State in Detroit, tackled “Genetics and CMT.” In addition to educating the participants about the different inheritance patterns found in CMT, they shared the pros and cons of prenatal testing, known as PGD or Preimplantation Genetic Diagnosis. In addition, they spoke at length about GINA or the Genetic Information Discrimination Act. For more information about GINA, please go to: http://www.eeoc.gov/laws/types/genetic.cfm.

Lastly, Carly reminded all the participants to register with the RDCRN or the Rare Disease Clinical Research Network, a site dedicated to informing patients or parents of patients of clinical research studies. If you have CMT, joining the Inherited Neuropathies Consortium will also help researchers identify and recruit individuals who are eligible for participation in future research studies.

In the next talk, Gita Ramdharry, physical therapist from the UK, discussed her topic “Physical Therapy, Orthotics, and Activity in Adults with CMT.” Dr. Ramdharry highlighted some of the primary physical issues she sees in people with CMT: loss of balance, muscle deconditioning, decreased hand function, pain, severe fatigue, and inactivity. To improve quality of life in patients with CMT, Dr. Ramdharry believes it is necessary to work with a CMT-knowledgeable physical therapist who can offer advice, ongoing assessment, and self management techniques. In her clinic, Dr. Ramdharry emphasizes stretching, exercise (never to the point of exhaustion), balance techniques, orthotics/splints, and muscle strengthening to increase fitness level and reduce effort expenditure in day-to-day tasks.

Finally, Dr. Joshua Burns, Associate Professor from the University of Sydney, addressed the audience on the “Assessment and Management of Children with CMT.” Dr. Burns briefly covered the CMT Pediatric Neuropathy Score, which effectively measures the impairment of children with CMT. Emphasizing the treatment aspect, Dr. Burns has found that good shoes, orthotics, stretching, and strength training make a positive impact on kids with CMT.

Steve Weiss drew the conference to a close and thanked all the presenters, the CMTA’s Support and Action Group facilitators, and our sponsors: Hanger Prosthetics and Orthotics, D&J Medical, Frederick Medical Supplies, Johns Hopkins Department of Neurology and Jonah Berger, author of *He Walks Like a Cowboy*. Special thanks go to all the volunteers, especially the members of the Weiss/Hughes/Berger families, without whom this fabulous conference would never have come to fruition. ★

FUNDRAISING FOR CMT: BEAUTY SALON DONATES PARTY PROFITS

Alexa and co-owner of the Osio NY Salon, Eva D’Ambrosio enjoy a private moment after Alexa’s birthday party.

Bobby and Eva D’Ambrosio, owners of Osio New York Salon in Merrick, NY, decided to donate $200 to the CMTA in honor of Alexa Arbore-Queen. Alexa had her 8th birthday party at the salon this past spring and the money that was donated was 100% of the profits made from the party. Bobby and Eva have supported the Queen family and have gone above and beyond to help find a cure for CMT. When Alexa thanked Bobby after the party, Bobby’s response was, “I am going to help find a cure for you!” Alexa was elated. Driving home after the party, Alexa cried and said, “I can’t believe how many people want to help us find a cure!”

Alexa was diagnosed with CMT Type 1A in 2008. She keeps a positive attitude and is enthusiastic about finding a cure. She headed up a fundraiser at her school in October 2010 where they raised $725 for the CMTA. Several family members have made donations in honor of Alexa, and her parents made a contribution to the CMTA in lieu of favors at their wedding.

The CMTA's Facebook Page Fights Loneliness

My name is Bethany Meloche. I'm 19, a junior in college, and from Ann Arbor, Michigan. I started volunteering with the CMTA earlier this year and was excited to be included in the production of a new project: the new Youth Tab on the CMTA's Facebook page.

I was 12 when I was first diagnosed with CMT. I don't remember what the doctor said. I don't even remember what I thought or felt. In fact, I don't remember that day at all, even though it would mark a tremendous shift in my life. What I do remember, in the years that followed, is the loneliness.

You're expected to feel "different" as you find your way in your teenage years. I really was different. I felt isolated from my peers; even my friends and family had limited understanding.

My friends didn't understand why I couldn't follow them out onto the grass. And while CMT was prevalent in my family, progression was usually slow; they were perplexed when it hit me so rapidly. As a teenager, I was trying to find my personal identity, and I didn't know how CMT fit into it.

I've since learned how to be comfortable and happy with myself, including how I fit into a community. But I wish I hadn't had to figure this out on my own. That's why I was excited to be involved in the creation of the new Youth Tab on the CMTA's Facebook page. We wanted to create a resource for our youth to connect, share, learn, support one another, and know they are not alone.

The Youth Tab connects young patients across the globe.

To me, the Youth Tab is only the beginning. We will continue to utilize the Internet. It will allow us to come together, share our own stories, and pass on our knowledge to others.

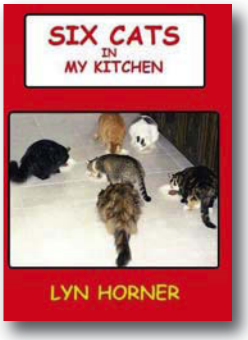
Bethany Meloche is a college junior and a contributor to the Youth Tab on the CMTA's Facebook Page.

Learning from others is invaluable, especially in a world where—even among the medical community—CMT isn't well known or understood.

As for me, the future is open and exciting. I hope to continue my involvement with the CMTA and their initiatives. Through awareness, we have the power to make our world a better place; through communication, we gain the knowledge and strength to deal with any adversity we meet. ★

CMTA MEMBER PUBLISHES NEW BOOK

Lyn Horner (a pen name) has been a long-time member of the CMTA and has just recently published a book she thought might be of interest to the readers of this newsletter. The book is entitled, *Six Cats in My Kitchen*, but it's much more than an animal lover's book. Although Lyn is clearly a cat person, having had six cats at one time or another in her life, she uses the cats as a way to tell the story of her life with CMT, her grappling with her daughter being diagnosed with the disorder, her care of aging parents, and her having to relocate her family.



Six Cats in the Kitchen is available through Amazon.com as a Kindle book. It is priced at $.99. It is not yet available in print format, but Kindle books can be read on devices such as PCs, iPhones, iPads, Blackberry, and Androids. ★

Family Garage Sale Benefits the CMTA

Twelve-year-old Jacob Mattheiss joined his family in a garage sale during the Long Hill, NJ, town-wide garage sale. This wasn't any ordinary sale, however, because Jacob decided to donate all the profits from his toy sales to the CMTA. His sale generated a whopping $200, which is to be matched enthusiastically by the town-wide garage sale sponsors, the Elks Club in Long Hill. When approached to see if they would consider a matching donation, they didn't hesitate.

"We were thrilled with the money we raised and the generous donation from the Elks," commented Jacob's mother, Lori Mattheiss.

Two hundred dollars is a lot of money for a 12 year old, but Jacob wanted to use the money he raised to support research to help find a cure for CMT. He was diagnosed when he was 10. Jacob's sister Kaitlyn is, also, an enthusiastic supporter of CMT research even though she isn't affected with CMT and just wants to help find a cure for her brother. Kaitlyn made bracelets with the letters CMT and a little foot charm to sell at the garage sale and at school to raise money. She is also planning on increasing awareness of CMT by incorporating it into her Girl Scout gold award project in the fall.


Kaitlyn (left) and Jacob Mattheiss both worked at the garage sale to raise money for the CMTA.

A few people stopped to check out the brochure and bulletin board and ask questions. One woman stopped to read the board and turned to us and said "I have CMT." We spoke for quite a while about her family having CMT and her not being sure whether her 9-year-old son has it or not. She was just recently diagnosed and was curious if she should have her son tested. ★

AFTER HER FAMILY'S SUCCESS WITH THE GARAGE SALE, KAITLYN MATTHEISS WROTE THE FOLLOWING ESSAY:

A few months ago my family had a garage sale, but it wasn't your ordinary garage sale. We were selling our old stuff, but my little brother Jake took all the money he earned from selling his old toys and stuff and donated it to the CMTA STAR program for research.

Not wanting to be completely outdone, I started working on a project of my own. Using an idea from a jewelry class I'm taking in high school, I started making clay beads out of Polymer clay. They featured clay feet. After making a few bracelets, I took some pictures and created a logo. The next day I made a Facebook page, Mission: Happy Feet. It started off a little slow, but quickly grew after word of mouth started to get around. So far, I've raised over $200 and I'm currently waiting to get t-shirts that I designed myself ready to sell.

So, here's a shout out to anyone with CMT. It doesn't take much to be successful in spreading awareness, supplying information or raising money. Whether by having a garage sale with flyers, or making and selling bracelets, you can go far. Take whatever you can do and turn it into something great.


Kaitlyn has made bracelets featuring "feet" which symbolize the CMT that her brother has.

THE CMTA "CIRCLE OF FRIENDS"

If you are interested in creating a fundraising Circle of Friends or want your family or friends to donate money to the CMTA on behalf of your birthday, anniversary, or special occasion, please let Jeana Sweeney know! You can email Jeana at: jeana@cmtausa.org. Working together, we can create a world without CMT!

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FUNDRAISING FOR CMT: HUNTER'S QUEST

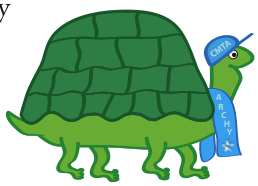
We decided to accept the Board Challenge and raise some money for the CMTA! It was decided that we would host a garage sale at our homes (next door to each other) on June 24-25. We received donated items from several family members in addition to the wide array of articles we had on hand ourselves. Boy, was it a lot of work, but well worth the effort.

Where we live, in Coal City, Illinois, they sure take their garage sales seriously. We had people stopping by two days before the sale even started and apparently 8 am means 7:30 am in these parts! The first few hours were a mad rush, and I was lucky to have my good friend Robin helping me out. In all we were able to donate over $250 to the CMTA, with a special thanks to Scott Nicholson for donating the ad space, baked goods, time, etc. We also had a neighbor donate her time and energy to support our worthy cause! She also let me know that there is a community garage sale coming up in September, so we hope to do it all again for Awareness Month. Now we have everything down pat, it should be a breeze!

—Ashley Doan and JoAnn Haase

Archy Travels West

You'll never guess where I am for summer vacation. I got invited to visit California and stay with the Ouellette-Bouchard family. My parents weren't too sure about letting me go so far away without one of them with me, but since Elizabeth Ouellette has a son with CMT, they decided she would know what to do if any problems arose.



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

So, after a body numbing plane ride, I arrived in San Francisco. I'll just say that everything that I've ever heard about Californians is true. They are much less excitable than their Eastern counterparts. When one piece of my luggage didn't turn up, Elizabeth was like "Oh, well. It will get here eventually and in the meantime, you can just wear your shell everywhere you go." I, of course, was completely devastated because I wanted to show off all my cool summer outfits. I tried to be brave about it all, but it was not the best way to start an exciting western adventure.

The house that Gilles, Elizabeth, and Yohan live in, is very nice. They have lots of wild animals in their yard. Elizabeth even found an opossum in her backpack in their garage. I think the most common animal is the grey squirrel, many of whom are my friends back in the Greenwoods. The weirdest animal is the one that lives in their house. They have a cat with no fur! She looks like a walking water bottle—all sort of rubbery looking, although she feels pretty good.

The family will be taking me horseback riding. I don't want them to know this, but I am terrified of getting up on one of those huge animals. Yohan rides one in spite of his CMT, but he is a teenager and has had experience riding since he was little. Besides, he's just an adventuresome person who will try anything. I usually just back into my shell when something comes up that I don't want to do. Here, of course, I'm visiting the family and it would be very rude to not do something they think I would enjoy and benefit from. Apparently, riding helps build core strength and is very good with improving balance and other problems of CMT.

Well, this is it! I'm leaving in a few minutes to go riding. Everyone except me seems really excited. I feel sort of bad because they went to so much trouble to set this up. They have a special horse at the stables for me and a special helper who will walk along with me in case I lose my balance or something. Sigh.

Archy and grey squirrel became good friends during his vacation. (Flat Archy stood in for the real Archy in the photo.)

Okay, the riding area is really pretty and the horses are beautiful, although still terrifyingly huge. I'm getting "suited up" so to speak so that I can ride. Getting up on the horse wasn't too bad because someone from the stables just picked me up and put me up on the horse with Elizabeth. She was very careful with me, but, alas, bad things can happen even when you are careful.

We had just started to make our first trip around the paddock when I somehow slipped out of Elizabeth's grasp and ended up on the ground. Fortunately, I have a shell into which I retreat in times of stress and I also fell on straw and grass. I didn't get hurt, but poor Elizabeth was a mess because she thought she had killed me. I'm fine, although this has made my desire to ride a horse even less than it was before.

My summary of this summer adventure in California is that, although California is very different from Greenwoods, it's a great place to visit. The people are friendly, the animals are, too, and the weather is great. And the best thing of all is that doing something that's not the norm for you is always a good thing. It makes you braver and smarter and more interesting. I think I grew up a lot this summer, and I feel very confident about taking on third grade. And best of all, I will have a great story for "What I Did This Summer," that awful essay the teachers always make you write at the start of school. ★

ASK THE DOCTOR

Dear Doctor,

My son has been prescribed the drug Gamastan S/D vials from Talecris. I wonder if there are any neurotoxic problems associated with this drug.

Dr. Louis Weimer replies:

That drug is for hepatitis A. It is not associated with neuropathy but any immune-altering treatment can occasionally cause an inflammatory reaction. However, treating the underlying hepatitis is very important.

Dear Doctor,

I am 40 years old and I have CMT with all the foot problems. My primary care physician prescribed me the statin drug Crestor to lower my cholesterol level. I am nervous about starting Crestor because I am afraid it will worsen my CMT symptoms. Can Crestor worsen my CMT?

Dr. Louis Weimer replies:

Yes, Crestor is rosuvastatin and seems to have the same side effects as other statins, such as Lipitor.

Dear Doctor,

I have been prescribed Medrol dose packs to help with severe burning sensations that no longer respond to Aleve. Do you know anything about problems in using these packs?

Dr. Louis Weimer replies:

A brief dose pack is probably safe and will not produce the more long-term problems with your muscles that steroids are known for. There are no known concerns regarding your nerves. You should find out the reason this is being used and the goal of this treatment.

Dear Doctor,

My father is 82 years old, having lived his entire life with a severe case of CMT. Most recently, he has suffered a life-threatening situation, where his vocal cords swelled and blocked his airway. The doctors performed a trac-airway and inserted a feeding tube in his stomach. He is home now, and the doctors remain stumped because the vocal cords remain paralyzed 7 weeks later. Is there any medical history to suggest CMT could be a contributing factor, relating to the nerves in the throat/vocal cords?

Dr. Steven Scherer replies:

The vocal cords contain muscles that are controlled by motor axons in the recurrent laryngeal nerve. CMT affects these motor axons in addition to the axons in the more familiar places (arms and legs), so it is not surprising that severe forms of CMT can cause hoarseness and even vocal cord paralysis. Paralyzed vocal cords cause difficulty breathing because they block air flow into and out of the trachea. Other conditions that affect the laryngeal nerve can also cause vocal cord paralysis, but if these have been ruled out, and your father has severe CMT, it seems reasonable to conclude that his CMT did indeed cause vocal cord paralysis in his case. ★

CMT WORLD LOSES REKNOWNED SCIENTIST

It is with sadness that we report on the death of Dr. David R. Colman, a valued member of the Medical Advisory Committee for the STAR initiative. Dr. Colman was Director of the Montreal Neurological Institute and Hospital of McGill University and the McGill University Health Centre.

Dr. Colman was a world-renowned scientist who focused on problems related to myelination, spinal cord injury, and nerve cell development and regeneration. His laboratory has made major contributions to the understanding of how nerves are protected and nurtured by the myelin sheath in the brain and in the peripheral nervous system, and how nerve cells communicate with each other across the synapse. He authored more than 110 scientific articles in publications such as *Science, Nature, Cell,* and *Neuron.*

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Abraham Beinhaker
Mr. & Mrs. Ezra Beinhaker

Richard Buenger
Mr. & Mrs. Ron Emmons
Mr. & Mrs. William Faries
Mrs. Constance Glaser Schwarze
Mr. & Mrs. James Haller
Ms. Pam Knipping
Mr. & Mrs. Sylvan Landau
Ms. Brenda Mathus
Ms. Sharon Purkey
Mr. & Mrs. Raymond W. Raney
Mr. & Mrs. Steven J. Rickert

Rose Caputo
Mr. Bruno Caputo

Gary & Sarah Cohen
Steve & Sandy Bernstein

Donald Doebereiner
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Ms. Jeanne Sexton
Ms. Faye Watson & Family
Woodmont Baptist Church

Darrel L. McNamar
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Jack Walfish
Mr. & Mrs. Paul Dann

Marjorie R. Williams
Citizens Management Inc.
Mr. & Mrs. Walt Geer

Uncle Bud
Mrs. Marcia Hoffman

IN HONOR OF:

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Osio New York Salon

Riley Ashe
Mr. Vince McCarthy

Dave & Anita Beron
Mr. Lawrence Hazan

Wil Brady
Mr. & Mrs. Wil Brady

Sandra Ettelson
Mr. James Stotter

Kay Flynn—Happy Birthday
Ms. Mona Coogan
Ms. Florence F.
Mr. George Gomez

Alan & Shirley Garmer—Happy 60th Wedding Anniversary
The Locke Ranch

The Robert Gordon Family
Mr. & Mrs. Tom Fleury

John R. Graves
Mr. Jack A. Graves

Robert Kramer
Mr. Andrew Kramer

Melinda Lang
Mr. Stephen I. Woods

Caitlin & Erin Leahy
Ms. Kendra Leahy

Miriam & Bryce Maples
Ms. Arlene Norgren

Jacob Mattheiss
Mrs. Lori Mattheiss
Stirling Elks #2392

Joe Metzger
Ms. Laurie Wilson

Beverly O'Free Rooney
Mr. Christopher Ouellette

Bridget Shields
Mr. Ed Diamond

Kelsey Shinnick
Mr. Matthew Cooper

Jeana Sweeney—Happy Birthday
Mr. Herb Beron
Mrs. Betsy Chandler
Ms. Linda Davis
Mr. Archie Giannella
Mr. Jared M. Gorentz
Mr. Eric Juda
Mr. Alan Korowitz
Ms. Melinda Lang
Mr. Patrick Livney
Ms. Cyndi Houston Michener
Ms. Elizabeth Ouellette
Ms. Victoria J. Pollyea
Ms. Billie C. Mercer Robles
Ms. Beverly O'Free Rooney
Ms. Michelle Rust
Ms. Megan Seese
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Mr. Chris Sweeney
Mr. Vasi Vangelos
Mr. Mark Willis

Missy Warfield
Ms. Joan Crowley

Ken Wysocki
Mr. Joe Redding

Oscar D. Zagorski
Ms. Michelle Zagorski

Will—Happy Birthday
Mr. & Mrs. Jeffery Rome

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.

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Occasion (if desired):
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In memory of (name of deceased)

____

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Address:____________________________

____

Amount Enclosed:____________ ☐ Check Enclosed
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Card #______________________________

Exp. Date ____________________________

Signature ____________________________

Gift Given By:

Name:______________________________

Address:____________________________

____

CMT UK International Convention

BY KAREN BUTCHER, SECRETARY, CMT UK

It's amazing to realize that CMT United Kingdom has been in existence for 25 years—it doesn't seem like five minutes! Some time ago, the Board decided that we needed to celebrate in suitable style, so we decided, instead of our usual one day Annual Conference, we'd go all out, and have a three-day Convention in April 2011, inviting our friends from all over the world.

We held our events at the Hilton Hotel in Coventry, which is in the Midlands, giving easy access to the hotel from all over the UK. We were overwhelmed when we were flooded with bookings—usually, I start panicking that no one will come by mid March, but not this year! We were particularly delighted that Mike Shy agreed to come to be our lead speaker, although he had a marathon journey from Hawaii to get to us. Delegates came from all over the UK, but we were also happy to welcome Daniel Tanesse from CMT France, Hiroaki Ohtake and his colleagues from CMT Japan, Marina Brocca from AICMT (Italy), Allison Moore and Carol Shapiro from the Hereditary Neuropathy Foundation, Tracey Lee representing CMTA Australia—and last, but never least—the CMTA's own David Hall!

We had a variety of speakers. Mary Reilly from the National Hospital for Neurology in London kicked off the convention with an update on research around the world, and that was followed by a series of workshops that delegates could choose from: exercise and physical therapy, rehabilitation management, orthopaedic surgery and genetics/neurology of CMT were the selections for Friday afternoon. We ended the day with a lovely dinner all together—a very good start to the Convention.

The CMT UK celebrated its 25th year with a convention and gala.

On Saturday, even *more* delegates turned up from all over the UK, giving us a record attendance number of 235! After introductions, Mike Shy gave us a wonderful update on all the great work that he is doing at Wayne State University, and all around the US, and in particular all about STAR, and how that is helping to get CMT research really rolling. After a coffee break, he took time to answer lots of questions for our delegates. Again, after lunch, we split into workshop groups that discussed pain management, orthotics, exercise and physical therapy, and pediatric neurology. But the highlight was yet to come.

You can't have a celebratory convention without a party, can you? It's just not done! So we celebrated our 25th Anniversary in some style, with a fabulous dinner, followed by a great live band, and a disco—the pictures here are evidence that Mike Shy and David Hall really know how to dance! We all danced till about midnight, by which time my feet were just about dead! It was a fabulous evening that we all thoroughly enjoyed. We even had an amazing birthday "cake" made by one of our members, made up of little boxes, each containing some chocolates!

Michael Shy (left) and David Hall (right) demonstrate their gift for dance at the gala.

Sunday was a quieter, more gentle day, with more workshops—our young people's event, pyschology, tai chi and a "getting to know you" session, allowing people to share their unique stories. The final lecture was an incredibly interesting talk by Paul Cooke, who is actually an orthopaedic surgeon, but he's made a study of the life of Jean-Martin Charcot, and we learned a lot about this amazing man. We finished with a lovely lunch, and said goodbye to all our new friends. We all had a wonderful time, and we'd like to thank everyone who took the time and made the effort to travel such a long way—particularly Mike Shy, who had been at a conference in Hawaii in the days immediately beforehand, and made the effort to travel for almost 36 hours to get to us. *You're really a STAR!* ★

SUPPORT AND ACTION GROUP NEWS

AZ – Phoenix

Dr. Saperstien was our guest in June. His talk concerned general genetics and the application to CMT. The meeting was videotaped, so let the facilitator know if you want a copy. The group was challenged to fund raise for the CMTA STAR Program. Each group member was asked to send in a check for any amount to the CMTA. The group also discussed Awareness Month. All group members were encouraged to visit the CMTA's new website and join the support group online! At the meeting, Ken announced that he will no longer be able to be the co-facilitator for this group. Everyone wants to thank Ken for his compassion, caring, and guidance. The group will meet again on September 10th.

CA – Los Angeles

The group met on June 26. They discussed the STAR initiative, Shop for the Cure, and the Macy's fundraiser, and they went over the CMTA literature. One of the group members took the time to show other members how to register on the website. The next meeting will be held at El Segundo with the South Valley group to celebrate CMT Awareness Month on September 10th.

CA – San Francisco Peninsula

At the last meeting, the group went over the new website, Awareness Month in September, and STAR updates. The group is planning on holding a garage sale in Los Altos at the beginning of October to raise research dollars for STAR research. If you have items you might want to donate or know friends or family who would like to donate items for the garage sale, please let the support and action group facilitator know. The group will have their 5th annual picnic on September 10th, from 3 to 7 pm.

FL – Tampa Bay

Dr. Franklin was invited to the May meeting to give a review of the current CMT research news. He discussed all that has been accomplished in understanding CMT, especially the new genetic codes and their positive impact on research. Dr. Franklin stressed the importance of knowing your CMT subtype, as with the research news, this typing will be crucial. Harry Quintero from Athena Diagnostics was also in attendance. He shared that many insurance carriers, as well as Medicare, are now paying for genetic testing. Also, for the first time a donation bucket was passed around and those in attendance were asked to contribute to the CMTA STAR program. The group was thrilled to discover $178 in the bucket. The next meeting will be held September 17th.

GA – Atlanta

In June, the group heard a presentation from Dorie Sokol, the director of the hand therapy program in Atlanta for Physiotherapy Associates. Dorie spoke about three types of hand therapy for a person affected by CMT: the benefit of exercises, hand splints, and adaptive equipment. The group also discussed Awareness Month, and they were given a STAR update. The group is planning a fundraiser/picnic at Stone Mountain Park. For more information about the fundraiser, please contact the support and action group facilitator. The next meeting will be August 20th at 2 pm at St. Martin in the Fields Episcopal Church in Atlanta.

KS – Wichita

At the last meeting, the group had the pleasure of "test-driving" the Polycom phone system, as they had a member call in who does not have transportation. The Polycom worked perfectly! The group talked about how helpful the Independent Living Resource Center has been for their group members. The group also discussed fundraising. They decided to collect can tabs as a starting point. The group has invited a representative from Athena Diagnostics as a guest speaker at their next meeting.

NM – Albuquerque

The group met on June 1st. Gary (facilitator) reported on CMTA activities including a research update, CMT Awareness Month, and fundraising. They then had a wonderful presentation by Dr. Janet Poole from the University of New Mexico Occupational Therapy Department on Assistive Devices for those with CMT. Afterwards, they had a conversation with Dr. Poole and exchanged a lot of information. They hope to set up a future collaboration

(continued on page 14)

CMT Support and Action Groups

AL—Birmingham Area
No group currently meeting
Will accept calls
Dice Lineberry
205-870-4755

AZ—Phoenix Area
Arizona CMT Support and
Action Group
Pamela Palmer
480-926-4145

CA—Los Angeles Area
South Californa CMT
Support and Action Group
Dottie Zagar
661-433-2533

CA—South Bay Area
San Francisco Peninsula/
South Bay CMT Support and
Action Group
Elizabeth Ouellette
1-800-606-2682 x107
Rick Alber
650-924-1616

CA—San Diego Area
San Diego CMT Support and
Action Group
Steve Gabbert
619-987-6022

CA—Santa Rosa Area
Santa Rosa, CA CMT Support
and Action Group
Carol O'Bryan
707-823-0165
Ronald Deghi
707-829-0911

CA—SF/East Bay Area
San Francisco/East Bay CMT
Support and Action Group
Donna Rennie
925-330-2790

CA—Visalia Area
Visalia, CA CMT Support
and Action Group
Melanie Pennebaker
559-972-3020

CO—Denver Area
Denver Area CMT Support
and Action Group
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

DC—Washington, DC Area
Washington, DC CMT Support
and Action Group
Steven Weiss
Kimberly Hughes
301-962-8885

FL—Inverness Area
West Central Florida CMT
Support and Action Group
Ronnie Plageman
352-860-1578

★FL—Jacksonville Area
Jacksonville, FL CMT Support
and Action Group
Bill Wilkens
904-268-4530

FL—Orlando Area
Central Florida CMT Support
and Action Group
Julie & Mark Collins
407-786-1516

FL—Tampa Bay Area
Tampa Bay, FL CMT Support
and Action Group
Vicki Pollyea
813-251-5512

GA—Atlanta Area
Atlanta, GA CMT Support and
Action Group
Susan Ruediger
678-595-2817
Jeannie Zibrida

IL—Chicago Area
Chicago Area CMT Support and
Action Group
Dale Lopez
708-499-6274

KS—Wichita Area
Kansas Area CMT Support and
Action Group
Karen Smith
316-841-8852

KY—Burlington Area
Pam Utz
859-817-9338

MD—Hagerstown Area
Hagerstown, MD CMT
Support and Action Group
Jeffrey Martin
301-582-2401

ME—Portland Area
Portland, ME CMT Support and
Action Group
Celeste Beaulieu
207-284-1152

MI—Chesaning Area
Chesaning, MI CMT Support and
Action Group
Carolyn Koski
989-845-5731
Ellen Albert
810-639-3437

MI—Kalamazoo Area
Southwest Michigan CMT
Support and Action Group
Jori Reijonen
269-341-4415

MN—Benson Area
No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MO—Anderson Area
No group currently meeting
Will accept calls/emails
Libby Bond
417-845-1883

MS—Mississippi/Louisiana
Clinton, MS CMT Support
and Action Group
Flora Jones
601-825-2258

NC—Triangle Area
Triangle, NC CMT Support
and Action Group
Betsy Kimrey
919-833-3991

NH—New Hampshire/Vermont
New Hampshire/Vermont CMT
Support and Action Group
Margaret Healey
802-535-2797

NJ—Central New Jersey Area
Central New Jersey CMT
Support and Action Group
Mark Willis
732-252-8299

NM—Albuquerque Area
CMT New Mexico CMT Support
and Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area
Las Vegas, NV CMT Support
and Action Group
Diane Cencak
702-560-3647

NY—Upstate New York Area
The Upstate, NY CMT Support
and Action Group
Melinda Lang
518-783-7313

NY—Greater New York Area
Greater New York CMT Support
and Action Group
Bob Wine
212-535-4314

NY—Horseheads Area
Horseheads, NY CMT Support
and Action Group
Angela Piersimoni
607-562-8823

NY—Long Island Area
Long Island, NY CMT Support
and Action Group
Ruth Korowitz
516-318-3202

NY—Westchester Area
Westchester, NY CMT Support
and Action Group
Beverly Wurzel
201-224-5795

OH—Greenville Area
Greenville, OH CMT Support
and Action Group
Dot Cain
937-548-3963

★OH—Zanesville Area
Zanesville, OH CMT Support
and Action Group
Tara Boehke
740-297-4940

OR—Portland Area
Portland, Oregon CMT Support
and Action Group
Debbie Hagen
503-333-7936

PA—Bucks County Area
Bucks County, PA CMT
Support and Action Group
Linda Davis
215-943-0760

PA—Johnstown Area
Johnstown, PA CMT Support
and Action Group
J.D. Griffith
814-539-2341
Jeana Sweeney
814-262-8427

PA—Northwestern Area
Eastern PA CMT Support and
Action Group
Joyce Steinkamp
814-833-8495

PA—Pittsburgh Area
Pittsburgh, PA CMT Support
and Action Group
Christine Miller
412-341-5749

RI—East Providence Area
Rhode Island CMT Support
and Action Group
Meredeth Souza
401-433-5500

TN—Nashville Area
Nashville, TN CMT Support
and Action Group
Mark Hollingshead
615-480-2044
Bridget Sarver
615-3909-0699

TN—Savannah Area
Savannah, TN CMT Support
and Action Group
Reagan McGee
731-925-6204
Melinda White
731-925-5408

TX—Dallas Area
Dallas, TX CMT Support and
Action Group
Whitney Kreps
972-989-5743

VA—Harrisonburg Area
Anne Long
540-568-8328

VA—Williamsburg Area
Williamsburg, VA CMT Support
and Action Group
Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Tacoma Area
Tacoma, WA CMT Support
and Action Group
Carol Hadle
253-476-2345

★WI—Milwaukee Area
Southeastern, WI CMT Support
and Action Group
Polly Maziasz
262-439-9009
Margaret Hoepner
414-788-9628

★WI—Brodhead Area
Southern, WI CMT Support
and Action Group
Molly Hawkins
608-921-0032

Virtual Groups*

Dave Hall's Virtual Support
and Action Group

Global Support and Action
Group Community

Virtual groups can be accessed at www.cmtausa.org. They can be found in the CMTA Online Community under Support and Action Groups. Click on Find a Group and choose either Global or Dave Hall's Virtual Support and Action Group.

TAKE ACTION: If there is no support group in your area, consider becoming a facilitator!
If you are interested, please contact Jeana Sweeney at jeana@cmtausa.org.

★ The CMTA welcomes four new support groups!

SUPPORT AND ACTION GROUP NEWS

(continued from page 12)

between the support and action group and the OT Department at UNM. The next meeting will be on Saturday, August 13.

NV – Las Vegas

Support group member Brian Prinzavalli began the last meeting with an informative and interactive presentation on his lifestyle choices with diet, exercise, and personal expectations and how he integrates those choices in his daily living. His presentation sparked a lively discussion among the members and how each of them has made lifestyle choices and changes in living with CMT. They explored the new website and the different groups available on the website that they can join. Traditionally the group does not meet during the summer heat, but it was suggested that Midsummer they should get together for a nice dinner out. Date, time, and location will be set soon.

PA – Bucks

In May, the group discussed the upcoming events including the Somerset Patriots game, the patient family conference, and Awareness Month. They then had a general discussion about what they have been doing. One of the group members told the group that she will be in a half-marathon in the month of November to raise awareness and funds for CMT. The group assured her that they would most certainly support her in her fund-raising journey.

Michigan – Southwest

In May, the group heard from Heidi Wakley, a registered dietician and nutrition counselor. She discussed healthy nutrition and took questions from the members. Their discussion included how to modify foods to help avoid choking and make swallowing easier. They also discussed ways to add fruits and vegetables to their diet, especially for people who do not like fruits and vegetables.

NY – Upstate

In June, the group heard from Mary Sloan, instructor/therapist and nationally certified massage therapist. Mary discussed the benefits of therapeutic massage, recommending that those with CMT use caution with deep tissue massage and hot stone massage, because they may not be able to feel if these forms of massage may be too much, which could lead to pain later. Next, Mary led the group in gentle stretching exercises to improve flexibility. Then to soothing music, they participated as Mary demonstrated various yoga positions; some while standing (behind a chair if needed for balance), others from a seated position. The group was then encouraged to participate in the Extraordinary Person–CMT Star contest. They also discussed the ValleyCats fundraiser, planned for August 12 and the Awareness Month proclamation from the mayor. The next meeting is scheduled for July 30 with Dr. Michael Shy.

WI – Milwaukee

A few members brought spouses to the June meeting—which is a great idea because CMT affects the family as a whole. The Awareness Month brochures, bracelets, and posters were passed out, which were met with great approval. They also discussed their upcoming fundraising plans through the Macy's-sponsored, "Shop for A Cure" event. Neurologist, Dr. Arshad Ahmed, attended the second half of the meeting and held a Q&A session in which he addressed issues such as pain management and low-resistance exercise. ★

In the last issue of the newsletter, the name of the Rhode Island – East Providence Support and Action Group leader, Meredeth Souza was misspelled in the write-up of her fundraiser. Also the correct location of the event was the Knights of Columbus Bishop Hickey Council in Riverside, RI. We apologize for the errors.

NEW CMT SUPPORT AND ADVOCACY GROUP STARTS ON DELMARVA PENINSULA

Saturday morning, October 1, will mark the first gathering of a CMT Support and Advocacy group on the Delmarva Peninsula. The group will meet in Easton, MD, at the new Talbot County Senior Center from 10 AM until Noon.

Group facilitator Missy Warfield of Easton, a CMT patient, has spoken with physicians, physical therapists, psychologists, and others who have agreed to address the meetings. For more information, please contact Missy at missywarfield@cmtausa.org.

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

4TH INTERNATIONAL CONSORTIUM

(continued from page 2)

In combination, gait analysis and AFO fitting can eliminate having to go back and back to have AFOs adjusted. Gait analysis shows how the foot touches down on the ground and also shows other weak and strong parts of the swing-through process in walking. Gait analysis labs are not in every hospital, but if one is nearby, it might be wise to visit there first, especially if the patient is still a child.

During breakfast on the second full day, Dr. Michael Shy said that almost all of the findings being reported on in the early session on Thursday were made possible by the STAR funding. To see the enthusiasm and energy of the scientists is to know that CMT is an important topic for research, and to listen to the researchers during the breaks is to understand how important the people behind the disorder are to them. More than one researcher talked about following a family through marriages, births, and even deaths—all because they had become friends during the years of researching the family's CMT.

I will say that the consortium is always a very tiring event, but it is also the one place I can go to get recharged about what is going on in the world of research. I might not understand everything that is presented, but I grasp enough of the lessons to know that we are really surging forward in our efforts to unravel what causes CMT and what can be done to help change the face of CMT in the years to come. ★

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	TOTAL			

☐ Check payable to the CMTA *(US residents only; non-US residents, please use credit card or international money order.)*

☐ Money Order ☐ American Express ☐ MasterCard ☐ VISA

Card Number: ______________________________ Expiration Date: ______________

Mail to: CMTA, P.O. Box 105, Glenolden, PA 19036

A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling, toll-free within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

THE CMTA Report

The Charcot-Marie-Tooth Association
P.O. Box 105
Glenolden, PA 19036
1-800-606-CMTA 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)
Gold salts
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)
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
Fluoroquinolones
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 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN can now be diagnosed by a blood test.
- CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.