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THE CMTA Report

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ✲ www.charcot-marie-tooth.org

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@charcot-marie-tooth.org

New Strategy, Infrastructure, and Science to be Funded by CMTA

2007 promises to be an exciting year for the CMTA, its members, and everyone who deals with Charcot-Marie-Tooth disorders. The excitement we envision is found in the new direction, strategy, infrastructure, and science we are funding.

The new direction for the organization is a plan to adopt, in cooperation with the Myelin Repair Foundation, a collaborative research process which hopes to result in developing therapies. The new strategy is to create a never-ending source of funding for research so that therapy targets are reached in a shorter period of time than with traditional research.

The new science is represented by the start of the High-Dosage Ascorbic Acid Clinical Trials that will begin on April 2, 2007, at Wayne State University, the University of Rochester, and Johns Hopkins Medical Center. In addition, the CMTA has committed to funding over a million dollars for research projects at the University of Miami Medical Center, Baylor College of Medicine, and the University of Pennsylvania.

The CMTA is also conducting the first CMT Prevalence Study in the United States in cooperation with, and through, a grant provided by the Pennsylvania Department of Health.

The new infrastructure we are creating will translate into new opportunities for the CMTA. We are expanding to a Chicago location to enable our awareness efforts to include the Midwest. We are creating a virtual office in California to enable our awareness efforts to proceed on the West Coast. These new locations will allow members and donors to get attention during normal business hours in their time zones.

> CMTA will expand its services with offices in Illinois and California.

We are also creating a full-time national development officer's position to help with continued research funding needs. With all of these plans, the CMTA continues to keep operating costs below 23% of our revenue.

Beginning this spring, the CMTA will communicate with our supporters on a quarterly basis to report on our progress and to encourage financial support of our efforts. We will still mail membership renewals on a monthly basis to individual members.

Quarterly appeals will allow supporters to choose to designate their gift to research, operations, or both and to choose to give to any or all of the appeals, based on their financial situation. As with all changes, this will take some time to adjust to, but we urge your cooperation in making this giving strategy successful.

—Charles F. Hagins,
Executive Director

INSIDE:

Ascorbic Acid Study Update

Information about the upcoming clinical trials for high-dose therapy

Revised contact information and additional details about the high-dose ascorbic acid clinical trials have been made available to us. The following is a summary of the information we have about the trials and who to contact if you would like to be considered for participation:

PURPOSE OF THE STUDY

The purpose of the study is to evaluate whether high doses of ascorbic acid have any effect on Charcot-Marie-Tooth disease type 1A (CMT1A) and whether or not it should be studied further. Ascorbic acid is also known as vitamin C and has been successfully used to treat a mouse model of CMT1A and studied extensively for other purposes. However, it has never been used to try to treat people with CMT1A.

NUMBER OF SUBJECTS

A total of 120 study participants will be enrolled through three participating centers: 48 each at Wayne State University (Detroit, MI) and Johns Hopkins University (Baltimore, MD) and 24 at the University of Rochester (Rochester, NY).

PARTICIPANT ELIGIBILITY*

In order to be included in the trial you must:

- Be between 13 and 70 years of age
- Have CMT1A diagnosed by genetic testing in either yourself or a first- or second-degree relative (this would include your children, grandchildren, brothers/sisters, nieces/nephews, parents, grandparents, aunts/uncles and half-siblings)
- Make 6 visits over 2 years to the study center (twice at the beginning and then once every 6 months for 2 years).
- Take 8 tablets per day of either vitamin C or a placebo (sugar pill) for 2 years.

You will not be eligible to participate in the trial if you:

- Are diabetic or have another condition that may cause a peripheral neuropathy
- Are pregnant or nursing
- Have ever had kidney stones
- Have ever taken the chemotherapy agent vincristine
- Have another serious medical condition
- Have been taking very large doses of vitamin C for a year or more
- Have another type of CMT.

In order to participate in the trial you, or a family member, must meet the following criteria:

- You, or a family member, must have been genetically tested.*
- The result of the genetic test must have been positive for CMT1A. (If you have been tested and are not sure of the results, the contact person at the study center will help you determine whether or not you have CMT1A.)
- You must be between the ages of 13 and 70.
- You must be able to make an initial visit to one of the study centers listed on the facing page, and you must be able to return to the study center once every six months during the two-year study period *

OVERVIEW OF STUDY DESIGN

If you decide to participate in this study, you will be asked to take eight (8) study drug or placebo capsules every day for two years. After an initial screening evaluation at the research site, you will return within three weeks for a baseline visit and then every six months for two years to participate in study visits.

This is a double-blind, placebo-controlled trial. That means you will be randomly assigned to one of two groups. One group—80 percent of all participants—will receive the ascorbic acid, and the other group—the remaining 20 percent—will receive the placebo. Neither you nor your study doctor will be told which group you are in. At the end of your partic-

*Although there is no fee for participation, neither is there any compensation. The study will not pay for genetic testing and participants are responsible for transportation to and from the study centers.

ipation in the study, you will be asked to guess whether you were taking the ascorbic acid or the placebo. At the end of the trial, when all volunteers have completed the study, you will be told which group you were in. ✻

STUDY CONTACT INFORMATION

If you meet the criteria outlined above and are interested in participating in the study, please use the information below to contact the study center nearest you:

Wayne State University
Detroit, MI
Principal Investigator:
Richard Lewis, MD
Site Principal Investigator:
Michael Shy, MD
Contact Person:
Lisa Rowe
Phone: 313-577-1689
Email: lrowe@med.wayne.edu

University of Rochester
Rochester, NY
Site Principal Investigator:
David Herrmann, MD
Contact Person: Patty Smith
Phone: 585-275-0581

Johns Hopkins University
Baltimore, MD
Site Principal Investigator:
Ahmet Hoke, MD
Contact Person:
Lora Clawson
Phone: 410-614-4346
Email: lclawson@jhmi.edu

MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

(Items marked with an asterisk "*" are required.)

*NAME: _____/_____/ _____
First MI Last

*ADDRESS: _____

*CITY: _____ *STATE: _____ *ZIP: _____

*COUNTRY/POSTAL CODE (IF NOT US): _____

*DAYTIME PHONE: _____ EVENING PHONE: _____

EMAIL (Required for website access and PDF newsletter): _____

Note: If you are joining now, you may purchase publications at active member prices. ACTIVE MEMBERS have paid dues within the past year. If you are unsure about your membership status, please call 1-800-606-2682.

	QTY	COST	TOTAL
ANNUAL MEMBERSHIP DUES			
Members have the option of receiving *The CMTA Report* in print, PDF via email, or both. Receive newsletter as: ☐ Print *or* ☐ PDF via email		$40	
Receive both Print *and* PDF Newsletters		$45	
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		**active members $15** nonmembers $20	
CMT Facts I ☐ English ☐ Spanish		**active members $3** nonmembers $5	
CMT Facts II ☐ English ☐ Spanish		**active members $5** nonmembers $7	
CMT Facts III		**active members $5** nonmembers $7	
CMT Facts IV		**active members $8** nonmembers $10	
CMT Facts V		**active members $12** nonmembers $15	
A Guide About Genetics for the CMT Patient *(No shipping and handling on this item only)*		**active members $4** nonmembers $5	
CMT Informational Brochure		FREE	
Physician Referral List: States: _____ _____ _____		FREE	
Letter to Medical Professional with Drug List		FREE	
Contribution to CMT Research Fund (100% of contribution is used to fund research)			
Shipping & Handling *(Orders under $10, add $1.50; orders $10 and over, add $4.50)*			
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, 2700 Chestnut Parkway, Chester, PA 19013; or fax to: 610-499-9267

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.

LIVING WITH CMT

A Visit to the Wayne State CMT Clinic, *Day One*

BY DANA R. SCHWERTFEGER

For me, the plan to visit the CMT Clinic at Wayne State University in Detroit, Michigan, began several months ago when it was suggested to me that if I had CMT Type 1A, I should be a participant in the high-dose ascorbic acid clinical trial that is due to begin shortly.

The hitch was that I hadn't been genetically tested and couldn't say for sure whether or not I had 1A. Dr. Michael Shy, the director of the clinic, said it would be helpful if he could review the results of my nerve conduction studies (NCS) before ordering the genetic test, so I spent a few hours digging through my "important papers" files and finally unearthed a report from 1983 and faxed it to him.

Dr. Richard Lewis performs a nerve conduction study on Yohan's wrist.

Several hours later, the verdict was in: normal nerve conduction velocity measured at the wrist is approximately 50 meters/second, and my NCS showed intermediate slowing—between 30 to 35 m/s—not the 20 to 25 m/s nerve conduction velocity that Dr. Shy said he would typically expect to see if I had type 1A.

Knowing that, Dr. Shy said it would make more sense to have the genetic test for type 1X done first, and if that came back negative, then he would order tests for other demyelinating forms of CMT. The moral of this part of the story is that a neurologist can usually determine from electrodiagnostic testing whether to order genetic tests for demyelinating or axonal forms of CMT, and that can save patients in co-pays.

Shawna Feely, a genetic counselor at the clinic, also helped me negotiate the health insurance maze, so I knew that my co-pay for the 1X test would be $167, a fraction of what I would have had to pay if the full CMT panel had been ordered.

I didn't have to travel to Detroit for the genetic testing, but I learned that Board Member Elizabeth Ouellette would be taking her son, Yohan, to the clinic in February, and that Alan Pappalardo, a possible employee of the CMTA as we expand to the Midwest, would be there on the 15th and 16th as well.

I had a standing invitation from Dr. Shy to be poked and probed at the clinic, so this seemed like the perfect time. Not only would I be examined at one of the premier CMT clinics, I'd get to pair up with Yohan and meet Alan, who might be working out of a satellite office in Chicago. We'd make it "CMTA Day at WSU!"

Well, almost the perfect time. I wasn't happy that the timing meant having to fly out on Valentine's Day, nor did I know that the whole Northeast would be in the middle of the worst ice storm of the winter that week.

I'm not terribly fond of flying, even in good weather, and the post 9/11 security rules do not favor people with disabilities. I have never been treated discourteously, but it's such a hassle. I have to go through the hand screening because I can't take off my shoes and walk through the metal detector like everyone else. The indignity of that aside, I'm always worried that my laptop and camera will vanish from the bin on the conveyor belt while I'm taking off my shoes and trying to stand still long enough to be wanded.

Sitting in an airport departure lounge isn't my idea of a great time, either, so I'm grateful

the brunt of the storm missed Motown, and my flight was only delayed an hour.

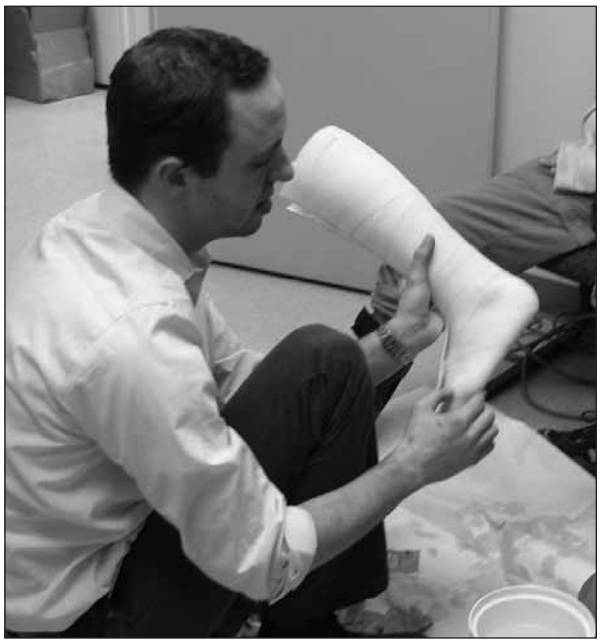
We stayed at a hotel in Greektown, which is only two miles from Detroit Receiving Hospital/University Health Center (DRH/UHC), but a half hour from the airport. The hotel has a shuttle, but it doesn't go to the airport, so if you make the trip be sure to consider the cost of cab fare in your budget.

As the name of the locale suggests, there are several Greek cafés and restaurants as well as a casino nearby, but I opted for room service because I was tired and I had to finish filling out the patient and family history forms for the clinic and the CMT North American Database. I had started that task on the plane, but my handwriting, which is not very good under ideal conditions, was rendered an illegible scrawl by the turbulence at 30,000 feet.

Thursday morning, upon my arrival at the clinic, I met with Shawna and Laurie, an Master of Science student. We went over my paperwork and insurance—WSU will bill insurance if you have it, but there is no cost for the visit if you don't—and then I went to an exam room to change and wait for Dr. Shy.

Had I thought to bring a pair of shorts, I would have been spared the indignity of having to wear one of those awful hospital gowns, but who brings shorts to Detroit in February? Answer: Anyone who reads the packet of information he is sent prior to the visit, or who reads about the clinic on the WSU website. (In my defense, I wasn't sent the packet of information because my decision to go was actually made on rather short notice.)

Dr. Shy began by asking about my family history, but I was adopted at a very young age, so there wasn't much to discuss. Then he did a basic neurological exam: vibratory, pin-prick, and hot/cold sensation tests, deep-tendon reflex tests, and an evaluation of muscle strength and function. No real surprises in any of those—I've been incapable of voluntary movement below the knee for over 20 years, and I've had reduced sensation for almost as long.



Sean McKale holds a cast made of Softcast, a fiberglass material that dries faster and is less messy than plaster of paris.

My next stop was electromyography for a nerve conduction study. Since this was my third one, I knew what to expect in terms of discomfort. Some people I've spoken with say that having the test done was the most painful thing they've ever experienced, but it's never bothered me. I'd rate it about the same as the tingle you get from putting your tongue on the terminals of a 9-volt battery, unpleasant but bearable. (Don't ask how I know to make that comparison!)

Of course, the technician didn't use a needle, just surface electrodes. He said he wouldn't do a needle electromyogram unless he suspected problems in the neuromuscular junction. He also performed the majority of the test at my wrist and only briefly examined my lower leg. (I asked so many questions, I'm not sure I remember all the answers, but I believe his explanation was that he could obtain accurate, or perhaps more accurate, readings at the wrist so there was no need to do more than an a confirmatory study of the lower leg.)

At lunchtime, I had a chance to meet Alan, who was also going through the clinic assessment. He is an intelligent, enthusiastic young man who is more severely affected than I am. Although capable of walking short distances while wearing braces, Alan uses a wheelchair—a situation I always find both unsettling and inspiring.

I've written before about my self-image and how I rarely

(continued on page 7)

GIFTS WERE MADE TO THE CMTA

IN HONOR OF

Yohan Bouchard
Mr.& Mrs. Raymond Mallette

Harrison Brenner's Bar Mitzvah
Larry & Stephanie Brenner

Stephanie DiCara
Judith & William Fouty

Peggy Johnson
Roger W. Johnson

Stacy Kaplan
Cravath, Swaine & Moore, LLP

Dorothye Knowles' birthday
Herbert Holly

Anna Marie Park
Mrs. Sylvia Barrett

Serenna Shaffer
Jesse & Louise Rodriguez

Jack & Ethel Walfish's Anniversary
Linda & Jerry Walfish

IN MEMORY

Dubby Bernstein
Barbara & Robert Bernstein

John Bradley
Mrs. Janet Bradley

Betty Chow
Jerry Hong
Jean Kuang
Rose Yuen

Mona Donovan
Allan & Bernice Blossom
Lane Towers

William R. Graves
Byron W. Graves, Jr.

James Haulenbeek
Ken Kobarg & Don Janner

P. Hundley's mother
Alice & Harry Cross

James Hunter
Randy & Tina Cettrall
Wayne & Barbara Fausett
Mr. & Mrs. Mark Neely

Raymond Koenig
A & E Golf Associates
Libby Anderson
Robert & Marie Austerman
Bob & Barb Brandner
Arlene Castner
Class of '46, Lockland High School
Rodney & Linda Donaldson
Ed & JoAnn Elmlinger
Bill & Sherri Federle
Bruce & Jac Lynn Musgrove
Sally Schutte
Andrea L. Settelmayer
Ann Settelmayer
Mr. & Mrs. James Settelmayer
Bill & Judie Smith
Eva Sulau
Vicki & Craig Ullery
Kasey Wendell
John & Miriam Williams

Ruth Linker
Laurence Linker

Audrey MacDonald
Jean Ayers
Mary Copenhaver
Andrew McGilvray
Ann McGilvray
Linda Morvant
Art & Gloria Poland

Walter Marohn
Kevin Jefferson

Florence McDonnell
The Estate of Mildred Burg
Mr. & Mrs. Harry J. Oxman
Ronald & Lois Silbergeld
Thomas C. Monnett, Jr.
Peter & Brenda Allen
Fred & Esther Cox
Claire Delozier
Huntingtown Elementary
Dr. Charles Varipapa

Rose Raiford
Mr. & Mrs. J. E. Bryant

David Reigle
Frances Davis

Dennis Reigle
Frances Davis

Rebecca Sand
Rhoda & Stephen Sand

Mary Sherwood
Angie Sherwood

John "Red" Wilson
Solutran/ Wendy Watt

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, 2700 Chestnut Parkway, Chester, PA 19013.

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

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____

_____

WAYNE STATE CLINIC

(continued from page 5)

think of myself as being disabled, even though I can't walk without braces and have difficulty doing some things with my hands. In my day-to-day phone conversations with patients and family members, I tend to use my own abilities and disabilities as a reference point, and I sometimes forget that other people with CMT are not capable of doing the things I am, so coming upon someone in a wheelchair is a reality check that reminds me that I can't see everyone with CMT the same way.

And yet, as unsettling a moment as that is, it's always inspiring to meet someone with a can-do attitude like Alan's. And it's a reminder that he is not a disabled person but a person with a disability. That may sound the same, but what I mean is that we sometimes see the disability first and the person second, and it should be exactly the reverse.

My next stop would have been an exam by Dr. Steven Hinderer, a physiatrist, but unfortunately he was in a meeting with the hospital administration, so it was back to Shawna for genetic counseling. She had a notebook with charts and diagrams, but she offered to skip her presentation in lieu of allowing me to just ask questions. Ordinarily, I would have been eager to do that, but personal concerns aside, part of the reason I went to WSU was to get an idea of what the experience was like for patients.

Shawna was happy to oblige, and as I listened I thought how easily it could have been me doing the presentation. And while it was a little strange to be told the same things, even using many of the same analogies, that Pat and I tell people every day when they call the office with questions, it was also reassuring to know we've been giving people accurate information.

After that, Shawna took Elizabeth, Yohan, and me downstairs and through the tunnels to meet with Sean McKale, an orthotist from Wright & Phillipis. Sean took one look at the posterior leaf spring AFOs I was wearing and said he'd like me to try something called a Blue Rocker Toe-Off. I had never tried the Toe-Off, but the Blue Rocker is apparently stronger and more durable than the original version.

He didn't have to cast me, though, because the Toe-Off is pre-formed from carbon fiber and not custom molded from thermoplastic. He did quickly come up with some insoles so that I could try the Toe-Off, but the prescription he wrote for me includes an insole which will be custom-molded to correctly position my foot.

Yohan, meanwhile, was cast for new AFOs and fitted for new night splints, so it was rather late by the time we wrapped things up, and Sean offered to take us back to the hotel. We talked shop all the way, and Sean and I wound up continuing our conversation over dinner at a Greek café. He is willing to answer patient questions, so we will be adding him to our ask-the-expert list.

In the next issue, I will be writing about our second day and our enrollment in a study of balance and CMT. I'll also have an update on my genetic testing and the Toe-Offs, which I hope to have by then, but if asked to give my overall impression of that first day, I would have to say that everything comes down to one word: trust.

So often in the course of dealing with CMT, we encounter physicians and health professionals who have little direct knowledge of CMT, or about whose level of expertise we have reservations. At the Wayne State CMT clinic, I had neither of those concerns. I felt I could absolutely trust the doctors to provide appropriate treatment, and I asked more than my fair share of questions. What I found most impressive in that regard was that if I lacked the scientific acumen to understand a particular concept, they were all willing and able to "dumb it down" for me. ✲

Yohan's grip strength is measured using a dynameter.

Fine-Tune Those Braces and *Use* Them!

BY MISSY WARFIELD

Like so many CMT patients with foot drop, I have had myriad braces over the years. Some have helped; others have been miserably uncomfortable. Often they ended up on the closet floor—unused.

That does no good at all! They didn't help my walking, and they cluttered the closet floor!

Lesson One: Talk to the orthotist to be sure that he or she fully understands your walking needs. Are you active (or would you be if you didn't trip so often)? What shoes must the brace fit into? How do you feel about the brace being seen by others? Be honest—with him and yourself.

Lesson Two: Get used to the AFO. Wear it every day for a few hours at the beginning. Wear it for a variety of activities. The brace will be your new "best friend," so get acquainted. Notice how it fits into your shoe. Concentrate on comfort—is your shoe too tight now, does the brace rub on your leg, ankle, or foot? Write those facts down and add them to the list before you revisit your orthotist.

The Silicone ankle foot orthosis comes in both adult versions and this one for children.

Lesson Three: Do, by all means, revisit the orthotist no sooner than two weeks after first trying the brace. You may have given up on it after a few days and tossed it aside. Someone—you or your insurance company— paid "big bucks" for that brace. What a waste! Try it again for the few days before revisiting the orthotist and review your notes. Ask that the brace/AFO be "tweaked" to accommodate your needs.

Lesson Four: Go over Lesson Two! And Lesson Three. And take another lesson from me:

After years of trying (and tossing) traditional AFOs, I read articles about the SAFO—the silicone ankle foot orthotic made primarily in England. Finally I had found something that seemed to be the result of earnest communication between patients and orthotists. Not only was it lightweight, but I could wear my own shoes with it. Eureka!

But wait. It was so emancipating, so good, that I wore it all day for the first few days. Too much. Too fast. Soreness! Something was not quite right. After only four days, I returned to the orthotist for some fine-tuning in two specific areas of the brace. It then seemed good, so I returned home and wore the brace daily for two more months. There was some discomfort, but I was walking with wonderful strides. I was not tripping and I was not nearly so tired. I was sure I'd found *the* brace for me!

Trouble was brewing. I was wearing two sores into the side of my foot—a foot with less-than-good circulation and healing power. After trying to protect the sores with bandages so that I could keep going, I was forced to seek medical help.

Much to my dismay, I was told to stop using the brace. The sores were so deep that bone infection was possible. I was told to stay off my feet; to elevate the sore foot and not to wear the brace. My new-found freedom was threatened!

Time to review Lessons One, Two, and Three! I communicated with the orthotist. I took the brace and my sore foot to the physician. He marked the brace where it was injuring my foot and we sent the brace to the orthotist for additional fine-tuning. I was "lost" for two weeks as the SAFO was undergoing its changes, but it was worth every minute.

That was more than two years ago and the SAFO has been my inseparable companion—daily—ever since. And all because I learned the lessons about working with the orthotist and making sure that the bracing works for me.

Don't toss your brace—whatever kind it is—into the closet or under the bed just because it is not comfortable. Fine-tune it. Wear it and enjoy walking! I do now! ✻

CMT in the News

Newspapers around the country feature stories about people with CMT

John Bermingham, a scientist at the McLaughlin Research Institute in Montana, has received a $1.8 million dollar grant from NIH to study a gene called Lgi4 which he discovered several years ago and which plays a role in the production of myelin in mice. Its importance is that it only plays a role in the peripheral nervous system and knowledge of how it works could help with diseases such as Charcot-Marie-Tooth syndrome. Without proper myelin, nerve transmission is about 100 times slower so that when people find themselves losing their balance, they fall on the ground before their brain can send a signal to shift their weight.

Richard Thorington, a curator of mammals at the National Museum of Natural History, is known as the "squirrelologist" for his work over the last 25 years studying the Eastern grey squirrel, a resident of the parks surrounding the White House. He began his studies in the 1960s studying primates in the tropics, but was diagnosed with Charcot-Marie-Tooth disorder in 1976, which eventually confined him to a wheelchair and kept him from traveling. He shifted his research to use the museum's unparalleled collection of 30,000 squirrel specimens.

"The disability didn't affect his eyes and observational powers," said his wife, Caroline, a printmaker who also photographs her husband's subjects. "He's always someone to say, 'what can I do?' and not to dwell on what he can't do."

Much of what Thorington has learned about the President's nutty neighbors appears in his new book, *Animal Answer Guide* (Johns Hopkins University Press) a compilation of his years of research on the squirrels as well as marmots, chipmunks, and prairie dogs. The book answers questions such as do squirrels fight (yes), see in color (yes), talk (yes) and swim (yes).

The American Association of People with Disabilities (AAPD) announced that **TyKiah R. Wright**, of Columbus, Ohio, received the 2007 Paul G. Hearme AAPD Leadership Award.

Ms. Wright is a strong advocate who has used her personal experience and entrepreneurial skills to establish WrightChoice, Inc. Wright grew up with Charcot-Marie-Tooth disease. After receiving a Master's of Business Administration degree, she found herself unemployed. This experience motivated her to help other high school and college graduates with disabilities strengthen their career development skills and successfully find jobs and internships.

Wright's belief in economic empowerment for people with disabilities has led to many honors, including being named one of *Ebony* Magazine's "2006 Young Leaders of the Future."

Teenage designer, **Phoenix Bess**, is described in *Vogue Knitting* magazine winter 06/07 as "poised to take the knitting world by storm" at the age of 14. She has published knitting patterns, is working on a book and is designing a line of handbags and accessories. Last year, she teamed up with a yarn manufacturer to help raise money to purchase a wheelchair for a teenager, named Kyann, who has Charcot-Marie-Tooth disorder. Phoenix donated a limited

edition design, the yarn manufacturer donated the yarn and purse form and the resulting kit, "Kyann's Midnight Cherry Rucksack" *(shown above)* was created. It sold on the Dream Weaver Yarns website at a fraction of retail value and all of the proceeds went to purchasing the much-needed wheelchair.

Kyann got her $12,000 electric wheelchair in midnight blue with sparkles because one teenager chose to help another! ✻

Silent Tears: A Mother's Story

BY CATHERINE DE SILVA

I am a mother of two children with CMT. My daughter, Amy, just turned 11 and has great difficulty with her hands, wrists, and finger mobility. She has undergone electromyograms, two tendon transfers to prevent her wrists from curving inward, and years of occupational therapy. Her feet are extremely wide, small, and arched severely, causing balance problems and ankle weakness.

My son, William, age 8, has the same high arch, and width and hammer toe issues affecting his balance, and his running ability is best described by saying that the kids nicknamed him "Franklin" after the turtle.

I stand back and watch the trials and tribulations my children go through week to week. They seem to grow in intensity as my kids grow older and are surrounded by their "normal" peers who just don't understand.

The simple things in life that people take for granted are always a brutal ordeal as a parent. Shopping for shoes: there are plenty of places in a mall, right? Well, try spending an entire day going from store to store and finding absolutely nothing other than "kiddie-looking" shoes from Stride-Rite to go with a suit or a dress for a formal event or better yet to be the new "school shoes" that everyone has. I stand in the supermarket parking lot and wait for several minutes for my daughter to try to pick up a "good luck" penny she finds on the ground, and I let her keep on trying and trying until her head comes up and she gives me that look that cuts deep into my heart. Is tough love the way to go? Do I make her keep on persevering or do I go over and assist her? My mind is racing into the future at this point. How is she going to be able to open her wallet and pay for her lunch? How is she going to make it on her own in middle school?

She has already completed our strict household rule of trying something three times. Then, before I decide the best answer for this particular moment, her brother or a nice person will come over and offer help and pick it up, for which, she graciously says thank you before she walks into the store with her head down and eyes welled up with tears.

> Is wanting a perfectly healthy child selfish of me to wish for?

The backbone in me continues to praise her efforts and we begin home therapy by putting coins down for her to pick up, as practice makes perfect. But, how much therapy is enough? Is it ever enough? She dances many evenings to keep her legs strong; she swims and gives up her lunch recess *every* day to lift weights in the nurses' office to keep her arms strong. She is a kid. Am I doing the right thing for her future? Will she understand that I am helping her in the end?

For all of you who have the joy of dealing with your school's special education department, I applaud you. I can say that I feel the pain and frustration that seems to never end. I often wonder if any of these people who are "looking out for the best interest" of your children have a child with special needs, because, if they did, I believe getting the needs of your child met would *not* be a problem. My husband and I battle for the simple needs and, when I say simple, I truly mean that. We ask that at the beginning of the school year, *all* teachers be informed of any limitations such as cutting with scissors in art class, or letting the gym teacher know that she can not perform the rings, do chin ups, climb a rope. Instead of being "unreasonable" and making the school get milk cartons with the punch-out hole, we had an arrangement that the person who takes the money would discretely open the milk, close it and put it on her tray so none of the other kids would find out. Well, what a surprise! This help was "overlooked" and I didn't find out until Amy came home crying that none of her class mates would help her and she went for a week with nothing to drink at lunch time.

Then, the gym teacher had the obstacle course where you had to climb things, and Amy

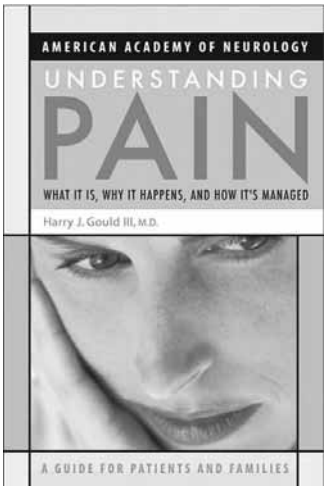
just kept going to the back of the line hoping her turn would never come. The teacher realized that she never went, and, in front of the whole class, he made her attempt it. In another class, he actually raised his voice about her form in throwing and catching a football. It was a good thing that I had a night to cool down before marching in to the school the next day to meet with the principal. While I was waiting, I could see his eyes and his attitude that "Mrs. de Silva" is here—like I am a criminal for asking for such simple things. I told the staff while I was waiting that as an adult it is frustrating to attempt to open a jar that just won't open or try to change a tire. If you are in a hurry and things just don't go right, how do you feel? If you have ever felt like that, then put yourself in Amy's position and have to live the rest of the school year knowing everyone watched you fail and you must live with the teasing that goes on.

Thankfully, William needs very little assistance or special consideration. He made me promise not to say a word to his football coach about his slow running or his inability to stretch his legs like the others; so I honor his wishes and silently bite my tongue when the coach demands more out of him than he is capable of doing. Silently, I wish for things to be different. I stop the tears from coming, and I tell myself that it could be worse and to be thankful for what I have. But, is wanting a perfectly healthy child selfish of me to wish for? As a Catholic, I wonder if my anger and silent tears and questions to God are going to send me to hell for these moments of weakness.

Amy is blessed with the gift of a beautiful voice which I tell her was given to her for a reason. However, she recently auditioned for a high school musical where they needed an elementary student to play the young girl for the main character. Approximately 60 young girls auditioned by singing, dancing, and reading a script. That evening, I received a call from the director that she had been chosen for the part. I can't tell you how excited I was, however the conversation continued with a statement that the staff noticed her hand didn't point straight "like the others." I enlightened him with the fact that she had CMT and when I stated the name of the disease you would have thought that it was anthrax that I had said. The tone and excitement in his voice dropped to a whole new level of disappointment. For some reason, I found myself almost apologetic because he wanted her to twirl a baton and I said, "if you would rather pick someone else then I understand." Why did I say that? No, I didn't understand. She was the best, and she deserved the part. Silently, the tears came and my composure began to break. I assured him that she is so determined that by the time of the performance, she would be able to twirl a baton in some manner. Then I was ashamed of myself for even offering him the chance to choose the understudy.

I often find myself thinking of the future. Will she ever be able to drive safely, shop, and try clothes on and get them off like everyone else? Will she ever be able to style her hair by herself and get ready for a date and apply makeup? These are the thoughts and feelings that keep me up at night; that make my mind drift off when I am driving or at work, and they are the source of the silent tears I cry every day for the helplessness I feel, for the ignorance of others, and for not being able to make everything right like a mother wants to do. ✲

OF INTEREST



Understanding Pain is the latest volume in the American Academy of Neurology Press "Quality of Life" series. It is a comprehensive guide for patients who wish to improve their understanding of the problems they live with. Chapters include the explanation and rationale for acute and chronic pain treatments, advice on collecting and organizing important information that should be communicated to your healthcare provider, and explanations of how pain is perceived and processed by the brain. ✲

SUPPORT GROUP NEWS

Alabama—Birmingham
The next meeting will be Saturday, April 28, 2007, at 10 AM. It will be held at the Lakeshore Foundation in Birmingham. The topic will be new treatments for CMT.

Colorado—Broomfield
The group has moved to a new location: The First National Bank, 12009 Sheridan Blvd. Broomfield, in the Home Depot Shopping Center. They meet bimonthly on the fourth Saturday, from 10-11:30 AM. For more information, contact Diane Covington at 303-635-0229.

Florida—Jacksonville
A neuropathy support group (not just CMT) is being run by a neurologist and neuropathy specialist, Dr. Alan Berger. The group meets at Glendale Community Church, 6411 Beach Blvd., Jacksonville, FL every month on the second Saturday, from 10-11:30 AM. For more information, contact Karen Perrin, at 904-244-9719.

New York (Westchester County)/Connecticut (Fairfield)
On January 20, 2007, Tricia Gressel, CSW, spoke at the support group meeting. She is the coordinator for the Westchester network for people with disabilities. This program is sponsored by the Junior Chamber of Commerce on the Hudson in Tarrytown, NY, and is funded by a grant. The group is composed of physically challenged individuals who are interested in socializing, meeting new people, and having new experiences in the community, including attending plays, concerts, and dinners, etc.

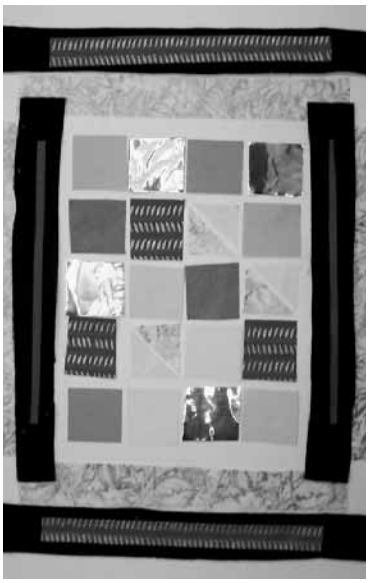
The network has also written a play based on the life of each participant. Advocacy Theater takes on a comical, honest and sensitive look at living with a disability and its numerous challenges. It was a very interesting presentation, and the group was appreciative of finding out about this program right in our own community.

Nevada—Las Vegas Area
The first meeting of the Las Vegas, Nevada, CMT Support Group was held on January 22, 2007 with 12 people present. We met from 1:00 to 3:00 p.m. at the Whispering Palms Community Center. The meeting was one of sharing and just getting to know one another—truly an eye opener for most of us. The MDA also had a representative there who helped with some of the organizing and provided refreshments.

The next meeting was March 19, 2007. Mitchell Warner of Ortho Rehab Designs spoke about bracing for CMT patients.

The next meeting will be a potluck picnic on May 19th. Call Mary for details at 702-369-6095.

Washington—Seattle
The Seattle CMT group met on Saturday, February 24th for our monthly gathering at University of Washington Medical Center. Taking a break from serious lectures and topics, we worked on something exciting and "off the beaten" track. Individuals in the group created collages, courtesy of the artist-in-residence supplies from UW Medical Center. Fanciful colored paper, metallic designs, and rainbows of colors were available to spark creativity. The exercise called on the participants to think about the roles they played in life and then use a different paper to represent each function in their life. After putting together a quilt of their different roles, the participants could think about how CMT might affect each role they play and if they wanted to make changes.



One support group member produced this "quilt" of the various roles he plays in life.

Each piece of art was entirely different and spoke to each person's uniqueness. ✻

CMT Support Groups

Support Group Liaison: Elizabeth Ouellette, 650-559-0123

Alabama—Birmingham
Place: Lakeshore Foundation Fitness Center
Meeting: Call for schedule
Contact: Dice Lineberry, 205-870-4755
Email: dkllrl@yahoo.com

Arkansas—Northwest Area
Place: Varies, Call for locations
Meeting: Quarterly
Meetings are not regularly scheduled so call ahead.
Contact: Libby Bond, 479-787-6115
Email: charnicoma57@yahoo.com

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)
Place: Sutter Medical Center of Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Louise Givens, 707-539-2163
Email: lbgivens@ix.netcom.com

California—San Francisco Bay Area/Santa Clara County
Place: Location to be determined
Meeting: Bimonthly
Contact: Elizabeth Ouellette, 650-248-3409 (C) 650-559-0123 (H)
Email: elizabetho@pacbell.net

Colorado—Broomfield
Place: First National Bank
Meeting: Bi-monthly on the fourth Saturday
Contact: Diane Covington 303-635-0229
Email: dmcovington@msn.com

Florida—Tampa Bay Area
Place: St. Anthony's Hospital, St. Petersburg, FL
Meeting: 2nd Sat of Feb, May, Aug, Nov
Contact: Lori Rath, 727-784-7455
Email: rathhouse1@verizon.net

Kentucky/Southern Indiana/ Southern Ohio
Place: Lexington Public Library, Northside Branch
Meeting: Quarterly
Contact: Martha Hall, 502-695-3338
Email: marteye@mis.net

Minnesota—Benson
Place: St. Mark's Lutheran Church
Meeting: Occasionally
Contact: Rosemary Mills, 320-567-2156
Email: rrmills@fedtel.net

Minnesota—Twin Cities
Place: Call for location
Meeting: Quarterly
Contact: Maureen Horton, 651-690-2709 Bill Miller, 763-560-6654
Email: mphorton@qwest.net wmiller7@msn.com

Mississippi/Louisiana
Place: Baptist Healthplex, 102 Clinton Parkway, Clinton, MS
Meeting: Quarterly
Contact: Flora Jones, 601-825-2258
Email: flojo4@aol.com

Missouri—St. Louis Area
Place: Saint Louis University Hospital
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664
Email: c.haislip@att.net

New York—Greater New York
Place: NYU Medical Center/ Rusk Institute, 400 E. 34th St.
Meeting: Third Saturday of every other month, 1-3 PM
Contact: Dr. David Younger, 212-535-4314, Fax 212-535-6392
Website: www.cmtnyc.org
Email: bwine@acm.org

New York—Horseheads
Place: Horseheads Free Library on Main Street, Horseheads, NY
Meeting: Quarterly
Contact: Angela Piersimoni, 607-562-8823

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Hospital
Meeting: Bimonthly, Jan, March, May, Sept, and Nov; 3rd Saturday
Contacts: Beverly Wurzel, 845-783-2815 Eileen Spell, 201-447-2183
Email: cranomat@frontiernet.net espell@optonline.net

Nevada—Las Vegas
Place: Whispering Pines Community Center
Meeting: Email for dates 1-3 PM
Contact: Mary Fatzinger
Email: cmt_suppgroup_lvnv@yahoo.com

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)
Place: Various locations in Raleigh
Meeting: Quarterly
Contact: Susan Salzberg, 919-967-3118 (afternoons)
Email: judae@bellsouth.net

Ohio—Greenville
Place: Wills Restaurant 405 Wagner Ave, Greenville
Meeting: Fourth Thursday, April–October
Contact: Dot Cain, 937-548-3963
Email: Greenville-Ohio-CMT@ woh.rr.com

Ohio—NW Ohio
Place: Medical College of Ohio
Meeting: Quarterly
Contact: Jay Budde, 419-445-2123 (evenings)
Email: jbudde@fm-bank.com

Pennsylvania—Johnstown Area
Place: John P. Murtha Neuroscience Center
Meeting: Bimonthly
Contacts: J. D. Griffith, 814-539-2341 Jeana Sweeney, 814-262-8467
Email: jdgriffith@atlanticbb.net, cjsweeney@ussco.net

Pennsylvania—Northwestern Area
Place: Blasco Memorial Library
Meeting: Call for information
Contact: Joyce Steinkamp, 814-833-8495
Email: joyceanns@adelphia.net

Pennsylvania—Philadelphia Area
Place: CMTA Office, 2700 Chestnut St., Chester, PA
Meeting: Bi-monthly
Contact: Pat or Dana, 800-606-2682
Email: info@charcot-marie-tooth.org

Washington—Seattle
Place: U of Washington Medical Center, Plaza Café—Conference Room C
Meeting: Monthly, Last Saturday, 1-3 PM
Contact: Ruth Oskolkoff, 206-598-6300
Email: rosk@u.washington.edu

ASK THE DOCTOR

Dear Doctor,
I have CMT and had breast cancer a few months ago. The oncologist wants me to take Arimidex. I am concerned because of the side effects that can occur. Do you have any information about Arimidex and CMT patients?

The doctor replies:
There is no known effect on CMT or neuropathy from Arimidex or similar breast cancer hormone treatments. There are some possible beneficial effects of some other hormone blockers, especially progesterone blockers, in animal models of CMT1, and this question is an active line of research, but the effects from Arimidex are likely to be clinically insignificant; the drug has demonstrated benefits in the proper breast cancer setting.

Dear Doctor,
Do you know about a vitamin called Metanx? My podiatrist said she had been using it on her patients with diabetes to treat their neuropathic pain. Does anyone know if it has ever been tried on anyone with CMT? Would it be unsafe?

The doctor replies:
I looked up this supplement on their website. The vitamin contains active forms of folate, B_6 and B_{12} and they claim it is more effective than regular supplements, but they have no requirement to prove their claim. The purpose is to reduce homocysteine levels, which are a risk factor for vascular disease, but so far, supplements are not proven to change underlying risks, only the lab test results. I see no harm in using this supplement unless it is taken in excess.

Dear Doctor,
Before knowing I had CMT I was being tested for other problems, and I was given Celexa for depression. On the very first dose after approximately four hours, I began to notice tremors in my legs. It moved to my arms and then affected my voice. It became so bad my PCP sent me to the ER where they administered sedatives through IV. I spoke in syllables like someone with advanced MS. It took several hours of treatment before I could leave the ER and several days of oral medications before the effect wore off completely. Did the Celexa have an effect on my nerves because of my CMT or was this just a fluke?

The doctor replies:
I know of no established link with Celexa (citalopram) and worsening of CMT or the causing of weakness. The drug is also not usually associated with tremors or lack of coordination except in the unusual situation called serotonin syndrome. This condition can occur very quickly after starting a medication that affects serotonin levels or after a sudden change in dosage. Many commonly used psychiatric drugs cause this problem in part. It happens more frequently when 2 or more drugs are combined, especially if one has monoamine oxidase inhibitor (MAOI) activity. I can't tell if that is what happened in this case without other information, such as other drugs being used.

Some of the common signs and symptoms of serotonin syndrome are sudden confusion, agitation, involuntary muscle jerks, sweating, shivering, tremor, diarrhea, fever, and lack of coordination.

Dear Doctor,
I have CMT and my doctor gave me 10 mg of Zetia. After taking the medication for several weeks, my legs started hurting badly. Has anyone else had any effects like this after taking it? I would really like to know if other CMT patients have experienced this with Zetia?

The doctor replies:
Zetia is a combination drug that contains the statin, atorvastatin, as well as ezetimibe. All statins are associated with a muscle complication that is usually minor but can be severe especially soon after starting the medication. Muscle pain is common, and anyone taking a statin should be assessed for myopathy or myositis if pain or weakness develops. A creatine kinase blood test is one initial step. Any drug that affects muscle strength is a potential problem for CMT patients even if the nerves themselves are unaffected.

Statin drugs are also suspected to affect nerve function, but the effect is probably rare and controversial. The studies performed did not account for the underlying reason why the patients need to take a statin drug. However, patients reporting nerve problems have more

WRITE TO US!

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Chester, PA 19013
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sensation trouble than motor problems or weakness.

Dear Doctor,

My husband has CMT and is 72 years old. He has been diagnosed with atrial fibrillation.

Last week, his cardiologist started him on Rythmol SR to get his heart in sync. He wants to eventually put him on amiodarone. I gave him your drug list. Because amiodarone is the drug of choice, he wondered if he could put him on it for just a month or two and then switch him to one of the other similar drugs that works a little less well.

Can you tell me what happens to a CMT patient who takes amiodarone. Does it make the condition worse, or could it make him sick or kill him?

The doctor replies:

Amiodarone does commonly affect the same type of nerve fibers affected by the most common forms of CMT—motor and sensory nerves. However, the effect is greater with high doses and longer treatments. Not all patients on amiodarone develop neuropathy, but there is a strong concern for anyone who already has neuropathy, including CMT patients. The risk must be weighed against the potential benefit, risk of the underlying problem, and adequate available alternative treatments. If he is treated, you should watch closely for signs of increased weakness or numbness. The drug, however, stays in the system much longer than most drugs, so if a problem occurs, the toxic effect may continue to worsen for a period after the drug is stopped. ✻

LETTERS

Dear CMTA,

I am a forty-two-year-old male who was diagnosed with CMT by electromyography six years ago. My biggest obstacle is the fact that I am a prisoner, so I have had to educate myself and fight for everything I get. My self-education is made all the more difficult by the fact that I still do not know what type of CMT I have. That gives you some idea of the wall against which I must bang myself daily. However, your newsletter and information have helped me get the proper medication, stop medications I shouldn't be taking, and get the proper devices to make my everyday life safe and comfortable. I cannot imagine what my life would be like without the educational materials and newsletters provided by your organization. Thank you so much for the invaluable help you've given.

—M.S.

Dear CMTA,

It's amazing how little the medical profession knows about this disease. I educated the nurses when my husband was hospitalized. Nurses that weren't even on his case were coming in to see his drop foot and how crippled his feet are. They were curious about his braces, and I told them about the high risk of falling for these patients. Ken described his burning sensations and his dexterity problems in his hands because he has no feeling left in them. We also told them about the dangers of a wet floor since it's too late before he realizes it's slippery.

The nurses thanked us for teaching them because they said that they get a lot of elderly patients, and patients who aren't as knowledgeable about this disease as we are.

Last summer, Ken was in the ER and the nurse didn't know about the disease. I told him about your website, and he looked it up. When Ken came in December, that same nurse volunteered to take him on because he understood the disease and knew what he should do. So, your website and your organization are helping everyday for people to understand this disease and its affect on those who have it.

—D.H., Internet

Dear CMTA,

I am 75 years old and I have known I have CMT for over 35 years. I have drop foot and balance problems. I fell twice in one week and decided it was time to do something.

In *The CMTA Report*, I had read about Hanger Orthopedics. I live in the Chicago area. I made an appointment with the facility near here and was fitted with braces. I have never been happier about my walking! My balance is so much better and I haven't fallen yet. The braces are light-weight and strap below the knee with Velcro. I did have to go back four times for adjustments until they were just right.

I wear them 8 to 10 hours a day and they fit in my SAS shoes.

If anyone has questions about these braces, I can be reached at 708-301-6132,

—Cecilia, Illinois

The CMTA Report is published by the Charcot-Marie-Tooth Association, a registered non-profit 501(C)(3) health organization. The opinions expressed in the newsletter are not necessarily those of the Charcot-Marie-Tooth Association. The material is presented for educational purposes only and is not meant to diagnose or prescribe. While there is no substitute for professional medical care for CMT disorders, these briefs offer current medical opinion that the reader may use to aid and supplement a doctor's treatment.

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 or vitamin B12 deficiency)
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 U.S.)
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?

- is the most common inherited neuropathy, affecting approximately 150,000 Americans.
- may become worse if certain neurotoxic drugs are taken.
- can vary greatly in severity, even within the same family.
- can, in rare instances, cause severe disability.
- is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- does not affect life expectancy.
- is sometimes surgically treated.
- 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).
- has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- 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.
- Types 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2E, 2I, 2J, 2K, 4A, 4E, 4F, HNPP, CHN and DSN can now be diagnosed by a blood test.
- is the focus of significant genetic research, bringing us closer to solving the CMT enigma.

THE CMTA Report

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