FEBRUARY–MARCH 1999

The CMTA Report

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A resource for information on Charcot-Marie-Tooth disease (Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy), the most common inherited neuropathy.

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A Research Survey and Evaluation Project on Charcot-Marie-Tooth Disorders

When the CMTA initially accepted the Arm-ington Research Challenge nearly four years ago, it was with the understanding that it signified a major organizational commitment to advancing CMT research. Financial resources are critical to the effort, but what is also needed is *a thorough understanding and complete knowledge base* of all CMT research activities. Recognizing this need, CMTA member Bob Buuck proposed that a project be undertaken to accumulate the requisite knowledge base for making informed, long-range decisions on CMTA research grants. The generous grant which made this project possible was made in the name of Robert and Gail Buuck and their children David, John, and Katie.

The request for proposals for the *CMT Research Survey and Evaluation Project* explained the need in this way: "The CMTA wishes to fund a project coordinated by a senior investigator in the field who has sufficient expertise and organizational backing to produce a comprehensive report which would include a survey/compilation of institutions, investigators, relevant research projects and funding sources, as well as an analysis, synthesis, evaluation, and recommendations on the most promising CMT research efforts." Ultimately, the report also would need to suggest how to maximize various research projects and whether collaboration between investigators was warranted. If collaborative efforts are underway, how are they working and what is the process? If there are no such examples, how might a collaborative effort take place or be structured?

Dr. Michael V. L. Bennett, Albert Einstein College of Medicine, Paul R. Flynn, Executive Director of the CMTA and Dr. Robert Lovelace, CMTA Medical Advisory Board chairman, spoke during a poster session at the Third International Conference on CMT Disorders. Dr. Bennett is conducting the CMT Research Survey and Evaluation Project.

In the search for the proper person to lead the project, the intent was to find an informed and experienced "outsider," one who could bring a critical eye and fresh perspective to the task. Dr. Michael V. L. Bennett, former chairman of the Department of Neuroscience at Albert Einstein College of Medicine and currently the Sylvia and Robert S. Olnick Professor of Neuroscience, was chosen for the project. Dr. Bennett has the ideal profile: a senior scientist who has

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Please see important membership renewal notice on Page 13!

Begin with Flynn

By Paul R. Flynn, Executive Director

For millions of years mankind lived just like animals. Then something happened which unleashed the power of our imagination. We learned to talk.

—Introduction to the song "Keep Talking," (Pink Floyd, The Division Bell), spoken by renowned physicist, Stephen W. Hawking.

As if it were not strange enough to begin by quoting Pink Floyd lyrics, I hope to explain the link between the above statement, a recent *New York Times* article, and Dr. Michael Shy's "philosophy" behind the Third International Conference on Charcot-Marie-Tooth Disorders. Additionally, I will illustrate how all this is relevant to the role of the CMTA and our new project with Dr. Michael Bennett: the CMT Research Survey and Evaluation Project. Are you ready? Here goes…

Science Times
The New York Times

TUESDAY, JANUARY 12, 1999

The Collaboration

Learning to Speak New Languages

Dr. West liked to joke that if Galileo had been a biologist, he would have written volumes cataloging how objects of different shapes fall from the Leaning Tower of Pisa at slightly different velocities. He would not have seen through the distracting details to the underlying truth: if you ignore air resistance, all objects fall at the same rate regardless of their weight.

But at their first meeting in Santa Fe, he was impressed that Dr. Brown and Dr. Enquist were interested in big, all-embracing theories. And they were impressed that Dr. West seemed like a biologist at heart. He wanted to know how life worked.

It took them a while to learn each other's languages, but before long they were meeting every week at the Santa Fe Institute. Dr. West would show the biologists how to translate the qualitative ideas of biology into precise equations. And Dr. Brown and Dr. Enquist would make sure Dr. West was true to the biology. Sometimes he would show up with a neat model, a physicist's dream. No, Dr. Brown and Dr. Enquist would tell him, real organisms do not work that way.

"When collaborating across that wide a gulf of disciplines, you're never going to learn everything the collaborator knows," Dr. Brown said. "You have to develop an implicit trust in the quality of their science. On the other hand, you learn enough to be sure there are no miscommunications."

In various planning discussions with Dr. Shy concerning the conference, he constantly emphasized that a major goal was to bring together diverse investigators, *people who don't usually speak to one another*. The lack of interaction or dialogue between certain researchers may be attributed to several causes: geography (i.e., they live and work in different countries), they simply do not know one another, and/or their areas of scientific specialty are very different. For instance, researchers doing work on CMT include geneticists, molecular biologists, clinicians, morphologists, and physiologists—*people who don't speak the same language.*

In the Science Times section of the New York Times on January 12, 1999, there was a fascinating article titled, "Of Mice and Elephants: a Matter of Scale." It recounts an unusual collaboration between two biologists and a physicist, who came together at the Santa Fe Institute, an interdisciplinary research center in New Mexico, which resulted in a novel theory (arguably a major breakthrough) to address a problem which has bothered scientists for decades: the origin of biological scaling. Now, I am not going to attempt to summarize the scientific premise behind their theory. I cite this example because the three researchers are in agreement; *their finding was made possible by collaborating across disciplines: a feat that required learning each other's "language."*

Dr. Michael Bennett is leading the CMT Research Survey and Evaluation Project. This project has several goals: to define the research "landscape," to identify the "significant lines of inquiry," and to determine areas for promising collaboration and research. The timing of the international conference and the initiation of the Survey and Evaluation Project, due in large measure to the vision of Bob Buuck, was especially fortuitous. Commenting on the value of the conference, Dr. Bennett saw it as *an important opportunity to establish relationships and modes of future communication and collaboration.*

The CMTA is uniquely positioned to play a leading role in the facilitation of dialogue and the creation of meaningful relationships that can influence the direction and results of CMT research. The Armington Challenge was a catalyst. The Third International Conference was a

"When collaborating across that wide a gulf of disciplines, you're never going to learn everything the collaborator knows. You have to develop an implicit trust in the quality of their science. On the other hand, you learn enough to be sure there are no miscommunications."

—Dr. Jim Brown, biologist from the University of New Mexico on collaborating with a physicist. New York Times, January 12, 1999

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powerful staring point. The CMT Research Survey and Evaluation Project is the "critical next step." There is a positive momentum building along with the coalescence of key players, resources, and exciting ideas. The CMTA must play a role in harnessing and directing the energy and "success potential" of this movement.

The CMTA can and must help bridge the gaps—geographic, interdisciplinary, and linguistic—separating CMT investigators. As was stated by Stephen Hawking in the Pink Floyd song, learning to talk "unleashed the power of our imagination." Relative to CMT research, I take that to mean, when the "right" people get together and can communicate effectively, anything is possible.

Are you up-to-date with your membership dues? Please see the important message about "Operations" on page 13.

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Members who are current with their dues are considered "active."
If you are unsure as to whether you are current with your member dues, please call the office at 1-800-606-CMTA.

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THIRD INTERNATIONAL CONFERENCE

(Continued from page 1)

excellent credentials, and an interest in and knowledge of CMT, but is also somewhat "detached" from direct CMT research. "Given Dr. Bennett's training and breadth of knowledge," said Dr. Robert Lovelace, CMTA Medical Advisory Board chairman, "we are very fortunate to have him leading this effort."

The great value in a project like this is that it will not only provide a CMT research survey but more importantly, a synthetic evaluation of the overall investigative effort—the report, and Dr. Bennett's insights, should be an excellent guide toward maximizing efficiency, suggesting new lines of inquiry, and proposing areas for collaboration.

"Making a compilation of CMT-related information available would be helpful to workers in the field," says Bennett, "but evaluation is valuable only insofar as it is correct and/or inspirational." Using his extensive neuroscience background and recent participation in the Third International Conference as a framework for inquiry, Dr. Bennett also will solicit commentary from leading investigators as part of his evaluation of research directions.

The Survey and Evaluation Project is an important follow-up to the Third International Conference on CMT Disorders in that it will provide a critical analysis not only of individual research focus, but more importantly, of the wide spectrum of efforts and how they relate to one another.

OF INTEREST

From NORD On-Line Bulletin

In a paper published in the November/December issue of *Genetics in Medicine,* Dr. Susan Hayflick reported that primary care physicians rarely refer patients for genetic counseling. Dr. Hayflick surveyed 1,642 primary care physicians in the northwest and found that internists were less likely to refer than pediatricians and obstetricians. Older doctors referred less often than younger doctors. The author feels that physicians' traditional view of geneticists is that they treat "only patients with rare and esoteric disorders" and that "primary care physicians need genetics education now."

Fostering Collaboration

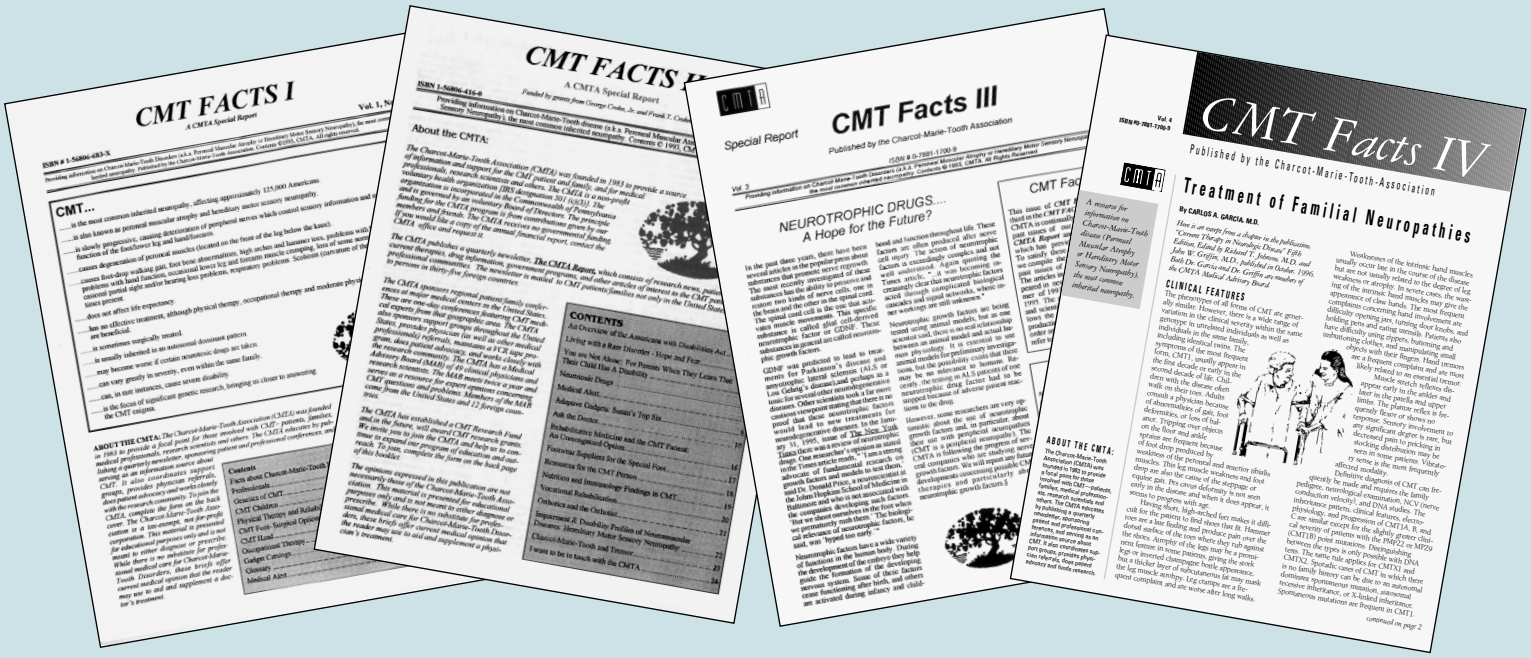
The CMTA is indeed fortunate to be working with Dr. Michael Bennett, who is leading the CMT Research Survey and Evaluation Project. Dr. Bennett earned his B.S. in Zoology from Yale University, achieving honors with exceptional distinction. After earning his doctorate in Physiology from Oxford University, Bennett did research work at Columbia University for ten years. In 1967, he joined the faculty of Albert Einstein College of Medicine and became a Professor of Neuroscience in 1974. Dr. Bennett served as chairman of the Department of Neuroscience at the College for 14 years and is currently the Sylvia and Robert S. Olnick Professor of Neuroscience.

Dr. Bennett has received numerous scholarships, fellowships and honors, among them Phi Beta Kappa, a Rhodes Scholarship and an election to the National Academy of Sciences. From 1958-60, Bennett served as a fellow of the National Neurological Research Foundation and from 1960-62 worked as a Senior Research Fellow at the National Institutes of Health. Dr. Bennett is widely published (more than 250 publications) and maintains memberships in several scientific societies, including the American Physiological Society, the American Society for Cell Biology, the Biophysical Society, and the Society for General Physiology and the Society for Neuroscience. He served in editorial positions with *Brain Research* (ongoing), *Journal of Cell Biology, Journal of Neurobiology, Journal of Neurocytology,* and the *Journal of Neuroscience*.

At the Third International Conference, Dr. Bennett participated actively in discussions and viewed the meeting as an important element in the process of fostering research collaboration. He was particularly impressed by the collaborative model developed by featured presenter Dr. Christine Van Broeckhoven, University of Antwerp, Belgium, and her colleagues in the European CMT Consortium. In his application for the Survey and Evaluation Project, Dr. Bennett expressed ideas and approaches that strongly resonated with the selection committee. The following section was reprinted from Dr. Bennett's application.

A model for collaboration in clinical research has been the Huntington's Disease consortium. This extraordinary collaboration may have resulted largely in response to charismatic leadership in the Huntington's Disease Foundation. Science is both competitive and collaborative. Scientists are driven by their desire to excel, for which they are rewarded, as well as by their desire for knowledge and understanding. Although competition is not really virtuous, it, like free enterprise, is a powerful motivator.

Nevertheless, science, like society, is in its essence a collaboration with rules and interdependence. Scientists trust and rely on each other; replication is the gold standard of validation, yet too much replication is a waste of effort and other resources. Openness in revealing ongoing research requires trust. At meetings such as the upcoming Conference (held in Canada on October 21-24, 1998), we hope to inform and to learn from others and to generate new ideas about their and our ongoing work.



Special Offer: Get All The Facts...

For the first time, you can get the entire *CMT Facts* Series (I, II, III, and IV) for the low price of $16.00, plus $3.00 for shipping and handling (see the order form on page 3). **This is a special offer being made to "active" dues-paying members of the CMTA.** Please see the important notice regarding membership on page 13.

Purchased separately, the *CMT Facts* Series would cost $21.00 for active members—that's a $5.00 savings for the whole set. Please note, only Facts I and II are available in Spanish.

Do you already have one or two issues in the series? Why not buy the full set and share those you already have with family members? You might consider giving a set to your doctors or making the series available to a local clinic or library to help raise awareness about CMT disorders.

The newest to the series, *Facts IV* is 32 pages in length with six different subject areas including: Medical Information and Research, CMT Survey Results, Living with CMT, Children and CMT, Legal Information, and Q&A.

CMT Facts I

- The genetics of CMT: An overview of the various types of CMT, demyelinating or axonal
- CMT foot-surgical options: Tendon transfers, osteotomies, and arthrodesis
- CMT hand: Splinting, surgical procedures and carpal tunnel syndrome
- Children and CMT: Questions and answers with Dr. Harold Marks
- Occupational therapy and CMT: Assessment, exercise, adaptive equipment

CMT Facts II

- Susan's top six adaptive gadgets…with photos
- Orthotics overview: For those considering braces/ ankle-foot orthoses
- You are not alone: For parents when they learn their child has a disability
- Rehabilitative medicine: How the physiatrist can help you
- Charcot-Marie-Tooth disorder and tremor
- Neurotoxic drugs: A review of what the drugs are and what they are prescribed for

CMT Facts III

- An overview of neuromuscular disease and where CMT fits in the picture
- Identification of the CMTX gene
- CMT and pregnancy: A survey of the effects of pregnancy on women with CMT
- Exercise and sports for children with neuromuscular diseases
- CMT hand surgery options: A discussion of typical surgeries with drawings
- Ask the doctor: 6 pages of questions answered by the CMT medical experts

CMT Facts IV

- Treatment of familial neuropathies
- Phrenic nerves and pulmonary function in CMT disease
- The CMT disability survey
- An orthotics survey of CMT patients
- Managing pain in CMT disorders
- Orthopaedic considerations for children with CMT
- SSI information and the Americans with Disabilities Act
- Shriners Hospitals for Children: "World's Greatest Philanthropy"

HNPP and CMT: Different, yet very

OF INTEREST

AMA and Court Take Stand on Herbs and Supplements

The American Medical Association (AMA) has decided to ask Congress to permit the FDA to regulate herbal remedies and dietary supplements by amending the Dietary Supplement Health and Education Act (DSHEA). The federal law prevents the FDA from regulating these products, and the agency can only act after it is shown that a product is a threat to public health.

The AMA House of Delegates said that there is no way for physicians to know what is in these products because they are not tested to prove safety and effectiveness and there are no manufacturing standards assuring that every pill contains the exact amount of ingredients that it is supposed to. Patients often neglect to tell their physicians that they are taking supplements, primarily because they believe that such products are harmless.

In the Summer of 1997, I had yet to meet anyone outside my family with HNPP. So when I spoke to a CMTA board member, I could only speak from my own family's experiences. We compared symptoms of the two diseases and they seemed so different. One was permanent; one was intermittent. One had physical deformities; one didn't. But we both shared many of the same issues regarding doctors, families, etc.

Since that discussion, I have learned more, met others, and had my own disease progress. Although differences remain between the two genetic mirror-image disorders, we have more in common than I once thought.

Genetics: CMT1A is caused by a duplication and HNPP a deletion at the same gene site. Both are autosomal dominant. In both disorders, there is a 50% chance of an affected child with each birth, regardless of the number of children.

Variability: Both disorders have extreme variability in symptoms, even within the same family.

Progression: Generally, both are slowly progressive disorders. A more rapid progression is possible in both disorders. Why this happens is still unknown.

Onset: CMT tends to begin in childhood or early teens, while HNPP tends to begin in the late teens to early twenties.

Number of people affected: Individual physicians estimate approximately 90% of people with HNPP remain undiagnosed or misdiagnosed. It will be interesting to compare CMT and HNPP's numbers once HNPP is more reliably diagnosed.

Pressure palsies: These sporadic periods of numbness and weakness are what make HNPP distinctive from CMT. They are caused by pressure or stretch on the nerves or repetitive use. Pressure palsies are generally not associated with CMT, although people with CMT may have carpal tunnel and other entrapment neuropathies which resemble pressure palsies.

Severity: CMT is generally considered a more severe disorder than HNPP, although both can have mild and severe cases.

Both HNPP and CMT share many of the same characteristics.

Doctors: For both groups, the most knowledgeable doctors are found at the larger teaching hospitals or universities. In the general community, outside these universities, most neurologists have at least heard of CMT, but few know about HNPP. This is because HNPP is, or was, considered a rare disorder, and it is only recently that more has been learned about it.

Diagnosis: The diagnosis for both CMT1A and HNPP can be confirmed by a blood test. Because these disorders are genetically opposite, one test can be done for both. If the test comes back positive for one, the other is automatically eliminated. One cannot have both CMT1A and HNPP.

PLEASE NOTE: In comparing symptoms below, it would be approximately the most severe 10%-20% of cases with HNPP who would most closely resemble those with CMT.

Foot deformities: This is typical of CMT with a high-arched foot, hammer toes, etc. Some people with HNPP (especially those with the polyneuropathy type of HNPP which resembles CMT) also have high arches and hammer toes.

Foot drop: This can happen in both disorders and is common in CMT. In HNPP, foot drop would be more likely to be intermittent at first and associated with pressure palsies in the leg. Permanent foot drop would more likely develop, if at all, as the disorder progresses.

Leg weakness: Can occur in both disorders. CMT usually shows muscle atrophy in the lower legs, giving the stork-like appearance to the leg. This is much less common in HNPP

Fatigue: Can be a problem for both.

Pain, muscle aches, and cramps: Pain may occur in both disorders but it is usually not "neuropathic" pain in HNPP. Cramps are frequent, most often in the limbs (legs and arms) and are produced by overuse of weak muscles. Low back pain is frequent and is due to the

similar

strain produced by the weak leg muscles and overuse of the paraspinous and back muscles. Back pain is frequently relieved by AFOs. Although it is not common, "neuropathic" pain definitely does occur in a portion of patients. It consists of aching, burning, and shooting pain in the distribution of affected nerves.

Hands and arms: In late stages, there may be severe hand deformities in CMT. In HNPP carpal tunnel syndrome is very common. HNPP also may have elbow and shoulder involvement. Function and sensation may be affected in both HNPP and CMT.

Surgery: Multiple surgeries are available to the person with CMT should they be needed. It is advised that those with HNPP only have carpal tunnel surgery once (if needed) and other nerve surgeries be avoided, owing to the possibility of further damaging the nerves.

Bracing: Shoe inserts and AFOs may be prescribed for both disorders, although the need is much more common in CMT.

PT/OT: Both can use physical therapy and/or occupational therapy to help with exercises and adapting activities of daily living.

Balance: Both disorders can have balance problems.

Emotional adjustments: CMT and HNPP may be benign disorders if the patients are asymptomatic (i.e. have few or no symptoms). These disorders do not shorten the life span and do not affect intellectual functions. However, both disorders can be very disabling for some people.

Work issues: Working or not working can be an issue for both. Because of the potential damage from repetitive use, those with HNPP need to be especially cognizant of work site adaptations such as ergonomic work stations.

Prevention: Prevention is the main issue in HNPP and not in CMT. People with HNPP should avoid pressure to superficial nerves at the inner side of the elbows, the carpal tunnel at the wrist, and the peroneal groove in the legs. Use of pads in pressure areas and avoidance of certain positions is very important.

Lupski and Warner Published in *Neuron*

A paper written by Laura Warner, a pre-doctoral student, and Dr. James R. Lupski of the Baylor College of Medicine in Houston (a member of the CMTA's Medical Advisory Board) was published in the September issue of the journal *Neuron*. The paper reported that the scientists had seen, at the molecular level, the damage to an important protein that is the cause of several genetic nerve disorders. Using a technique known as X-ray crystallography, researchers were able to pinpoint how the atoms in one molecule of a very important protein attach (or don't attach when the gene is flawed) to the atoms of another molecule of the protein. They describe how that damage can lead to effects ranging from numbness and stumbling to crippling and death.

At the center of the three disorders is the white sheath, called myelin, which wraps around the nerves outside the brain and spinal cord. Myelin is the crucial element in the bodies of all large animals which enables nerve signals to move over distances of inches and feet from the spinal cord to the hands and feet. In this study, the key to the myelin breakdown is a protein called P_0 that is the chief structural element in myelin. When the gene for P_0 is defective, the myelin cannot wrap around the nerve and may break down altogether.

The Baylor scientists described five new mutations in the P_0 gene and how they disable the P_0 protein. Levels of damage to nerve function determine which of three disorders a patient has: Charcot-Marie-Tooth syndrome, Dejerine-Sottas syndrome, or hypomyelination. When the nerve signals fail, muscles cannot respond and they become numb. In the mildest cases, the neuropathy that results can cause numbness in the hands and feet and some clumsiness. In the most severe cases, crippling can result and infants can die when the muscles of the diaphragm are unable to support breathing (which is the case in hypomyelination).

The most common and mildest of the three disorders is Charcot-Marie-Tooth, which occurs in about 150,000 people in the United States. About 40% of CMT patients have the mutations described in this new paper. The effects of CMT often occur in the mid-20's, as the failure of the nerves to send signals causes a wasting of the calf muscles. Patients walk on the outside edges of their feet, causing sprained ankles and frequent falls. As the disease progresses, the patients develop a walking pattern in which they lift the foot from the knee, which can cause back problems and makes climbing stairs very difficult. Later, numbness sets in and the hands can become affected.

Dejerine-Sottas syndrome results from a more severe loss of muscle control. It is usually seen in the first two years of life and delays normal milestones, such as walking. As the disease progresses, it leads to complete crippling. Patients may die of related causes such as a failure of the diaphragm muscles to keep the patient breathing through a bout with pneumonia.

Congenital hypomyelination is the rarest and most severe of these disorders, often resulting in death in the first few weeks of life. No myelin wraps the nerves at all, and the nerves that control breathing fail.

Work on these disorders might lead to treatments in which defective proteins would be replaced through gene therapy or managed through drugs. Such treatments, though, are believed to be a decade or more away.

CMTA Plans to Publish Cookbook

If you like to eat or like to cook, you can definitely contribute to, and benefit from, this fundraiser currently in the planning stages. The CMTA hopes to publish a cookbook containing recipes from our members representing all the regions of the United States. Contributions from foreign members will be encouraged, as well.

This is one fundraiser that everyone can be part of. We hope to solicit drawings from children to decorate the divider pages of the book. Artists' renderings of food or meals will make each section unique, and each piece of art will be signed by the young artist. We hope each of our readers will send a favorite recipe to the office, signed and listing the city and state from which the recipe comes. Family favorites are always appreciated. If we receive enough to fill a section, we will also feature recipes from men and favorites of children who cook.

In addition to the solicitation of recipes, we are looking for a few volunteers who would be willing to work more directly with the office in organizing the recipes, checking for duplicates and reviewing recipes to see that all ingredients are included. (You'd be surprised how many recipes for beef stew don't include beef—a fairly obvious omission.) We also need some volunteers to sell books. We will rely on our support groups to spearhead that task, but individuals who can take books to the office and sell at least 20 books are definitely needed. (The price will not be known until closer to printing time.) This is one fundraising effort that almost anyone should be able to support and we are hoping that it will serve to involve some of our membership who have previously not been part of our efforts.

The contact person in the office is Pat Dreibelbis, Director of Program Services. Having worked on the compilation of cookbooks for her PTO and her church, she is enthusiastic about the "fun" that this fundraiser can create and the opportunity to get more great recipes to try out on her family and friends. Desserts are always in ample supply, so get creative and send your favorite appetizer, main dish, or vegetable. Any good ideas for barbecue recipes would be appreciated, too. Since Paul Flynn stands to be one of the major "taste-testers," he is anxious and ready for the recipes to begin arriving!

Who are these people and what are they smiling about? Paul Flynn (who has grown a beard since page 1), Executive Director and Georgette Farr, Administrative Assistant, are about to enjoy sour cream coffee cake; its tempting recipe is included here to stimulate interest (and salivary glands) about the upcoming fundraiser cookbook.

SOUR CREAM COFFEE CAKE

Preparing: 20 minutes *Baking:* 50-60 minutes

Nut topping:
1 cup chopped pecans
4 teaspoons sugar
1 teaspoon cinnamon

Mix topping ingredients.

Batter:
1 cup butter or margarine, room temperature
2 cups sugar
2 eggs
1 cup sour cream
1 teaspoon vanilla
2 cups flour
1 1/2 teaspoons baking powder
1/4 teaspoon salt

Preheat oven to 350 degrees F. Grease and flour a bundt or tube pan. Cream butter and sugar until light and fluffy. Add eggs, 1 at a time. Fold in sour cream and vanilla. Sift together flour, baking powder and salt and add to the butter mixture. Place less than 1/2 of the batter in the pan. Sprinkle with 1/2 of the nut topping. Add another layer of batter and another laying of topping. Finish with remaining batter. Bake 50 to 60 minutes. Let set 5 minutes. Remove from pan.

—Pat Dreibelbis

Editor's note: This is a guaranteed crowd pleaser and an almost brainless "make from scratch" hit. My reputation as a great baker has been enhanced by good recipes like this one…which really aren't difficult at all. Give this recipe to new brides, as I do, for their first cookbook.

GIFTS WERE MADE TO THE CMTA IN HONOR OF:

Betrothal of Meredith and Steven
Rebecca Brezel

Charles Bergmann
Sarah Bergmann

Gordon Bradwick
Karol Hitt

Cathy Brooks
Kenneth and Janice Dunham

Stephanie DiCara
See page 12.

Carol and Stuart Feen
Vivian and Michael Feen

Paul R. Flynn
Arla M. Van Almen

Henry Friedmann's 75th Birthday
Agnes Aronsohn

Megan Knuth
1998 Ashford Blast for Charity

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Hillard Nick Tripp
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A gift was made in memory of the following individuals by Kay Conlee:
Gene Buffaloe
Fred Campbell
Laura Crimm
Doris Eckenroth
Mae Lawhon
Mrs. Longwood
Noel McGinness
"Bo" Miller
Carl Oates
Hershel Orr
J. Effie Reeves
John Sargent
Thomas Lee Williams

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, 601 Upland Ave., Upland, PA 19015.

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:_____

_____

OF INTEREST

Do you work for Kodak or one of the national drug store chains? We are looking for contributions of disposable cameras to help us with the publication of the newsletter. The cameras are invaluable for taking pictures at conferences, fundraisers, and support group meetings. If you don't work where cameras are manufactured or sold, would you be interested in contributing to their purchase? You can direct a contribution to the office with the notation that it is to help with the purchase of cameras. Thank you!

Book Review

By William Schenck

Charcot: Constructing Neurology
Christopher Goetz, Michel Bonduelle, and Toby Gelfand
Oxford University Press, 1995, $55

Those of us with CMT are used to unusual reactions when we name the disease, but few of us know much about J. M. Charcot, the man who named our disease. Jean-Martin Charcot was born in Paris in 1825, the city where, with the exceptions of his travels, he spent his entire medical career. From 1862 until his death in 1893, he was associated with the Salpetriere, a Paris hospital which, under his direction, became the international center, or in the author's words, "the Mecca" of neurological study, teaching, and when possible, treatment.

It isn't clear why he began to specialize in neurology, but by his death, Charcot was an international figure in neurology and one of the founders of modern neurology. He wrote over 700 articles; his collected works fill eleven volumes. His medical lectures at the Salpetriere were so popular that not only medical students, but patients, international visitors, even journalists and artists attended. Charcot was a commanding, even a domineering, personality. His knowledge and teaching guided neurological study during and after his lifetime through the students he trained.

It is difficult to convey his achievements, as he didn't cure diseases, but rather discovered and treated them. This book explains the almost primitive state of medical care and knowledge before Charcot and shows its progress under Charcot (and others) during the second half of the nineteenth century.

CMT itself receives little mention in the book since it was only one of many disorders that Charcot diagnosed. "Charcot studied neuropathic causes of atrophy and collaborated with his student Pierre Marie to provide a description of peroneal muscular atrophy. Since the disorder was also described in the same year (1886) by Howard Tooth in London, the disorder became known as Charcot-Marie-Tooth disease." He is more famous for his work with ALS (known here as "Lou Gehrig's disease" but called "Charcot's disease" in Europe.)

This book is a medical history whose primary audience is the medical professional. I, as a layperson, sometimes found myself out of my depth. And I would have liked the book to have included more details about Charcot as a person, but as he left no diaries and few personal items, these omissions are not the authors' fault.

While I wouldn't recommend that every CMT patient run out and buy this book, I enjoyed learning more about the man who named my disease.

William Schenck has been a member of the CMTA since 1994. He lives in Falls Church, VA.

Missing Members

Newsletters could not be sent to the CMTA members listed below because no forwarding address was available. Do you know how to get in touch with these "lost members?" If so, please have them contact the CMTA to update their records. Thank you.

AA, FPO
E. S., 34052

Alabama
W. F., Birmingham

Arizona
J. N., Phoenix
L. M., Scottsdale

California
M. M., Carnelian Bay
G. N., El Cajon
W. M., Sunnyvale

Connecticut
A. S., Stamford
C. K., Stratford

Florida
A. D., Daytona Beach
L. A., Delray Beach

Georgia
J. W., Peach Tree

Illinois
G. F., Champaign

Indiana
D. J., Indianapolis

Iowa
D. L., Cedar Rapids

Kansas
R. G., Wichita

Maryland
D. K., Baltimore

Michigan
T. E., Southfield

Mississippi
M. F., Jackson

Missouri
E. H., Springfield

New Jersey
H. T., Freehold

New York
J. G., Westhampton Beach

Oklahoma
S. M., Miami

Oregon
A. C., Corvallis

Pennsylvania
C. W., Philadelphia

South Carolina
K. M., Blacksburg
K. H., Charleston

Tennessee
J. J., Kingsport

Texas
C. B., Austin

Virginia
S. M., Richmond
T. J., SE Roanoke

Wisconsin
R. S., Appleton
J. H., Fond Du Lac

Above and Beyond

A feature of The CMTA Report *that highlights the outstanding volunteer commitment of a CMTA member.*

By Paul R. Flynn, Executive Director

What's the "Buzz" all about? Buzz is a whirlwind of positive energy and great ideas. Buzz is an avid learner and educator.

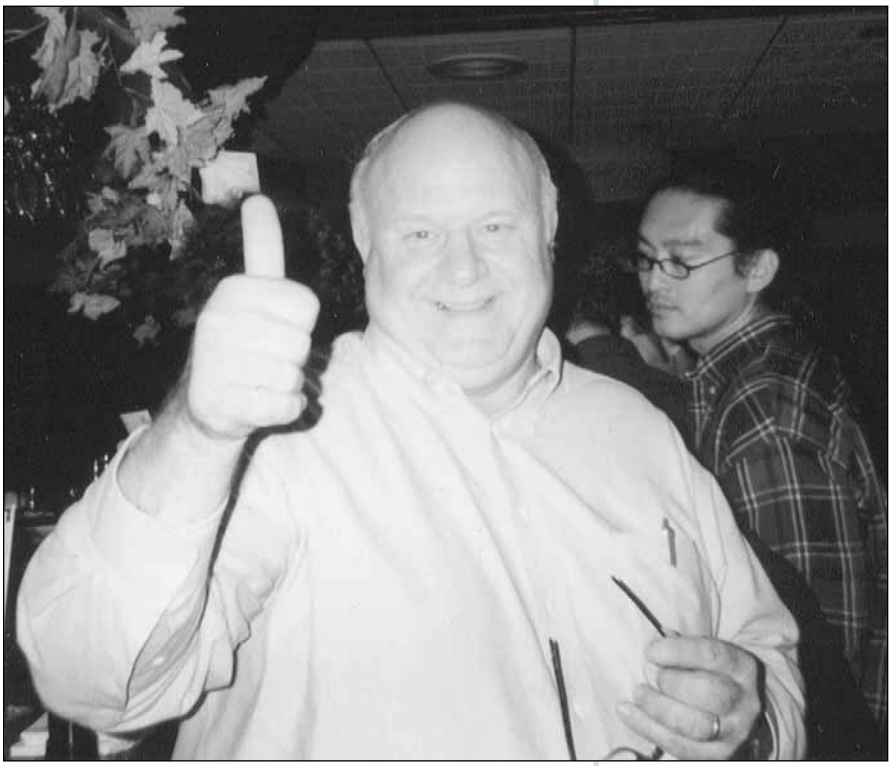
Buzz is a visionary and a videographer. Buzz is motivated and a motivator. Who's Buzz you ask? Richard "Buzz" Van Almen, CMTA member, volunteer, and friend.

I met Buzz at the Wayne State University patient-family conference in October of 1997, where he videotaped the entire proceedings. Much of his footage was used for the tapes that were later created for the CMTA library. No one asked Buzz to do this: he realized it was a great opportunity to capture important presentations and was pleased to be of service. Education is Buzz's vocation; video production became his avocation.

We stayed in touch after that conference because Buzz wanted to keep involved. When he heard about plans for the Third International Conference, he saw another opportunity…

Of course the CMTA would want to tape the meeting. We could not afford to let pass this historic gathering without archival footage nor could we afford to pay someone to do videotaping. Buzz volunteered again. It was a marathon program devised by Dr. Michael Shy; speakers scheduled from breakfast through after dinner, with special interviews planned during the breaks. But there were no breaks for Buzz. I know because I was his roommate during the conference. He was awake before me and sometimes went to bed after me (but that was partially because I wanted to be asleep before the "buzz saw" started!).

Before the Conference, Buzz realized that his balance and gait were deteriorating and that ankle foot orthoses (AFO's) would be necessary. His greatest concern was that he become acclimated to the new braces in time for the meeting so he could reliably maneuver about for filming and have enough endurance. Those must be miracle AFO's because he never slowed down!!



For Richard "Buzz" Van Almen, it was all systems go and "action, action, action" at the Third International Conference on CMT Disorders.

While he was being fitted for the AFO's, he was intrigued by the process. He saw the experience as a wonderful learning opportunity and, more importantly, perhaps a teaching opportunity as well if he could later videotape the process, start to finish. Buzz knows that many people are reluctant to try AFO's but might do so if they better understood the benefits. From Buzz's perspective, video is not just for instructional or informational content but also for the purpose of "demystifying the unknown."

The willingness to give and be of service is a Van Almen family trait. Buzz's wife Sandy (aka "Bamavan") graciously hosted me for an overnight stay on a trip to Detroit. Buzz's middle son Marty did the same when I traveled out to Chicago on CMTA business. Come to think of it Buzz's other sons, Rick and Scott, live in Arizona and Ohio respectively. Hmmm, where's that number for my travel agent?

Outpouring in Honor of Stephanie DiCara

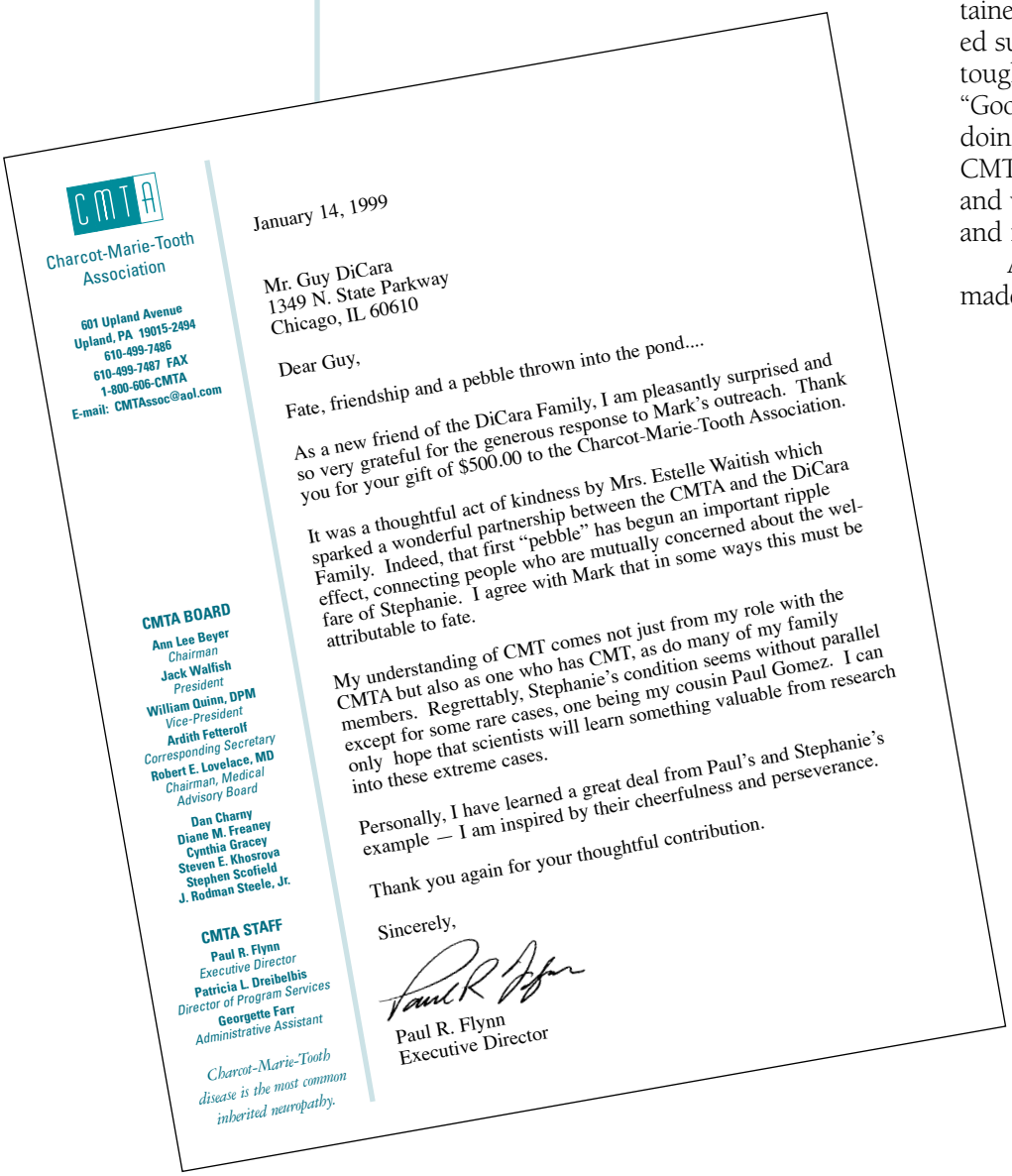
Members should recall the touching story of Stephanie DiCara, first printed in the fall issue of the newsletter. Stephanie's dad Mark is an attorney in a suburb of Chicago. Mark's friend and client, Mrs. Estelle Waitish, made a very generous gift to the CMTA in honor of Stephanie, who has a rare and very severe form of CMT. This thoughtful and completely spontaneous act by Mrs. Waitish made Mark realize that others of his clients and friends might be supportive of "Stephanie's Cause" as well, if asked.

Mark drafted a compelling and heartfelt letter which he sent to several dozen, as he puts it, "friends who happen to be clients." In addition to recounting the "diagnostic odyssey" which took him to numerous doctors and finally the Mayo Clinic for confirmation of Stephanie's CMT, Mark shared a powerful analogy in his appeal for support. "You see," he said, "people like Christopher Reeves or Michael J. Fox do not have CMT, therefore, Estelle and Stephanie's story was an example of connecting unaffected people to this obscure disease."

As Mark noted, "Mrs. Waitish's 'pebble thrown into the pond' has resulted in a tidal wave for Stephanie." The generous outpouring was immediate and remarkable—roughly 40 people have given contributions totalling more than $9,500. Notes accompanying the gifts contained remarks like, "Stephanie's dad has provided such comfort and assurance to me during tough times… this was the least I could do," and "Good luck with the important work you're doing, I wish I could do more to help…" The CMTA is indeed engaged in very important work and we are so very grateful to the DiCara's friends and family for their generous support.

As of January 29, 1999, the following people made gifts in honor of Stephanie:

Anonymous
Carl A. Abbate
James J. Aiello
Frank Albachiaro
Jack Anderson
Fred I. Broberg
Robert L. Bruns
Ludwig A. Coco
Thomas C. Corrigan
John R. Dawson
Guy M. DiCara
Mary & Sam DiCara
Lorraine B. Dusek
Wilbur S. Edwards
Ellen and Bradley Falkof
Judith A. & William J. Fouty
Gerry A. Goldman
Michael A. Goldman
Sandra A. Hasse
Charles A. Hempfling
Huber Electric, Ltd.
Genevieve E. Huck
John J. Keller
Joseph W. Koss
Nicholas P. Kyros
Robert Lasecki
Patricia J. Leverick
William B. Matt
Warren Nicholas, Jr.
Warren A. Nicholas, III
James Nuzzo
Kenneth I. O'Callaghan
Irving G. Pfaff
Thomas J. Pyziak
U.S. Refrigeration
Steve Richie
Janet B. Schoettler
Grace Schurecht
Dr. and Mrs. Daniel Schwartz
Valerie & Randall Seiler
Jacqueline K. Snavely
Audrey E. Veath
Estelle R. Waitish
Martin R. Wolf
David A. Wurzbach



CMTA
Charcot-Marie-Tooth Association

601 Upland Avenue
Upland, PA 19015-2494
610-499-7486
610-499-7487 FAX
1-800-606-CMTA
E-mail: CMTAssoc@aol.com

January 14, 1999

Mr. Guy DiCara
1349 N. State Parkway
Chicago, IL 60610

Dear Guy,

Fate, friendship and a pebble thrown into the pond....

As a new friend of the DiCara Family, I am pleasantly surprised and so very grateful for the generous response to Mark's outreach. Thank you for your gift of $500.00 to the Charcot-Marie-Tooth Association.

It was a thoughtful act of kindness by Mrs. Estelle Waitish which sparked a wonderful partnership between the CMTA and the DiCara Family. Indeed, that first "pebble" has begun an important ripple effect, connecting people who are mutually concerned about the welfare of Stephanie. I agree with Mark that in some ways this must be attributable to fate.

My understanding of CMT comes not just from my role with the CMTA but also as one who has CMT, as do many of my family members. Regrettably, Stephanie's condition seems without parallel except for some rare cases, one being my cousin Paul Gomez. I can only hope that scientists will learn something valuable from research into these extreme cases.

Personally, I have learned a great deal from Paul's and Stephanie's example — I am inspired by their cheerfulness and perseverance.

Thank you again for your thoughtful contribution.

Sincerely,

Paul R. Flynn
Executive Director

CMTA BOARD
Ann Lee Beyer, Chairman
Jack Walfish, President
William Quinn, DPM, Vice-President
Ardith Fetterolf, Corresponding Secretary
Robert E. Lovelace, MD, Chairman, Medical Advisory Board
Dan Charny
Diane M. Freaney
Cynthia Gracey
Steven E. Khosrova
Stephen Scofield
J. Rodman Steele, Jr.

CMTA STAFF
Paul R. Flynn, Executive Director
Patricia L. Dreibelbis, Director of Program Services
Georgette Farr, Administrative Assistant

Charcot-Marie-Tooth disease is the most common inherited neuropathy.

Most People Don't Like to Hear About Operations...

As someone with CMT who's had three operations, I know the feeling. In this case though, I am talking about "office operations," specifically, the functions of the CMTA and our operating funds. Most people do not realize that this membership organization is like a small business, requiring a steady revenue stream to maintain its operations and serve you.

I am reminded of a statement made by a work-study student from my previous job at Seton Hall University Law School, "…what do they think we live on, love and fresh air??" If only that were possible.

The number of dues-paying members and/or donors in general who contribute unrestricted operating dollars to the CMTA is not keeping pace with our growth and expenses. Add to this a lackluster response from the recent Annual Appeal and a postal rate increase and what we find is that the CMTA cannot afford to conduct business as usual.

For some, there have been at least three months between this and their last newsletter. That's because we were unable to mail the December issue to nearly 7,000 of the 13,000 people on the mailing list. **Regrettably, we can no longer provide *The CMTA Report* to those members who are not in some way financially supporting the organization.**

There are exceptions. A small number of members contact us detailing their inability to pay dues (be it a matter of living on social security disability or simply modest means), and we will continue to send the newsletter gratis. If you qualify for this arrangement, please notify me of this in writing as we would happily include you within this policy.

Additionally, if you support the CMTA exclusively through the CFC/ ICA or other workplace campaign (which maintains anonymity), please notify us of this as well.

Certainly, this is not the type of message I looked forward to sharing, but necessity dictates that I do so. If you have not sent your member dues but do so in response to this appeal, we will gladly send you the newsletter you missed. Please take the time to send your $35 today. Thank you.

Paul R. Flynn
Executive Director

URGENT!
MEMBERSHIP RENEWAL REQUESTED

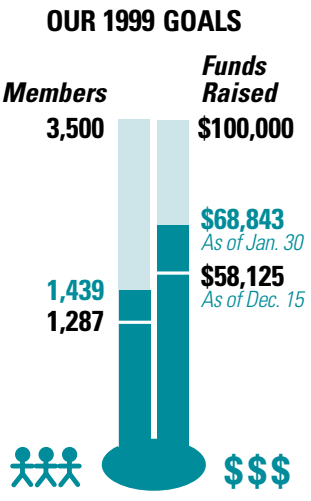
Does the back cover of your newsletter have the above imprint? If so, please read the "Operations" letter on this page to find out how you can continue to receive The CMTA Report.

How We're Doing

There is strength in numbers, if we all do our part. That was the message of the Membership Appeal back in July. Though the giving response is ahead of last year, we must do better still.

We must convert the expansion in our membership numbers into demonstrable strength. That begins with greater financial support through membership dues.

Organizational effectiveness or "clout" derives in part from sheer numbers. Ultimately, all members will benefit from the CMTA's growing ranks, but this presupposes a corresponding growth in financial support. If you have not done so already, please help the CMTA flex its muscle: ***DUE your part, today!***



A Journey Toward Wellness, Part V: *"Self-basting"*

By CYNTHIA GRACEY

"Healing is simply attempting to do more of those things that bring joy into your life."

—O. Carl Simonton

I have a friend who refers to the ability to care for one's self as being "self-basting," just like some of those turkeys or chickens that are processed to baste themselves as they cook. I love the phrase, as it reminds me, with a touch of humor, that if a turkey in the oven can take care of itself, why not me?

One of the best ways to increase the experience of well-being and energy available to us is to make the time to take care of ourselves. Many of us spend most of our waking hours taking care of business, others, our jobs, our homes, and the seemingly endless list of important responsibilities that fill our days. Even in sleep, we can be so preoccupied with all our "busyness" that deep, revitalizing rest remains elusive. The result is that we pay a very clear price in our physical well-being.

So, what are some simple ways that you can nurture yourself? What acts of kindness, relaxation, or gifts of fun do you—or could you—bestow upon yourself? Perhaps a massage, an afternoon stretched out with a good book, a ski weekend, a yoga class, time spent daydreaming, an early morning walk alone in some beautiful natural setting, a babysitter who will take the children out so you can enjoy the privacy of your own home, or an evening in the company of a friend. All can be delightful ways to "recharge." If possible, consider taking a whole day for yourself, perhaps at a beach, the mountains, the desert, a park, or a spa. Or, maybe you can create the time for a weekend at a retreat once or twice a year as a way to reflect and gather energy.

In order to maintain a high level of health and vitality and to restore my energy, I have learned that I need a certain amount of solitude in my home. This need goes back to childhood. I can remember growing up in a household where there were periodic violent alcoholic outbursts. I can vividly recall how my whole nervous system would seem to be on a hypervigilant reactive mode for days. But if I could get time alone in my house (my room was not enough because I needed to know that no one could violate my solitude), I could begin to reorganize my internal energies. To this day, I structure time alone in my home each day. Weekends, when most people relax and recharge, can be my most stressful days of the week, as they are filled with my boys, my husband, and friends—all good and wonderful pleasures in my life, but which rarely leave me with a moment alone in my home.

Alexandra Stoddard in the book *Embracing Our Essence* talks about the concept of "time tithing." She "urge[s] everyone to time tithe 10% of their daily lives—which is really only about 9 hours a week for the waking hours—and use that time for contemplation." (p. 108) You might consider the equally potent question of "When was the last time you took nine hours a week just to nurture and energize yourself?" Nine hours a week breaks down to a little more than an hour each day. If that seems like too much, even 10 to 15 minutes each morning and evening can be a start.

When large blocks of time are not available, it is still possible to nurture ourselves by weaving art, music, and simple rituals into our daily lives to refresh and inspire us. Even doing the dishes can seem less of a chore when we play music that soothes or energizes us, depending on our mood.

I have found that the simple act of lighting scented candles during the day energizes me. So does going outside and pruning a bush in my garden or walking around my house and feeling the sunshine on my back. These are simple energizers and yet so potent.

My writing partner Minx is not normally the country-western "type." But when she cooks, that is precisely the music that energizes and keeps her going as she makes lengthy preparations for elaborate meals.

It is also possible to create a sanctuary or retreat in a garden or a corner of a room where you can go and surround yourself with tranquility. By doing so you create the possibility of bringing yourself back to center and therefore establishing a more natural conduit for energy.

When we are off center, our lack of internal alignment makes it difficult for energy to flow

OF INTEREST

The Web site of the duPont Hospital for Children and The Nemours Foundation, KidsHealth.org, is one of the largest and most visited sites in the US for expert information about children's health. With special areas for kids as well as parents, and lots of fun features and interactive learning, it's no wonder KidsHealth has won almost every major online award and is logging several million hits a month. Check it out at http://KidsHealth.org

freely through us. To get back to a centered place may be as simple as connecting with a few precious objects on your desk that remind you of who you are, where you are heading in life and what really matters. Pictures of loved ones, a visual image of a desired outcome, potpourri, candles, potted herbs or fresh flowers, a journal to write down thoughts and reflections—all these things can stimulate the restoration of vitality.

So, when you have a moment, list the things that energize, "feed," or really nourish you and that give you pleasure.

From whom do you get energy, nourishment, pleasure, or revitalization?

Circle or mark the things mentioned above that are especially energizing, nourishing, pleasing or revitalizing.

What are your five top sources of energy, nourishment, pleasure, and revitalization?

1. _____

2. _____

3. _____

4. _____

5. _____

How many do you access on a daily basis?

Any surprises? Any insights?

What other new possibilities for self-nurturing have you been wanting to try? Would you be willing to commit to trying at least one new way each month?

This article comes from a workbook entitled *More energy, simple practices* written by my writing partner Minx Boren and myself. Usually this workbook comes in conjunction with attending a workshop on how to generate more energy for healing or for the creative process.

Also, the complementary therapies workshop with the Upledger foundation will not be held until November. Please call the CMTA office and let them know of your interest and as the dates are finalized and the agenda set, we will contact you. Thank you all for your interest, your calls of acknowledgment and your desire to share your insights and journeys.

As always, I will be delighted to address any questions that you might have on any of the above. Send them to Cynthia Gracey, PATH Consulting, 1109 Harbor Drive, Delray Beach, FL 33483 or email me at pathcg@aol.com

The Power of the Press

The Taylor family of Weaubleau, Missouri, read Dr. Paul Donohue's column (medical questions and answers) in an issue of Capper's Weekly and discovered that the "foot problems" that had plagued James Taylor for years probably had a name—CMT. The family, after calling the CMTA for information, were directed to the Golihar Shoe Store in Versailles, MO, where the Clarks, certified pedorthists, make special shoes for many people with CMT. The family posed in the shoe store after James was seen and fitted with shoes and orthotics. Several members of the family have the typical CMT high arch and hammer toes.

Pictured left to right: Wynetta Taylor (holding Tara), Tammie (holding Holly), James Taylor and, in the back, Buck, holding his son, Cole.

Charcot-Marie-Tooth: The "Cajun" Crippler

An article about the prevalence of Charcot-Marie-Tooth Disorder in southwestern Louisiana appeared in January 1999 in a Lake Charles, Louisiana, newspaper. The article recounts the high incidence of CMT in the population of that area, as noted by Dr. Carlos Garcia as early as the 1970's. He began finding the crippling disease in many families of Cajun descent, so he started getting groups of Acadians together to trace their ancestry. Because the disease often strikes multiple members of the same family and because families with Acadian backgrounds flourish in Southwestern Louisiana, there is thought to be an abnormally high percent of the population with CMT, many of the cases undiagnosed.

Medical Terminology Common in th

UPCOMING CONFERENCE

A conference on CMT disorders will be held at the Scottish Rite Hospital, Dallas, Texas, on Saturday May 15, 1999. Anyone who lives outside of the state of Texas and would like to receive a registration form, please call or write the office and leave your name and address. Registration forms will be available by the first week in April.

Editor's Note: Phone calls, e-mail questions and letters to the office frequently involve the misunderstanding of one or more terms that a doctor has used in describing the cause of CMT, the symptoms of the disorder, or the treatment. Here we offer a brief glossary of terms from the American Medical Association's Medical Encyclopedia that you are likely to encounter at some point in the management of your disorder. We suggest you keep this "dictionary of CMT terms" in your files for future reference.

Atrophy: Shrinkage or wasting away of a tissue or organ due to a reduction in its size. Atrophy is commonly caused by disease or immobilization. Nerve damage can cause muscle atrophy.

Balance: The ability to remain upright and move without falling over. Keeping one's balance is a complex process that relies on a constant flow of information about body position to the brain. Information about body position comes from three sources: the eyes, sensory nerves in the skin, muscles, and joints (called proprioceptors, which provide information about the position and movement of the different parts of the body), and the canals of the inner ear. (Editor's Note: A person with CMT lacks proprioception [defined below] because of sensory loss.)

Bilateral: Affecting both sides of the body.

Brace, orthopaedic: An appliance worn to support part of the body or hold it in a fixed position. A brace may also help the movement of a limb when movement would otherwise be impossible. For a person who has lost the ability to flex the foot upward and drags the toes on the ground with each step, they can be fitted with a device called a footdrop splint that keeps the foot permanently at right angles to the leg and thus allows walking.

Brachialgia: Pain or stiffness in the arm. It is often accompanied by pain, tingling, or numbness of the hands or fingers and weakness of hand grip.

Brachial plexus: A collection of nerves that pass from the lower part of the spine and the upper part of the thoracic spine down the arm. This collection of nerves controls the muscles in, and receives stimulation from, the arm and hand.

Calcaneus: The heel bone. The Achilles tendon is fixed to the back of the heel bone and controls the up and down movement of the foot.

Central nervous system: The anatomical term for the brain and spinal cord, often abbreviated CNS. The central nervous system works in tandem with the peripheral nervous system (PNS), which consists of all the nerves that carry signals between the CNS and the rest of the body.

Chromosomes: Threadlike structures present within the nuclei of cells. Chromosomes carry the inherited, genetic information that directs the activities of cells and, thus, the growth and functioning of the entire body.

Clawfoot: A deformity of the foot that includes an exaggerated arch and turning under of the tips of the toes.

Clawhand: A deformity of the hand in which the fingers are permanently curled.

Contracture: A deformity caused by shrinkage of scar tissue in the skin or connective tissue, or by irreversible shortening of muscles and tendons.

Demyelination: Breakdown of the fatty shields that surround and electrically insulate nerve fibers. The sheaths provide nutrients to the nerve fibers and are vital to the passage of electrical impulses along them. Demyelination "short-circuits" the functioning of the nerve, causing loss of sensation, coordination, and power in specific areas of the body.

Distal: Describing part of the body that is farther away from a central point of reference, such as the trunk of the body. The fingers are distal to the arm. The opposite of distal is proximal.

DNA: The commonly used abbreviation for deoxyribonucleic acid, the principle carrier of genetic information in almost all organisms. DNA is found in the chromosomes of cells.

Dorsum: The top aspect of the foot. The opposite of dorsal is ventral or anterior.

EMG: The abbreviation for electromyogram, a test in which the electrical activity in the muscle is analyzed after being amplified, displayed, and recorded. An EMG is done to reveal the presence of muscle disorders or disorders in which the nerve supply to the muscle is impaired.

Exacerbation: A worsening. (Editor's Note: Neurotoxic drugs can cause an exacerbation of CMT.)

Footdrop: A condition in which the foot cannot be raised properly. It hangs limp from the ankle joint, causing it to catch on the ground when walking.

Gait: The style or manner of walking. Some neuromuscular disorders are evaluated on the basis of altered gait, i.e., CMT.

Gene: A unit of material of heredity. A gene consists of a short section of DNA contained within the nucleus of a cell. It influences the specific workings of a cell; the activities of the same gene in many different cells specifies a particular physical or biochemical feature of the whole body.

Genetics: The study of inheritance, i.e., how the characteristics of living organisms are passed from one generation to another.

Hallux: The medical name for the big toe.

Hallux rigidus: Loss of movement in the large joint at the base of the big toe.

e Diagnosis and Treatment of CMT

Hallux valgus: A deformity of the big toe in which the joint at the base projects outward and the top of the toe turns inward. A hallux valgus often results in a bunion (a firm, fluid-filled swelling over the joint).

Hammer toe: A deformity of the toe in which the main toe joint is bent upward like a claw. The deformity is caused by an abnormality of the tendons in the toe.

Idiopathic: Of unknown cause.

Kyphosis: The term for excessive backward curvature of the spine. Kyphosis usually affects the spine at the top of the back, resulting in either a hump or a more gradually rounded back.

Median nerve: A branch of the brachial plexus; one of the main nerves that runs down the arm's full length into the hand. The median nerve controls the muscles of the forearm and hand. This nerve also conveys sensations from the thumb, index finger, middle finger, part of the ring finger, and the palm at the base of those fingers.

Myelin: The fatty material composed of lipids and protein that forms a protective sheath around some types of nerve fiber. Myelin acts as an electrical insulator, increasing the efficiency of nerve impulse conduction. Abnormal breakdown of myelin is called demyelination.

Neuropathy: Disease, inflammation, or damage to the peripheral nerves, which connect the central nervous system to the sense organs, muscles, glands, and internal organs. Symptoms include numbness, tingling, pain, or muscle weakness.

Neurotoxin: A chemical which damages nervous tissue. The principal effects of neurotoxic nerve damage are numbness, weakness, or paralysis of the part of the body supplied by the affected nerve.

Occupational therapy: Treatment aimed at enabling people disabled by physical illness to relearn muscular control and coordination, to cope with everyday tasks and, if possible, to resume employment.

Osteotomy: An operation in which a bone is cut to change its alignment or to shorten or lengthen it.

Paraparesis: Partial paralysis or weakness of both legs and sometimes, part of the trunk.

Paresis: Partial paralysis or weakness of one or several muscles.

Paresthesia: Altered sensation in the skin that causes numbness or tingling. (Pins and needles syndrome.)

Patella: The medical name for the kneecap. The patella is held in place by the quadriceps muscle at the front of the thigh.

Peripheral nervous system: All the nerves that fan out from the central nervous system (brain and spinal cord) to the muscles, skin, internal organs, and glands. Diseases and disorders affecting the peripheral nerves are grouped under the term neuropathy.

Peroneal muscular atrophy: An inherited disorder characterized by wasting of the muscles, first in the feet and legs and then in the hands and forearms. The condition, also known as Charcot-Marie-Tooth disorder, is a result of degeneration of some of the peripheral nerves or of the myelin sheath which surrounds them.

Pes cavus: Clawfoot.

Phrenic nerve: The principal nerve supplying the diaphragm. It carries all of the motor impulses to, and some of the sensory impulses from, the diaphragm, and plays an important part in controlling breathing.

Proprioception: The body's internal system for collecting information about its position relative to the outside world and the state of contraction of its muscles (i.e., maintaining balance). This is achieved by means of sensory nerve endings within the muscles, tendons, joints, and cells in the balance organ of the inner ear. Information from these sensory nerve endings helps the muscles contract so that balance and posture are maintained.

Proximal: Describing a part of the body that is nearer to a central point of reference, such as the trunk of the body. The opposite of proximal is distal.

Scoliosis: A deformity in which the spine is bent to one side. The chest and the lower back are most commonly affected. Scoliosis usually starts in childhood or adolescence and progressively becomes more marked until the age at which growth stops.

Supination: The act of turning the body to a supine (lying on the back with the face upward) position or the hand to a palm forward position. Movements in the opposite direction are called pronation.

Tendon: A fibrous cord that joins muscle to bone or muscle to other muscle.

Tendon transfer: An operation to reposition a tendon so that it causes a muscle to perform a different function. Tendon transfer may be used to restore function impaired by a deformity such as clubfoot, paralysis, or thumb movement.

Tremor: An involuntary, rhythmic, oscillating movement of the muscles of part of the body, most often the hands, feet, jaw, tongue, or head. Tremor is caused by rapidly alternating contraction and relaxation of the muscles.

Varus: The medical term for an inward deformity of a part of the body. For example, in genu varum (bowleg), the lower leg is displaced inward.

Wristdrop: Inability to straighten the wrist so that the back of the hand cannot be brought horizontal with the back of the forearm. This causes weakness of grip because the hand muscles can function efficiently only when the wrist is held straight.

X-linked disorders: Sex-linked genetic disorders in which the abnormal gene or genes are located on the X chromosome, and in which almost all those affected are male.

CMTA Support Group News

Dr. Melody Ryan, University of Kentucky College of Pharmacy, and Robert Budde, support group leader, led a question and answer session on the drugs which are neurotoxic to CMT patients at the January support group meeting in Lexington, Kentucky.

California, Bay Area Support Group

On January 16, 1999, the group listened to speaker, Megan Eoyang, who is a senior certified TRAGER practitioner. TRAGER work is gentle movement bodywork which re-educates the autonomic nervous system. Megan has worked with people who have CMT with interesting results, some of which include cessation of pain, improved balance, increased dorsiflexion, and more relaxed movements. The next meetings will be March 20th and May 15th. Contact Ruth (see listing on page 19) for more information.

California North Coast Counties

On February 6, 1999 the meeting focused on the story of leader Freda Brown's accident on her scooter and a presentation by Rehab Mobility Services about the customization of wheel chairs and scooters. The representative, Gary Fritzsche brought samples for members to examine.

Editor's note: The North Coast Counties support group publishes a nice little newsletter for their members which includes comments about past meetings as well as announcements for upcoming meetings. The latest issue also included a personal account of a trip to an MDA clinic.

Lexington, KY, Support Group

On January 16, 1999 the group heard Dr. Melody Ryan, from the University of Kentucky College of Pharmacy, give an excellent presentation on medications that should be avoided by CMT patients and why. She also answered questions following her talk. Eight people attended the meeting. In March, the group plans to have a physical therapist make a presentation. The group is most interested in learning more about the merits of exercise and the amount and type of exercise which would be best for persons with CMT. They are also interested in the use of orthotic devices, sources for braces, and the personnel who create such equipment.

Dallas-Metropark, TX, Support Group

Shari Clark and Greta Lindsey, leaders of the Metroplex CMTA Support Group, report that their December and January meetings were very well attended and very informative. At both meetings there were several new members. At the December meeting Dr. Robert McMichael presented an overview of the different types of CMT. In January, Dr. Susan Iannaccone gave us information regarding pediatric CMT and both doctors answered questions from the group. The February meeting will have a physical therapist and an orthotist. Anyone interested in attending please contact Greta (817) 281-5190 or Shari (817) 543-2068 (metro).

Attention Support Group Leaders and Members!

Would you like to see yourself, your family, or members of your group featured on this page? We need reports of meetings and events that your group holds and we also need PICTURES to print with those reports. Grab your 30 seconds of fame by submitting a picture for the newsletter. (Hint: Pictures in which 25 people appear tend to reduce each person to "pea-size," so close-ups are preferred.)

YOUR PICTURE COULD BE HERE!

CMTA Support Groups

Alabama/Greater Tennessee Valley
Place: ECM Hospital, Florence, AL
Meeting: Quarterly
Contact: William Porter, 205-767-4181

Arkansas—Northwest Area/ Springdale
Place: Harvey and Bernice Jones Center for Families, Springdale
Meeting: 3rd Saturday of each month
Contact: Libby Bond, 501-795-2318

California—Berkeley Area
Place: West Berkeley Library
Meeting: Quarterly
Contact: Ruth Levitan, 510-524-3506

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)
Place: 300 Sovereign Lane, Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Freda Brown, 707-573-0181

California—Napa Valley
Place: Sierra Vista Convalescent Hospital, Napa
Meeting: Quarterly
Contact: Betty Russell, 707-747-4864

Florida—Boca Raton to Melbourne
Place: Columbia Medical Center, Port St. Lucie
Meeting: Quarterly
Contact: Walter Sawyer, 561-336-8624

Florida—Miami/Ft. Lauderdale
Place: North Broward Medical Center, Pompano Beach, FL
Contact: Al Kent, 954-742-5200 (daytime) or 954-472-3313 (evenings)

Kentucky/Southern Indiana/ Southern Ohio
Place: First United Methodist Church, Lexington, KY
Meeting: Quarterly
Contact: Robert Budde, 606-255-7471

Massachusetts—Boston Area
Place: Lahey-Hitchcock Clinic, Burlington, MA
Meeting: Every other month, the first Tuesday
Contact: David Prince, 978-667-9008

Michigan—Detroit Area
Place: Beaumont Hospital
Meeting: Three times each year
Contact: Suzanne Tarpinian, 313-883-1123

Michigan—Flint
Place: University of Michigan, Health Services
Meeting: Quarterly
Contact: Debbie Newberger/Brenda Kehoe 810-762-3456

Minnesota—Benson
Place: St. Mark's Lutheran Church
Meeting: Quarterly
Contact: Rosemary Mills, 320-567-2156

Mississippi/Louisiana
Place: Clinton Library, Clinton, MS
Meeting: Quarterly
Contact: Betty Aultman, 601-825-5626 Julia Provost, 601-825-6482

Missouri/Eastern Kansas
Place: Mid-America Rehab Hospital, Overland Park, KS
Meeting: First Saturday each month except January, July, and September
Contact: Ardith Fetterolf, 816-965-0017, fax: 816-965-9359

Missouri—St. Louis Area
Place: St. Louis University Medical Health Ctr.
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664

New York (Horseheads)
Place: NYSEG Meeting Room, Rt. 17
Meeting: Quarterly
Contact: Angela Piersimoni, 607-562-8823

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Hospital
Meeting: Monthly, Saturday
Contact: Kay Flynn, 914-793-4710

North Carolina—Archdale/Triad
Place: Archdale Public Library
Meeting: Quarterly
Contact: Ellen (Nora) Burrows, 336-434-2383

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)
Place: Church of the Reconciliation, Chapel Hill
Meeting: Quarterly
Contact: Susan Salzberg, 919-967-3118 (evenings)

Ohio—Greenville
Place: Church of the Brethren
Meeting: Fourth Thursday, April-October
Contact: Dot Cain, 937-548-3963

Oregon—Willamette Valley
Place: Brooks Assembly of God Church
Meeting: Monthly
Contact: Regina Porter 503-591-9412

Texas—Dallas/Ft. Worth
Place: Harris Methodist HEB Hospital
Contact: Greta Lindsey (817-281-5190) or Shari Clark (817-543-2068)

West Virginia/North Central
Place: VFW Conference Room, Elkins, WV
Meeting: Quarterly
Contact: Joan Plant, 304-636-7152 (evenings)

Ask the Doctor

Dear Doctor,

Does anyone have any suggestions for dealing with hand pain? As a graduate student, I do a lot of typing at this time of year and my hands are sore and swollen. I take Advil every 4 hours and ice my hands at night, but they still bother me.

The Doctor replies:

Anti-inflammatories and non-steroidal analgesics are appropriate, but should be taken with due attention to the instructions. Better, would be to ask an occupational therapist who specializes in upper body/arm problems for advice about posture. For instance, your keyboard may be at the incorrect level.

Dear Doctor,

I have been wearing AFOs for over 20 years. Although I have severe muscle atrophy below both knees, I'm otherwise very athletic and I don't think I need AFOs that come up to within several inches of my knees. AFOs even an inch or two shorter would be a blessing, especially on hot summer days. Every orthotist I've seen has refused to make the AFOs shorter. Is there some reason they must be a certain height, or could they be made shorter? I've never found any orthotist who will explain the reasoning behind the way they are made now.

A doctor replies:

More details are needed for a full answer, but normally orthotics end within a few inches of the knee to give the patient better stability, especially if the lower leg muscles are weak and atrophied. You should, however, seek the advice of a physiatrist, an orthopedist, or a podiatrist in case you would qualify for simple, in-shoe orthotics.

A Podiatrist responds:

AFOs can be custom built and fitted for any size individual. AFOs are made from molded polymer plastic and can be height and size adjusted. Braces are made to "hold up" a drop foot and stop the foot from slapping the ground. They can also be built to give side-to-side support to prevent spraining or rolling over of the ankles. Although AFOs have a height/strength relationship, they can also be adjusted for comfort. The higher up the leg, the more structural support. If the brace is made too low on the calf of the leg, irritation and rubbing can occur. Also, the ability of the brace to hold up the foot is compromised.

The question of the height should be directed to a certified orthotist/prosthetist. However, adjustments can always be made to make the brace fit more comfortably.

Dear Doctor,

My Dad has CMT and over the last several years, he has suffered from periodic swelling of his feet to the point where he can't walk at all. Now, his right hand is extremely swollen. Is this a symptom of CMT? What can be done to ease the pain and swelling?

The Doctor replies:

Normally, swelling of extremities or joints is not a direct result of CMT, unless there is trauma to a numb joint. An evaluation for arthritis or even a systemic cause of extremity swelling, such as heart failure, would be in order.

Dear Doctor,

My friend's son, 6 years old, has CMT and is supposed to wear leg braces. Should the leg braces be worn all day and taken off at night or only worn at night when the child is tired? He toe-walks all the time when he is not in the braces.

A doctor replies:

If the child toe-walks without the braces, he should certainly wear them as much as possible. However, fittings and adjustments are frequently needed in this age group, and you should keep closely in touch with his physiatrist/pediatrician.

Dear Doctor,

Is CMT disorder ruled out as the cause of peripheral neuropathy appearing past middle age? I read in the Handbook *about CMT disorders that full clinical expression is usually completed by the third decade. I began to have numbness, tingling, and cramping in both feet about the time I turned 62. I was referred to a physical therapist who said, "I would consider this something like a Charcot-Marie-Tooth-like problem." Thereafter, I was sent to a neurologist who, after looking at me and the PT's report, dismissed me with the words, "You have Charcot-Marie-Tooth. There is no cure and no treatment and I can't do anything for you."*

Now, nearly 7 years later, I still walk or bicycle for an hour six mornings a week. My feet, most of my ankles, some areas of my lower legs, and the

outsides of my knees have no sensation of touch. I have high arches and "cocked up" toes and my feet feel like I'm wearing tight shoes.

Other than heel pain in one foot, I have had little discomfort except a tendency to leg cramps and what I call "nerve shocks" which make me jump and feel like electric shocks from a nerve conduction study. I've experienced foot drop on isolated occasions.

Did I misinterpret the physician's guide to CMT or did the neurologist make too hasty a diagnosis?

The Doctor replies:

It is rare to have initial symptoms of CMT after the age of 30, but examples of onset even in the 5th or 6th decade have been seen. Naturally, common causes of neuropathy in the older patient should be excluded, such as diabetes and alcoholism, as well as an easily treated disorder such as B12 deficiency. Rarer causes include the autoimmune collagen vascular and paraprotein diseases, endocrine neuropathy, and neuropathy due to remote cancer. The last would be unlikely in your case after 7 years. Genetic testing is currently only valuable for CMT if slow nerve conduction velocity of a symmetric type can be demonstrated—which is not mentioned in your case.

The Neuropathy Association, Inc. (1-800-247-6968), may be helpful to patients who do not have CMT. In any case, you should be in close contact with your neurologist or physiatrist.

Members of the CMTA's Medical Advisory Board answer questions from readers.

A Special Thank You

The CMTA gratefully acknowledges its leadership donors to our recent Holiday Appeal. The following members contributed gifts of $1000 or more in support of the CMTA's operating fund.

John R. Dawson
William Ettelson
Jeanette Higgins
Roger D. Hopwood
Doris L. Lancaster
Prudence H. Ryan
J. Rodman Steele
Patrick T. Torchia
Lowell L. Williams, M.D.

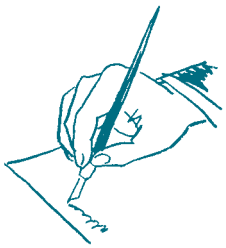
The CMTA gratefully acknowledges recent donors to the 1999 Membership Appeal.

Members listed below contributed gifts of $250 or more in support of general operations.

Patricia R. Benson
H. Parry Desmond
Marlene J. Fairchild
Stuart Feen
Mari L. Ivener
JoAnn Jones
John Karnes
Walter F. Kelly
Robert A. Kramer
Weston C. Overholt
James G. Sauerwald
Kathleen E. Shannon
Michael J. Sorenson
Lawrence Wechsler
Aimee Willliamson

Children's CMTA Report to Come

The CMTA is planning on publishing a newsletter devoted to children's issues and ideas. For that reason, we are soliciting articles (or ideas for articles) from or about children, as well as letters and "Dear Doctor" questions. If you submit an article, please include a picture for publication. Articles, letters, and pictures should be sent to CMTA, 601 Upland Ave., Upland, PA 19015 by April 1, 1999.



WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

601 Upland Ave.

Upland, PA 19015

The CMTA reserves the right to edit letters for space.

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.

Letters to the Editor:

Dear CMTA,

Would you please send me more introductory brochures? My neurologist has not heard of the CMTA and I told him I would send him some information. The second set is for my sister who also has CMT.

I want to thank you tremendously for all your help to CMT patients. I am so glad I discovered your existence at a time when I desperately needed the knowledge and support you provide. I have been dealing with CMT all my 50 years, but doctors didn't correctly diagnose me until I was 23 years old. The last few years have brought more problems that were even more serious—the inability to maintain my balance while standing in one spot and then serious foot drop on the right side. Occasional tripping resulted in several falls over the past year.

In November, my insurance company provided me with a lightweight plastic brace to prevent my foot from dropping and it works like a miracle. It has totally solved the problem. I'm not in fear of falling now.

It has meant so much to me to have your articles and the book, which I ordered, to explain what was happening to me.

Thank you. *—M.M. Massapequa, NY*

Dear CMTA,

The following is a history of my family's experience with CMT. My mother's grandparents were from Akron, Ohio, and one of them gave it to my mother's father and one or more of his sisters. The girls had the bent spine (scoliosis and/or kyphosis), but my grandfather's spine was straight. His muscles were all weak. He was a farmer and had to come in and sleep during the day. He and all the other members of our family had the big knuckles and crooked fingers.

My mother's father gave it to my mother and one of her sisters, who is still living. That sister gave it to her daughter, whose spine was so curved forward that she had to have surgery which increased her height by 5 or more inches. Her fingers look just like mine. The tips of the fingers turn down. She was a school teacher, but has become so disabled that she has left teaching.

My own mother's spine was curved slightly to one side and her muscles were weak. She had to take naps for energy. Out of our family of four children, I was the only one to inherit it. I am now 69 and my spine is not curved. My muscles are modestly stiff and weak. Extra sleeping during the day helps me recover my energy.

I cannot do manual labor. I could never walk long distances or throw a baseball. I can do light work (working on my antique car), but then I'll be tired for three days. In the army, I waddled like a duck, but resting for a week would bring me back to more normal.

My feet have extra high arches and are short and wide, but I am a short man at only 5 feet, 4 inches. I was able to teach in the community college for 23 years. The muscles in my hands are now wasting, mostly between the thumb and forefinger. I walk very slowly now, always with a cane for support. I can no longer type with the touch system.

I gave the disease to all four of my daughters. Fortunately, all of us have adjusted and have a good work ethic, so none of us have ever been on welfare. My mother lived to 86.

Sincerely, *—R.W. Cedar Rapids, IA*

Dear CMTA,

I'm a pastor, age 36. I have CMT with the burning feet and severe cramping of the lower legs. I also have hammer toes. I live in pain every day of my life. I have found rest at night from the pain and cramping with a "cocktail" of Mineral Rich, fresh squeezed celery juice (three stalks), carrot juice (two carrots), and one apple. Mineral Rich is a liquid vitamin and mineral supplement found in most health food stores. This drink helps to alleviate foot burning and muscle cramps after "juicing" for three days.

If anyone would like to email me, please do so at mirror@tir.com *—D.E. Internet*

Dear CMTA,

I want to report on my sons' involvement with therapeutic electrical stimulation (TES). We went to see the PT (physical therapist) this summer. She videotaped my sons walking a long distance, a short distance, running, jumping, sitting, standing on one foot, and hopping on one foot. She tested every muscle in their bodies including back and stomach, forearms, hands, fingers, and wrists. She measured the calf muscles in several different directions and areas. They were weighed and their height was measured. This was recorded on videotape for the files and for my orthopaedic doctor and anyone else studying TES in relation to CMT.

Every three months, the boys will be re-evaluated and any progress, or lack of it, will be recorded. Although we see only one PT, a team is actually monitoring the boys. We are approach-

ing our second month with TES, so they will be reevaluated in a few weeks. I first learned of TES on the Channel 2 News. They called it a "miracle update."

A little boy with cerebral palsy had to hold on to tables to move around his preschool classroom when he first started with TES. Now, they reported, he is running around in the sand at the park. TES may not work on every person and it can take several months to work. For that reason, I am not measuring my boys' legs at home. I want to leave that to the medical providers.

My one son, Adam, looks worse as he grows. His legs are like tooth picks. They are so weak that he can't walk without his AFOs and his knees bend back when he walks. If TES will work, it will take longer with Adam than with his brother, Spencer. I am already seeing some improvement in him.

If you would like information on TES, my PT's e-mail address is NDPT@earthlink.net. She has a packet of information that she mails out to educate people about TES.

—Jenny, Internet.

Dear CMTA,

I would like to report a dramatic change brought on by acupuncture treatment. I am 66 years of age, and the symptoms of CMT became evident some 15 years ago. Two of my brothers who have CMT tried acupuncture and reported no success, so I did not try it myself. But a cousin of the same family told me recently that a series of acupuncture treatments had been helpful. I have been taking Tui Na (deep Chinese massage) therapy for about a year with a practitioner who does acupuncture, so I asked her to combine the massage with acupuncture last November. The next day I discovered that my sense of balance had improved so enormously that I could balance easily on either foot and walk with much greater confidence and security. Also, the degree of sensation in my feet increased greatly.

I have been having the same treatment at two-week intervals, and the improvements in the condition have been sustained. When I asked the therapist to describe the treatment for the purpose of this letter, she said it was a regular acupuncture treatment of the legs and that the stimulation of the needles was manual, not electrical.

I would be interested to know if others with CMT have reported similar success with acupuncture.

—A. C. Toronto, Ontario, Canada

AT-HOME:

Lighten Up—Your Wheelchair, Walker or Cane

By Ralph Bagnall

What happens if you use a mobility device such as a cane, wheelchair, or walker and the power goes out? What if you're outside after dark? How can you see where you're going if you can't hold a flashlight? Mounting a light on your cane, wheelchair, or walker could solve the problem. But, now you are faced with another dilemma. Most canes, wheelchairs, and walkers are made of aluminum or other non-magnetic material, which makes the apparantly simplest solution—mounting a flashlight with a built-in magnet onto the mobility device—impossible. But here are some alternatives that should solve your problem.

First, Black and Decker offers a unique product that is ideal for your needs. The Snake Light has a long bendable body that can be twisted securely around the framework of a mobility device. Most department and hardware stores carry the Snake Light, which is available with either disposable or rechargeable batteries.

Next, Nite Ize manufactures a whole range of headbands, clips and holders for most flashlights—even a holder that mounts on a helmet! The holders are available in a variety of sizes and can be used with small pen-lights that use AAA batteries or heavy-duty flashlights that require D-cell batteries. Nite Ize products are available in most hardware and department stores. Visit their Internet Web site at http://www.niteize.com or call the company at (303) 449-2576 for more information.

Finally, for ready-made flashlight holders, check the yellow pages in the telephone book for companies that sell supplies to police and other emergency service agencies. These companies usually carry a huge variety of flashlight accessories and holders, and most are willing to help you find the product that meets your specific needs.

If these alternatives don't work, the following are a few do-it-yourself ideas I've used. Use inexpensive clamps, made of copper, brass, or aluminum, that come with an adjustable pivot in the center. These clamps are generally used to secure pipes to each other and are easy to find in hardware or plumbing supply stores. Simply secure one side of the clamp to the tube on the wheelchair, walker or cane, then secure the other side to the flashlight.

Use an automotive hose clamp along with a spring clip designed to hold brooms, mops, and garden tools on walls. Simply mount the spring clip to the wheelchair, walker, or cane, then pass the hose clamp through the center of the spring clip.

Finally, here's a tip for mounting a light on a walker. Cut a strip of plastic from the side of a clean milk jug. The strip should be 1 to 2 inches wider than the flashlight and long enough to wrap over both the flashlight and the horizontal bar of the walker to form an inverted "U" shape. Cut an "X" at each end of the strip, big enough to push the flashlight through. Push the back of the flashlight through the first "X," then wrap the plastic over the bar and push the flashlight into the second "X."

With a little imagination, you can find a number of bright ideas to shed some light in the dark!

MEDICAL ALERT:

These Drugs Are Toxic to the Peripheral Nervous System and can be harmful to the CMT patient.

Adriamycin
Alcohol
Amiodarone
Chloramphenicol
Cisplatin
Dapsone
Diphenylhydantoin (Dilantin)
Disulfiram (Antabuse)
Glutethimide (Doriden)
Gold
Hydralazine (Apresoline)
Isoniazid (INH)
Megadose of vitamin A*
Megadose of vitamin D*
Megadose of vitamin B6* (Pyridoxine)
Metronidazole (Flagyl)
Nitrofurantoin (Furadantin, Macrodantin)
Nitrous oxide (chronic repeated inhalation)
Penicillin (large IV doses only)
Perhexiline (Pexid)
Taxol
Vincristine

Lithium, Misomidazole, and Zoloft can be used *with caution.*

Before taking any medication, please discuss it fully with your doctor for possible side effects.

*A megadose is defined as ten or more times the recommended daily allowance.

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).
- … 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).
- … does not affect life expectancy.
- … has no effective treatment, although physical therapy, occupational therapy and moderate physical activity are beneficial.
- … is sometimes surgically treated.
- … 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, 1X, and HNPP can now be diagnosed by a blood test.
- … is the focus of significant genetic research, bringing us closer to answering the CMT enigma.

The CMTA Report

Information on Charcot-Marie-Tooth Disorders from the Charcot-Marie-Tooth Association

CMTA

601 Upland Avenue
Upland, PA 19015
1-800-606-CMTA

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URGENT!
MEMBERSHIP RENEWAL REQUESTED