

# The CMTA Report

AUTUMN 1999

Vol. 14, No. 4 ISBN #1067-0181

*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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## Hurricane Floyd Devastates CMTA Offices

By **PAT DREIBELBIS**

**N**o one likes to read about national disasters and displaced families, but the stories pepper our big city papers up and down the east coast of the United States during hurricane season. What we don't expect to read about or live through is a hurricane-related disaster inland around Upland, Pennsylvania. But, that's just what we must report to you in this newsletter.

On September 16, 1999, as heavy rains pelted the building in which our office was located, the news came over the phone from the receptionist's office that we were being evac-

uated because the water in the creek behind our parking lot was rising at an alarming rate. I, personally, have worked in this building for the last nine years and the most water damage we have experienced is the parking lot being inundated for a day or two. So, it was with some degree of confidence that we left on Thursday, feeling we would be back on Friday and life and work would go on much as before.

Friday morning, access to the roads around our building was cut off as fire trucks, electrical workers and gas company employees filled the

*continued on page 2*



*Overnight, water spilled into the CMTA offices and rose up over the desk tops, destroying resource files, publication reprints, and computer equipment.*

**EMAIL CMTA AT:**  
CMTAssoc@aol.com



*A car trailer hangs from a tree outside the CMTA offices after Hurricane Floyd.*

## HURRICANE FLOYD

*continued from page 1*

area. Still, we had no idea what kind of devastation awaited us. I got close enough to the parking lot to see a pop-up camper in a tree near the creek area, but I was naively sure that the building had remained untouched. Such was not the case.

On Monday, when I arrived for work, most of the tenants were grouped near the main door discussing the absolute chaos they had found in their offices. It's really difficult, even now, to describe the power of the raging water and what it had done to all of our possessions. The desk tops had even been under water. Mud and brown water were everywhere and our beloved computers were completely caked with the silt. All our newsletters, our books, our reprint files

## Thank you, Paul!

I believe that you, our readers, may have noticed that the last issue of *The CMTA Report* did not contain the column, *Begin with Flynn*. It had appeared regularly for the approximately two years that Paul Flynn served as Executive Director of the CMTA.

Paul has decided to seek his future in another area of community service. We knew from the beginning that Paul's interests lay in work with inner city organizations, as demonstrated by his ongoing commitment to a group called Newark Cares.

In the two years that Paul functioned as our Executive Director, he was an effective voice for the CMTA in many areas.

He was a major contributor to the success of our Third International Conference on Charcot-Marie-Tooth Disorders, which elevated the CMTA's standing in the neuro-muscular research field.

His outgoing personality enabled him to make many friends who have become donors to the CMTA, some of whom donate very generously.



*Under Paul's leadership the CMTA raised more money for research than ever before.*

It was Paul who had the foresight, conviction, and ability to convince the Armington family to increase their \$25,000 challenge to a donation of \$50,000 in each of two years if we could raise \$150,000 as an organization. Paul made sure we met those goals each year.

Paul initiated several fundraising opportunities that allowed individuals to hold events in their own home towns to raise money for the CMTA. Events such as the Westchester Broadway Theater, the Trotter Event, and the Oklahoma Songfest increased both our revenues and our "name recognition" around the country.

Additionally, Paul has set in motion the mechanics which will result in more dues-paying members for the CMTA than ever before in our history.

Paul, I will miss the mental gymnastics of our many discussions as they related to the health and welfare of the CMTA and its constituencies. All of us at the CMTA wish you the best for the future.

Jack Walfish, PE, CCE, *President*



and virtually all aspects of our day-to-day business were ruined. It was very difficult not to cry. For days after seeing the flooded-out office, most of us closely tied to the organization had trouble sleeping. It was too disturbing. The one saving grace in all of this was that our electronic data was backed up on tapes and our "server" contained all of our software information. We still exist as an organization!

The clean-up work is still on-going. If you have requested information or have sent your membership contribution, please be patient if the thank you's and the packets are slow to arrive at your home. The monetary losses we have sustained are enormous; the loss of time and efficiency are incalculable. Since we rent our space and since floods are unheard of in this particular area, we were not insured for this terrible loss. Our computers, our printers, our fax machine, even our Pitney-Bowes postage meter fell prey to the raging water. We have contracted to have our paper files dried and sanitized professionally, but that is an expensive, 4- to 6- week process. If you have tried to call the office, you know that the phone lines have yet to be fixed. Only recently, we have been told that we must vacate the building because it is not going to be renovated. So, now moving is also on the list of things to accomplish.

Like someone who has been robbed or whose home was damaged by fire or flood, we feel as though things will never be the same...and, perhaps they will not. But, we are like the Phoenix, rising not from the ashes, but from the waters. We ask your help and your understanding.

## Your Help Is Needed...

Donations to help the CMTA rebuild its resources would be greatly appreciated. Checks can be sent to:

The CMTA  
Attn: Flood Relief  
601 Upland Avenue  
Upland, PA 19015

# CMTA MEMBERSHIP/ORDER FORM

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_ Email: \_\_\_\_\_

**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.*

	QTY	COST	TOTAL
<b>Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians</b>		active members \$15 inactive members \$20	
Membership Dues		\$35	
<b>SPECIAL OFFER FOR ACTIVE MEMBERS ONLY: CMT Facts Series (I-IV)</b>		active members \$16	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 inactive members \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 inactive members \$7	
CMT Facts III		active members \$5 inactive members \$7	
CMT Facts IV <b>NEW PUBLICATION</b>		active members \$8 inactive members \$10	
<b>VCR Double Tape: Wayne State Conference</b>		active members \$25 inactive members \$40	
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CMT Informational Brochure <input type="checkbox"/> English <input type="checkbox"/> Spanish		FREE	Send Self- Addressed Stamped Envelope
Physician Referral List: States: _____		FREE	
Letter to Medical Professional with Drug List		FREE	
<b>Contribution to CMTA Research</b> <i>10% will be applied to administrative expenses.</i>			
<b>Shipping &amp; Handling</b> <i>Orders under \$10 add \$1.50, orders over \$10 add \$3.00</i>			
<b>TOTAL</b>			

Check payable to the CMTA (US Residents only).  
Foreign residents, please use a credit card or International Money Order.

VISA  MasterCard  American Express

Card Number \_\_\_\_\_ Expiration Date \_\_\_\_\_

Signature \_\_\_\_\_

Mail to the CMTA, 601 Upland Ave., Upland, PA 19015

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

## OF INTEREST

Board President Jack Walfish recommends the Fiskars line of products called "Softouch." They are ideal for heavy users and people experiencing weakness in their hands. The cushion-grip handles reduce thumb and finger discomfort. An easy-action spring gently opens the blades after each cut, reducing pressure on the hand and joints. A large slide lock keeps the blades closed for safe storage and portability.



# Ethical, Legal, and Social Issues:

*(The following information was taken from a video produced by the Human Genome Project and the Alliance of Genetic Support Groups. It was funded by the National Institutes of Health.)*

Although the rapid advances in genetic technology are offering hope to many individuals and families affected by genetic disorders, new issues are being raised about who has access to genetic information and what the consequences might be if confidentiality is not maintained. Issues of privacy, confidentiality in health insurance, employment, and within families will be discussed.

## HEALTH INSURANCE

Most people in the United States have some kind of health insurance to provide protection from economic catastrophe that could occur from medical costs associated with major illnesses or accidents. The large majority have private health insurance often associated with a job, and about 10% are covered by public programs such as Medicaid or Medicare. Most private health insurance companies are businesses that are accountable to shareholders who want to make a profit. It is in their interest to insure people who are not going to cost more than what they determine is "acceptable risk." This often puts insurers at odds with people who have the most need for medical care.

This is a particular concern of people with genetic conditions that affect health. These individuals not only have to deal with the medical and emotional impact of their condition, but also worry about how much of the cost will be paid by insurers, what will happen if they reach the maximum cap, or if their coverage will be dropped. Those without insurance coverage prior to a diagnosis may have difficulty ever getting health insurance coverage unless they are able to be covered by a group plan which assigns "risk categories" on the basis of group, rather than individual, risk. A genetic condition may be considered pre-existing if a family changes insurance carriers. If turned down by one insurer, they may be put on a computer list available to other insurers. Once this occurs, it may be difficult to ever get private health insurance coverage.

Even when a family has health insurance, the procedures for getting reimbursed for medical expenses need vigilance. Some insurers have

a one year limit for insurance reimbursement and when bills are returned for more information or there is a need to appeal, the 12 months can go by quickly. If this happens, the insurance company is no longer responsible for paying the bills.

There are other insurance considerations which arise as a result of genetic testing. One is a concern about losing insurance just for being tested. Another is being considered to have a pre-existing condition if the testing shows the person to be at risk for a genetic condition. Individuals may avoid being tested for these reasons. This would be unfortunate if such knowledge would encourage life style changes to reduce risks or the seriousness of the condition. Conversely, testing could be pursued hoping that no risk would be found which would reduce the high premiums established on the basis of a family history of a genetic condition.

As research continues, increasing numbers of diseases will be found to have genetic components. As more is understood about inherited risks, more persons could potentially enter the same risk category.

This could eventually have a leveling effect or it could increase the numbers of persons excluded from private insurance. Persons with genetic conditions need to be especially aware of insurance limitations and exclusions as well as legislation that may protect them.

Efforts are currently underway to establish ways of preventing genetic discrimination in insurance. For example, recommendations to protect against genetic discrimination have been developed for state and federal policy-makers that may be incorporated into legislation. The recommendations include:

1) Insurance providers should be prohibited from using genetic information, or an individual's request for genetic services, to deny or limit any coverage or establish eligibility, continuation, enrollment, or contribution requirements.

2) Insurance providers should be prohibited from establishing differential rates or premium payments based on genetic information or an individual's request for genetic services.

3) Insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information.

4) Insurance providers and other holders of genetic information should be prohibited from releasing genetic information without prior writ-

# Genetic Disorders

ten authorization of the individual. Written authorization should be required for each disclosure and include to whom the disclosure would be made.

Consumers and providers may want to monitor and advocate for these recommendations in state and federal legislation.

## ISSUES IN THE WORKPLACE

Individuals with genetic conditions resulting in visible disabilities have long been disadvantaged in the workplace. Being able to do the job as well as or better than other applicants has not necessarily resulted in employment or promotions. Unemployment, under-employment, and lower wages have been all too common for persons with disabilities.

Since 1990 the Americans with Disabilities Act (ADA), in concept, prevents employers from openly denying employment or firing an individual solely on the basis of a “disability” if there are “reasonable accommodation[s]” that can be made in the work setting to allow the person to perform his/her job. Implementation of ADA, however, relies on employers and employees knowing the law and interpreting what accommodations are reasonable.

Testing for genetic conditions prior to the onset of symptoms also could result in genetic discrimination if testing results become known to employers. This could happen as a result of pre-employment physical examinations or routine health screening offered or required by employers.

In some companies, review of medical records and health questionnaires are used to determine ratings for company health insurance. There may be a financial advantage for employers to avoid hiring persons they think might increase health costs. This raises the concern of whether in the future, genetic testing will be offered or even required by employers.

The ADA mandates that an employee’s health information be considered confidential. Exceptions are made if managers, first-aid, and safety workers need to know.

Under the Equal Employment Opportunity Commission (EEOC) guidelines, “a person has a disability for the purposes of the ADA if she or he 1) has a physical or mental impairment that substantially limits a major life activity, 2) has a record of such impairment, or 3) is regarded as having such an impairment.

The ADA is an important step in protecting persons with genetic conditions against discrimination in the workplace. It does not guarantee equal access to insurance provided through employers or offer protection from social discrimination by other employees. It does, however, establish a legal precedent that discrimination based on an individual’s genetic makeup is not acceptable in the workplace.

## FAMILY PRIVACY

As noted earlier, genetic tests reveal information, not only about the individual being tested, but also about his or her family members. When all family members are in agreement about wanting or not wanting to know the results of genetic tests, there is no problem. When there is disagreement, however, difficult situations can occur. For example, an individual may have to decide between protecting his or her own privacy or sharing information with other family members that could possibly be useful to them in terms of prevention or early treatments. Two individuals who have the same risk may feel differently about wanting to know. Situations such as this can result in strained relationships between family members. Even if one family member has no reservations about sharing genetic information, others in the family may not want to receive it, or they may feel the need to “protect” some other family members from facts they feel will harm them emotionally.

In addition to privacy among members of the same family, families and professionals may need to choose how much genetic information to share with outsiders, such as schools, employers, and insurance companies. Sometimes, sharing information can be useful. For example, children with specific conditions that affect learning could possibly be helped if their teachers knew their diagnoses.

Perhaps certain teaching styles would be better than others. There is also the risk, however, that a child could be “labeled” or given fewer opportunities because of reduced expectations.

Despite the efforts that have been made to increase public understanding about individual differences (including genetic differences), much work is needed to prevent discrimination against those with “differences” of any kind.

## OF INTEREST

"While working in the durable medical equipment industry, I was bothered by the fact that families had powered wheelchairs they could no longer use and had no way to get them to someone who could use them. I now maintain a bulletin board for free used power chairs (not manual) and try to make a match."

—Thomas Thurlow,  
Senior Wheels,  
1-800-360-8765



# Questions and Answers about HNPP

By **MAUREEN HORTON, RN** and  
**DAVID A. BLASS, MD**

*(Editor's note: Both Maureen Horton and Dr. Blass are diagnosed with HNPP. In this question and answer session, Maureen Horton is the questioner and Dr. Blass the answerer.)*

*Although interest and understanding are growing, HNPP, in general, remains a disease known only to a few. Most of the people with HNPP whom I have met are trying to find medical help and information in dealing with their HNPP symptoms. People with HNPP seem to have two choices: they can travel long distances once or twice a year to see a research neurologist experienced in HNPP; or, they can see their local neurologist who has little, if any, actual experience in treating people with HNPP. As a primary care physician yourself, what do you see as your role in treating people with HNPP?*

Unfortunately, the current system, which is, at times, cumbersome for people with HNPP, evolved for a variety of reasons that are still in place. Though I have learned a great deal about HNPP, this is a neurologic condition which I think is still best handled by a neurologist. I can serve in the role of advisor, but since many of the decisions to be made are based on electrical studies (NCV, EMG), the neurologist is the best person to do this.

*What do you mean by your role as an advisor?*

The ancillary functions—administrative paperwork for equipment, emotional support, integrating the disease into the rest of care, etc.—are all important, but no different than I do for my other patients with other medical conditions.

*Just how educated do you, as a primary care physician, need to be in treating someone with HNPP?*

The question of knowing nothing about HNPP and still being able to treat patients for other conditions I think can be resolved fairly readily. First, the capsule comment, "I have a condition which makes my nerves very susceptible to injury, and that injury may resolve slowly or not at all" will bring the treating doctor into the correct frame of reference. This should allow the physician to decide if the proposed treatment can be pursued directly, or if an alternative is a better choice, or if referral/consultation is needed. Second, extra questions and vigilance by the patient can provide another level of comfort that the correct course is being followed. Each of these steps requires the patient to be proactive, which I think is appropriate in any condition or illness.

*I have heard some physicians say, "I don't know about this disease and I'll probably never see it again in my practice. Let the neurologist handle it." Can you, indeed, "Let the neurologist handle it?"*

A neurologist who is willing to "handle it" has two things going for her/him. One is the extensive training in neurologic symptoms, drugs, procedures, etc. and the other is the comfort with the nature of these disorders which is lacking in someone with a different professional background. My feeling is that if a doctor tells you that she/he isn't comfortable making decisions about your condition, you should be pleased that this comment was made with your best interest in mind and find someone with the expertise/comfort level needed.

*When would it be appropriate to refer to a researcher?*

I think that it is better to be seen/treated by someone who is familiar with your condition and will be willing to keep up with new developments than someone who happens to be nearby. In most cases, this will turn out to be a researcher or academic neurologist.

*Knowing that the local neurologists do not know as much about HNPP, how comfortable are you in referring to them?*

## (Hereditary Neuropathy with Liability to Pressure Palsies)

This really depends on the stage of the patient's illness. A person with peripheral nerve complaints seemingly explainable by their occupation or a known injury who has not been diagnosed with HNPP can receive a very good evaluation of the nerves, including the electrical studies, from a community-based neurologist. The vast majority (maybe even 100%) of people who come to me with carpal tunnel syndrome, for example, will not have HNPP. Add to this the fact that diagnosing HNPP involves some tests that are either painful (EMGs) or expensive (HNPP blood test), and most people with nerve complaints won't be offered these tests. Many who are offered them will refuse. If a person with a "suspicious" history suggesting HNPP, a local neurologist can still get enough information to come to the correct diagnosis. However, obtaining the information does not assure that the diagnosis will be made; this depends on the experience and knowledge base of the physician. For this reason, I prefer sending such a person to an academic/university-based neurologist for diagnosis and eventual treatment. A person who has already been diagnosed with HNPP and comes to me as a new patient should also be seen by an academic neurologist.

### *What would you say to a patient who had HNPP and came to see you with stomach and bowel problems, for instance, and thought it was due to his or her neuropathy?*

This is a difficult question and should be addressed by a true expert in the field. The appearance of a new symptom in a person with a rare condition could be due to the condition itself or to the many other conditions which can befall anyone. This question raises the issue of whether or not the whole book on HNPP has been written yet; we just don't know at this time.

### *What advice do you give about exercise?*

Exercise is recognized as good in virtually all corners of medicine. It can have important health benefits in the areas of cardiovascular risk, lipid control, weight management, bone strength, and frame of mind. Most doctors would probably advise that all patients engage in some sort of exercise on a regular basis if their medical condition allows. "If their medical condition allows" is

the key phrase, and in some people, medical concerns may override the clear benefits of exercise.

### *And what about exercise when the ideal (minimum, three times a week for 30 minutes) and reality don't mix? What can or should be done to decrease the risk for cardiovascular disease? Or, shouldn't that be a worry anymore?*

Reality has to be the winner. The good news is that concepts of exercise are changing. You don't have to go to a gym or get on the treadmill to get exercise. Walking is exercise, and so is going up stairs. The current feeling is that an increase in activity during daily living can have many of the health benefits mentioned above. Exercise is also cumulative, so that three ten-minute walks count as thirty minutes of exercise. I advise people to be practical (work within the limits of their condition), but be creative (park on the far side of the parking lot at work or at the store) and above all, be persistent. There are a number of other things that can be done to improve a person's cardiovascular outlook independent of exercise. These include weight and cholesterol control, smoking cessation, consideration of hormone replacement therapy in post-menopausal women, and blood sugar control for people with diabetes.



VISIT OUR HOMEPAGE  
at

[www.charcot-marie-tooth.org](http://www.charcot-marie-tooth.org)

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## DIET AID OR DIET DISASTER

**T**he Diet Soda Dilemma... from *Caffeine Blues*, by Dr. Cherniske suggests that drinking diet soda may put on weight rather than helping with its loss. He says, "Your body, its needs and its functions are exactly the same as they were 10,000 years ago. But instead of pure, clean water, you reach for the pull tab on a can of cola. You take a long drink of an artificially colored, chemically flavored mixture of carbonated water, phosphoric acid, sweeteners, preservatives and caffeine. To add insult to injury, some of the aluminum from the can may have leached into the beverage, despite the so-called protective coating."

"And, if it's a diet cola, your brain registers the intense sweetness of aspartame and instructs the intestinal tract to prepare for an enormous intake of calories. Your body creates enzymes to convert future calories to fat, just like it did 10,000 years ago. So even though the beverage contains only one calorie (a concept your brain and body do not understand), you remain primed to create fat as soon as you eat some real food. That's why the more artificial sweeteners you consume, the more likely you are to actually gain weight—as confirmed by a study of 80,000 women over a period of six years."



## OF INTEREST

Board Member and CMT patient, Dr. William Quinn, sent in a brochure about a new brace that has applicability to some CMT patients. Called ToeOFF, the device is a gait rehabilitation orthosis which is suggested for drop foot due to neuromuscular disorders, i.e. Charcot-Marie-Tooth disease and other lower extremity neuromuscular deficits. It helps with ankle instability. It looks dramatically different from the typical AFO, as the picture illustrates. You can check out the device at the web site for Camp Healthcare at [www.camphealthcare.com](http://www.camphealthcare.com) or by calling 1-800-492-1088.



# On the Care and Feeding of Your New AFOs

By **BERNIE DORIN**

*(Editor's note: This is another in the series of personal accounts by members who wear and "swear" by their AFOs (braces). Last issue, we featured a similar article by Dana Schwertfeger. If you have a similar experience or philosophy to share or one that is the completely opposite viewpoint, please send it to the office and we will publish your views as well.)*

I did not realize until recently that a substantial number of people with CMT felt that they were unable to tolerate AFOs. If you've been fitted for AFOs, you probably need them, so to be unable to get them comfortable enough to wear is more than unfortunate. It probably limits your mobility and is potentially dangerous to your well-being. I have been wearing AFOs for almost 25 years and in that time I've had to break in several pairs of AFOs. It was never easy! However, my personal experience has convinced me that we are talking not about an insurmountable obstacle, but just another problem to be solved.

If you are lucky enough to be able to walk away in new AFOs and not have to go through a period of adjustment, then you are indeed lucky, and what follows is not for you.

My daughter will soon get her first pair of AFOs, and based on my experience only, here is the advice I will give her.

The adjustment process may take several visits. Don't be discouraged. Think of the time and effort involved as an investment now for years of improved well-being, rather than merely an expenditure of time and effort. There's a big pay-off for wearing your braces.

Don't expect this to be like buying a new pair of shoes. You are doing something unnatural to your feet, with hard plastic. It may take some adjustments to get them functional and comfortable.

Communicate as openly and specifically with your orthotist as you can. He/she is there to help you, and wouldn't be in that profession if helping people wasn't important to him/her. You will be working with an orthotist, not a psychic, so feedback is your responsibility. And, by the way, your orthotist knows you will need some adjustments.

*A satisfied AFO customer offers tips on getting just the right fit...*

Your new AFOs may feel comfortable when you first put them on—and why not? They were made from casts of your feet and legs. However, it has been my experience that after about 15 to 30 minutes of walking in them, a pressure point is apt to show up. If you know that in advance, why not walk around in the vicinity of where you are being fitted and get the first adjustment before you leave the area? If you can manage the time, check with your orthotist and schedule a quick check-up after about a half an hour of walking. I also suggest that before you leave, you schedule another follow-up visit for about a week later.

Rather than wear your new AFOs until you can't tolerate the discomfort, wear them only at home at first, and only until you begin to get uncomfortable. You don't want to provoke a sore on your foot. Repeat the process on successive nights, hopefully wearing the AFOs a little longer each time. An accommodation between my feet and the braces seems to take place, so that by the time of my appointment, I've gotten past the "break-in" problems and we can deal with the difficult pressure points.

In addition to the discomfort of AFOs, two other common complaints I've heard are the unpleasantness of the plastic against the leg, particularly in warm weather, and the odd look of AFOs, which adds to the negative feelings associated with looking "different."

I deal with the first issue by wearing a pair of light-weight over-the-calf stockings under the brace. It doesn't get too warm for me. I deal with the second issue by wearing a normal mid-calf sock over the brace. This has not only a cosmetic effect, but it makes the brace feel more secure in my shoe. (Both of these tips will be less effective when you are wearing a skirt or dress than if you are in slacks and socks.)

I'm sure there are other issues for some people regarding AFOs, but I hope that any of you who have been having problems with new AFOs will find some help in my experiences.

**GIFTS WERE MADE TO THE CMTA IN HONOR OF:**

**Mr. and Mrs. Jim Charam**  
Judy Siref & Steve Fradkoff

**Stephanie DiCara**  
Ellen Allen  
Mr. & Mrs. Anthony DeSanti

**Jason M. Everhart**  
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Anthony Monti  
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Lamar Nance & Family  
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Doug, Terry & Kevin Sutherland  
Bill & Eunice Toussaint  
Dr. Carl & Alison Turner  
Mrs. Maria Turziano  
Joe & Bernice Williams

**Minette Schwartz**  
Reeva Sterling

**Ida & Herman Whatley**  
Barbara Phillips

**Erma Whitaker**  
Barbara Phillips

**Nadine Wolf**  
Barbara Phillips

*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: \_\_\_\_\_

\_\_\_\_\_

# Membership Dues and Other Fund

In the last few months, it has become apparent that many members of the organization are unaware of the purpose of the three different fundraisers that occur during the fiscal year. Because the membership drive comes shortly after the research fundraising, many people were upset to receive a letter suggesting that they were not “current” with their dues. They had, in many cases, just sent \$50 or more to the research fund. How could they not be “current members”?

What most people do not understand is that research money is “restricted” funding. That is, with the exception of the 10% which can be used to offset the cost of raising the research money, the rest of the gift to research

is directed to a special bank account, and it cannot be used for anything other than issuing grants and fellowships. So, while a gift to research is crucial to the on-going task of finding a cure for CMT, such gifts cannot help the organization in its day-to-day functions.

Membership dues are the backbone of the CMTA. These funds allow us to operate an office, publish a newsletter, offer an 800 number and employ personnel, as well as the less glamorous and less visible jobs of paying bills, buying postage, and periodically upgrading our equipment and software. While this might not seem as noble as funding research, the money from membership is quite literally what allows us to exist as an organization. Even if

Dear CMTA,

Many thanks for the July reminder that arrived in the post to renew our membership to receive your wonderful magazine. We truly appreciate all the interesting articles and information on CMT in the magazine. We sent our subscription last year, but are not longer in a financial position to continue contributing.

We have a very special daughter with CMT, inherited through me and my side of the family. She has had 10 operations on her feet (in South Africa) and has constant problems with pressure sores under her feet that refuse to heal. In Zimbabwe there is very little knowledge and information about CMT. Our family doctor has been a great support, but I keep him informed with your magazine and articles. We have a team of doctors who are working to alleviate these pressure sores and help us find shoes that she can wear. Unfortunately, these doctors are in Johannesburg, South Africa, with is a distance of 1200 km from our home. We make the trek nearly every school holiday for assistance. We have just ordered Surgical Boots, made to order, which cost the equivalent of Zimbabwe \$20,000 for a pair, to say nothing of the cost of traveling up and down for fittings.

We soldier on to meet her needs and feel embarrassed to plead poverty to you. Our daughter faces all her problems with such acceptance and is an example to all of us. Despite my CMT, I continue to teach Grade 2 and Remedial Lessons in our local primary school.

Please consider our case.  
C.G., Zimbabwe

Dear CMTA,

I am a 38-year-old mother of a very active 6 year old. I struggle daily to be a mental health nurse, a mother, a wife, and a housekeeper. I am active in MDA fundraisers for CMT. I also have multiple sclerosis. My medical bills are more than my monthly earnings. I was saddened by the letter I received in July. I enjoy receiving The CMTA Report. It provided me with a sense of belonging, education, as well as filling many other needs.

I am not financially able to pay \$35 to be a part of the association. If anything, I could use assistance myself. I would like to know what my options are to continue receiving the newsletter.

Due to the severe fatigue and neuropathy, I will soon have to quit work, which will only add to my stress. I pray daily for a cure for CMT that has taken away many of my life choices.

I thank you for your time and consideration of my request to continue to receive the newsletter.  
K.D.

# raising....

you can pay only a few dollars, that money is important and appreciated. It is also the gift which is coded to indicate who will receive the newsletter on an on-going basis.

The third fundraiser is timed to occur between Thanksgiving and the New Year. The annual appeal, as it is called, is also money for operations, but it is usually directed to special, one-time projects, such as the publication of new booklets (one on genetics and one on children and CMT are being worked on right now), the hosting of special conferences and, in this year's case, the rebuilding of the CMTA's office following the devastation of hurricane Floyd. We must replace many of our pieces of equipment so that we can function and grow in the new year.

We look to our members in helping with that.

Hopefully, this explanation of our fundraising efforts will eliminate some of the confusion that arose from the term "inactive" in regard to membership. Please, whenever you receive any mailing from this office that is unclear, call and discuss it with us. We are happy to check our database (we aren't infallible and found several mistakes during the last mailing) and explain anything that isn't clear.

For those of you who were generous to give an extra portion to the membership appeal, we include here (on the left) two of the almost 500 requests we received to continue the newsletter subscription even though the person was unable to send \$35.

## Support Group Leader Sings for CMT Awareness

Each week, on Wednesday afternoon, Libby Bond, the leader of the NW Arkansas Regional CMT Support Group, loads her two youngest children and her granddaughter along with her karaoke player and musical tapes in her van to go to a restaurant to sing. She starts at 5 PM and sings until the 8 PM closing. She sings favorite country music, old and new, and inspirational tunes. She jokes that she sings for CMT awareness and that isn't Country Music Television! Her theme song is Mark Wills' "Don't Laugh at Me" because she remembers feeling just like that as a kid growing up and feeling very different.

She decided that singing would be a way to be in the public eye and get the message out for CMT awareness. In addition, she passes out brochures provided by the CMTA called "What is CMT?" She benefits from keeping her lungs, her diaphragm muscle, and vocal cords exercised and from knowing that she may be helping others in the process. She has made at least two contacts who have been added to the support group. When she started the group in November of 1998, her list contained three people in addition to herself. She now has a list of 49 patients.

In addition to singing at the restaurant, Libby sings Thursday mornings at an adult day care center locally and every other week at a nursing home. Since retiring, she has looked for ways to serve in the community and give purpose to her life. She volunteers in her youngest children's classrooms and babysits her granddaughter to help her oldest daughter.

Even though CMT has put limits on her life, she feels much more fulfilled now, for she has a different perspective on what is important. "I have time for the things I love and enjoy doing now, and life is much more meaningful." She feels she can influence more people with her disability than she did without it. "Sometimes our lives take a different direction and we aren't sure why, but I know at this time what I need to do and am trying to do it."



### OF INTEREST

*AT YOUR OWN SPEED* is a first-of-its-kind Internet radio program by and for the physically challenged community. You can access it at [www.ownspeed.com](http://www.ownspeed.com). The host is Dr. David Koffman, who has been in private practice since 1974. A brain stem injury took him off his feet in 1992 and last year, multiple sclerosis took him out fully. A senior fellow of the American Board of Disability Analysts, he worked with the disability community for many years, never thinking he might someday belong to it.

He might interview Tom Whittaker, the amputee who climbed Mt. Everest or Marti Ford, Chairperson of the Social Security Task Force on the Work Incentive Bill. Every show will inform, entertain, and inspire.



## CMTA Support Group News

### SUPPORT GROUPS NOW FORMING!

New groups are organizing in Denver, CO and Detroit, MI.

Groups are needed in Philadelphia, Seattle, Salt Lake City, and Southern New Jersey. Are you interested in helping? Call the office at 610-499-8872.

*Half of the attendees at the last Los Angeles area support group posed before leaving for home. The leader, Serena Shaffer, is third from the left, sitting on the floor in the first row.*

### ■ California - North Coast Counties: Freda Brown, Group Leader

The summer meeting featured Wanda Lickteig, Occupational Therapist at California Pacific Medical Center. She discussed rehabilitation and ways to conserve energy and accomplish tasks. Another speaker was Abby Wolfson, of the MDA. She discussed the services of the MDA and discussed the summer camp program of the MDA.

The group is working on getting their local newsletter/brochure in neurologists' offices throughout Marin, Mendocino, Napa, and Sonoma counties.

### ■ California - San Francisco Bay Area: Ruth Levitan, Group Leader

The most recent meeting, September 18, 1999, was held at the West Berkeley Library and 22 members attended. There were six new members attending. Nancy Oehrle, a clinical psychologist, gave a presentation on the challenges and coping strategies of dealing with chronic illness. There was an active discussion and exchange of ideas.

Ruth shared with the group the book she had just purchased, *Numb Toes and Aching Soles*. She learned about it from *The CMTA Report* and she termed it "a winner." She said in her report, "If the *Handbook for Primary Care Physicians* is my "bible," then *Numb Toes* will become my encyclopedia!"



*The Dallas/Ft. Worth Support Group held their first picnic at the Bedford Boy's Ranch in Bedford, Texas. Over fifty people attended and were pleased with the handicapped-accessible pavilion that allowed everyone to enjoy the outside area.*

The next meetings for this group are scheduled for November 20, January 15, March 18, May 20, and June 15.

### ■ Florida - Boca Raton to Melbourne Cynthia Gracey, Teri O'Hare

A tentative meeting is being planned for November 18, 1999, at the Upledger Institute in Palm Beach Gardens. Call Cynthia for further information at 561-243-0000.

### ■ Kentucky/Southern Indiana/Southern Ohio: Robert Budde, Group Leader

The September 16, 1999 meeting was attended by nine CMTA members and four spouses and children. Roger Hopwood visited with Dr. Florian Thomas in St. Louis, MO on a personal CMT-related visit and took with him a large series of group-generated questions. Roger brought back with him the answers to all of these questions as well as his own and shared all this information with us during a two-hour presentation and Q-and-A session. Everyone participated and felt that more time for discussion was still needed. The next meeting on November 13 will address this. They will also decide on a speaker for January 2000 and give him or her a list of concerns and questions.



# CMTA Support Groups

## Alabama/Greater Tennessee Valley

**Place:** ECM Hospital, Florence, AL  
**Meeting:** Quarterly  
**Contact:** William Porter, 205-767-4181

## Arkansas—Northwest Area

**Place:** Harvey and Bernice Jones Center for Families, Springdale  
**Meeting:** 3rd Saturday of each month  
**Contact:** Libby Bond, 501-795-2318  
**E-mail:** charmicoma@netzero.net

## California—Berkeley Area

**Place:** West Berkeley Library  
**Meeting:** Quarterly  
**Contact:** Ruth Levitan, 510-524-3506  
**E-mail:** rulev@pacbell.net

## California—Los Angeles Area

**Place:** SHARE Unity Room, Marina Del Ray  
**Contact:** Serena Shaffer, 818-841-7763  
**E-mail:** SerenaM71@aol.com

## 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  
**E-mail:** pcmoble@home.com

## Colorado—Denver Area

**Place:** TBA  
**Meeting:** TBA  
**Contact:** Marilyn Munn Strand, 303-403-8318  
**E-mail:** mmstrand@aol.com

## Florida—Boca Raton to Melbourne

**Place:** Upledger Institute, Palm Beach Gardens  
**Meeting:** Quarterly  
**Contact:** Cynthia Gracey, 561-243-0000

## Florida—Miami/Ft. Lauderdale

**Place:** North Broward Medical Center, Pompano Beach, FL  
**Contact:** Al Kent, 954-742-5200 (daytime) or 954-472-3313 (evenings)  
**E-mail:** marbearwld@aol.com

## 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  
**E-mail:** baseball@ma.ultranet.com

## 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  
**E-mail:** ardi5@aol.com

## 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  
**E-mail:** alma622@worldnet.att.net

## 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  
 Maryann DiStefano-Hill  
**E-mail:** moonglow21@aol.com

## Texas—Dallas/Ft. Worth

**Place:** Harris Methodist HEB Hospital  
**Contact:** Greta Lindsey, 817-281-5190 or Shari Clark, 817-543-2068  
**E-mail:** jdsbclark@webtv

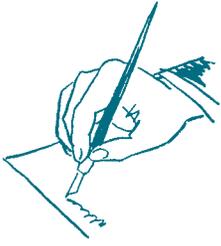
## West Virginia/North Central

**Place:** VFW Conference Room, Elkins, WV  
**Meeting:** Quarterly  
**Contact:** Joan Plant, 304-636-7152 (evenings)

## BOOK REVIEW

***Managing Pain Before It Manages You*** by Margaret A. Caudill, MD, Guilford Press, 1995. Carefully conceived from the author's many years of working with chronic pain sufferers, this book teaches skills for coping with pain, step-by-step techniques to help you understand the pain process. Dr. Caudill discusses factors that increase and decrease pain, medications, relaxation and exercise techniques, and more. \$15.96, via Amazon.com





## 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

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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,

I have found your staff to be extremely helpful while my daughter was going through the process of trying to get Social Security Disability benefits due to her severe case of CMT. After 3 1/2 years of going through the process and finally having to turn to the Appeals Council in Falls Church, VA, she has been approved for benefits.

Her only source of healthcare is the CMT Clinic located at Georgetown Medical Center in Washington, DC. Now she must wait 2 years to be eligible for Medicare. Through the CMT clinic, she has just been fitted for new shoes and braces.

We have met with Congressman E. Clay Shaw, Jr. and his staff and Congressman James Moran's representative and an advisor to the Subcommittee on Social Security (which Congressman Shaw chairs). They gave us an hour of their time.

I would be happy to pass along our experiences to anyone needing advice about going through this tortuous process.

—Doris Franklin  
MMLDJF5897@aol.com

Dear CMTA,

The first thing I do when I come home is take off my plastic AFOs. Has anyone found a "slipper" to wear around the house that gives enough support to keep one from tripping on things like area rugs?

—R.K.

Dear CMTA,

I was sorry to read the short column about Carnitine and coQ10 in the May 1999 issue. The article failed to point out the extensive research done by Folkers and Simonsen regarding neurological disorders and coQ10 deficiency. Their research clearly shows low blood levels of coQ10 in some patients with CMT and the muscular dystrophies. Their double-blind study used cardiac output as the objective measure of increased muscle competency during supplementation with coQ10. Participants indicated increased ability to exercise.

My own experience with coQ10 which I started 3 years ago based on this work, has been nothing short of life-changing. Prior to taking coQ10, I barely had enough energy to perform the activities of daily living. Now, I have the strength to take care of myself and my husband

and enough left over for regular exercise. My recovery time from over-exertion is now a night's sleep and a light day. Prior to supplementation, I would be bedridden for 24 hours after exertion.

Even though I find it expensive, I take 360 mg/day and am grateful that I have found something that has made such a difference.

—A.S., Florida

*(Editor's note: The author of the preceding letter enclosed an abstract from a Medline search concerning the double-blind study she refers to. The abstract did find an improvement in cardiac function and physical performance in CMT patients and those with other muscular dystrophies. The authors were K. Folkers and R. Simonsen at the University of Texas, Austin.)*

Dear CMTA Members,

Here is a list of the ten most important foods to eat organic. This is an excerpt from *The Green Guide*, a newsletter published by Mothers and Others, NY.

1. Baby Food. Babies are extraordinarily susceptible to pesticides. Two organic brands (Earth's Best and Well-Fed Baby) are available. Or, make your own by cooking and pureeing organic produce.

2. Strawberries. Do you know what it takes for a fragile, beautiful strawberry to make it through the rigors of factory harvesting and a long truck drive to your table? More chemicals than you can shake a stick at. Strawberries are one of the most chemical-intensive crops in America. Enjoy them in season from local organic farms.

3. Rice. Domestic rice is grown with heavy doses of pesticides. Since it has a long shelf life, buy organic rice in quantity whenever you find it and store it for use over time.

4. Other Grains. When our diets include more fiber, they also include more chemicals (which come free as a bonus with the conventionally grown grains.) Shift to organic grains to avoid this problem.

5. Got Milk? We hope not. Today's commercial brands are loaded with bovine antibiotics and growth hormones.

6. Corn. Corn is not typically a problem with pesticide residues. But when you take into account that the average American eats 11 pounds of corn a year, organic corn makes more sense. Eat local organic corn in season and freeze some for later.

7. Bananas. This tropical favorite has a short window of ripeness and a very long distance to market. This adds up to a heavy dose of chemicals along the way.

8. Green Beans. Over 60 different pesticides are used on green beans. Even beans used in baby food have been found to be contaminated.

9. Peaches. Nothing beats a peach, until you realize that they have the highest rates of illegally applied pesticides.

10. Apples. A decade after the dangers of Alar were exposed, apples are still soaked in pesticides. Put only organic apples in your pie.

—M.B. via email

Dear CMTA,

I'm 27 years old and from Ontario, Canada. I was diagnosed with CMT when I was 16 years old. I'm always looking for new information about CMT, or anything that people with CMT are having success with. I ran across your association while surfing the Internet for this information.

Just to let your members know, I was introduced last year to magnetic products. Slowly, I started feeling increased energy and stability when I was walking. I decided to keep using the products and have not stopped. In the year that I have been using the products, my energy has increased, so much that I now work out 3 times a week and am now taking Tai Chi one night a week for two hours. A magnetic bracelet I wear keeps my usually bent pointer finger straight.

I work full time and feel very good about the number of extra activities I am now doing. I would like to know if anybody else has used these products. I would like to know if they are having the same success.

—M.M.

Cyours@idirect.com

Dear CMTA,

I have CMT Type 2. I am 46 years old. I was diagnosed with CMT in 1969. After several years of trying shoe inserts and AFOs, I decided life would be easier without the help of any devices. In the past year, I have noticed some loss of strength in my lower leg muscles. After ankle surgery last November, I went to a local sporting goods store and found an ankle brace that meets my needs.

The brace is made by Pro Orthotics Devices, Inc. PO Box 31401, Tucson, AZ 85751. These

braces slip over my foot and cover half of the foot and go about 4 to 5 inches above my ankle. They have laces which tighten around the ankle and foot. They also have straps which wrap around the foot and ankle. I add a pair of Wolverine lace-up boots and I'm ready for a day at the construction site.

I am a construction inspector for the city of Houston and I also have a home inspection business. On the weekends, I enjoy riding my classic motorcycle.

—J.S., TX

## How I Live with CMT...

By EMILY LOUER

*CMT has meant learning the arts of...*

1. Pacing in everything you do: Work, errands, cooking, cleaning.
2. Organizing your time. I think, every night, about what I need to do the next day. What is not necessary gets done another day. Set priorities and do not forget yourself on the list!
3. Setting up a network of helpers. I hire a high school student for 1-2 hours to do my weekly leg work. What would take me hours to do (and a lot of pain), she can do easily in two hours and with a smile. I pay \$15 to \$20 for this, which is money well spent.
4. Learning how to say "no" in a nice, but firm way. My friends know not to judge me by what I can do, but rather by who I am.
5. On a slow day, I turn on music and bake, or cook a good meal that the family can eat for two nights. If possible, I get all the odds and ends done and then I do something just for me, i.e. manicure, hair washing, whatever.
6. Learning some form of relaxation exercise, other than sleeping.
7. Learning how to delegate jobs around the house. It may not always work, but for the most part, it does. If I cook and set the table, someone clears the table and someone else washes the dishes.
8. Swimming at least once a week, no matter what stage of CMT you are at. (Check with your doctor before undertaking any new exercise.) When in the water, move and stretch your fingers and toes, even if they don't move well. They will do something.

*This is what I've mastered so far... there's always more to learn. I hope this helps someone else a little.*

## 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*



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

Non-Profit Org.  
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